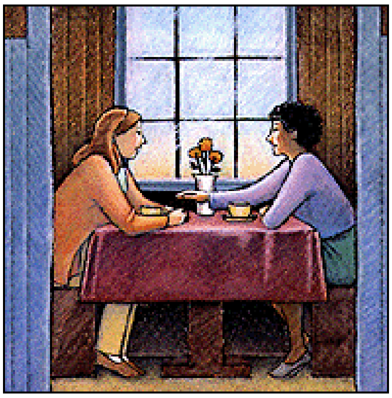
Queensland University
of Technology

Queensland
Cancer Fund

THE EXPERIENCE OF GYNAECOLOGICAL CANCER SURVIVORS: SUPPORTIVE CARE NEEDS AND USE



VANESSA BEESLEY

BHLTHSC(PUBHLTH), BHLTHSC(HONS)

THIS THESIS IS SUBMITTED IN FULFILLMENT OF THE DEGREE
DOCTOR OF PHILOSOPHY, 2006
AT QUEENSLAND UNIVERSITY OF TECHNOLOGY,
SCHOOL OF PUBLIC HEALTH.
MEMBER OF INSTITUTE OF HEALTH AND BIOMEDICAL INNOVATION.

ABSTRACT

Gynaecological cancer survivorship has been addressed in only a limited body of research. After completion of treatment, women with gynaecological cancer face many challenges. It is pertinent that we understand the wellbeing and morbidity issues of this group of survivors, as well as their supportive care needs and use. With this understanding, it will be possible to better target health care initiatives and services to those gynaecological cancer survivors who require help. Accordingly, the objectives of this study were to determine the prevalence of site-specific morbidities, support being utilised, and unmet needs, as well as to determine the correlates of supportive care needs and use.

To address this, a cross-sectional mail survey of 1774 Queensland gynaecological cancer survivors three months to five years post-diagnosis was conducted in 2004 (56.5% response rate, n=802 of 1420 eligible participants). Women were recruited from the Queensland Gynaecological Cancer Registry, which covered approximately 85% of all gynaecological cancer patients in Queensland at the time of this study. The questionnaire measured a range of factors to reflect a social-ecological perspective. This broader perspective was utilised to extend the current understanding which is limited to a biopsychosocial approach. Main outcomes were measured with standardised and validated instruments where possible, including the Supportive Care Needs Survey, Functional Assessment of Cancer Therapy, Duke-UNC Functional Social Support Questionnaire and the Active Australia Survey.

The results of this survey showed that while quality of life was high on average (median 91, range 30-108), some women experienced debilitating site-specific conditions. Ten percent reported being diagnosed with lower limb lymphoedema and eight percent of women reported that their gynaecological cancer had made sexual relations too difficult or too uncomfortable.

Women accessed multiple sources of support within their communities including a variety of support services (54%) and complementary therapies (29%). Characteristics associated with use of support services include: younger age, being retired, having been diagnosed with a gynaecological cancer other than uterine, having had open bowel resection, having been treated at multiple centres, being in remission, being obese. On average, women reported having excellent social support (median 37, range 8-40). Some women made changes to healthier

behaviours following their cancer diagnosis, such as increasing their fruit and vegetable intake (23%) or physical activity levels (10%) or decreasing their alcohol consumption (24%) or cigarette smoking (10%); however, nearly half (44%) of women decreased their physical activity level. A population comparison of health behaviours between gynaecological cancer survivors and Queensland women highlighted the significantly lower level of sufficient physical activity and higher level of obesity in the cancer survivor population, as well as the low levels of adequate vegetable intake in both populations.

Forty-three percent of gynaecological cancer survivors reported having at least one moderate or high level unmet supportive care need. In particular, needing help with fear about the cancer spreading, concerns about the worries of those close to them, uncertainty about the future, lack of energy/tiredness, and not being able to do things they used to do, were most important to this group. These leading need items were all within the psychological and physical/daily living supportive care domains. Some unmet sexuality and health system/information needs were also reported. Groups with higher odds of unmet needs included those women who more recently completed treatment, whose disease was still present, who had children still living in the home, who had diagnosed lymphoedema, who experienced treatment-related menopause, who were unable to work due to illness and who lived in rural and remote regions of Queensland.

These results indicate that women with gynaecological cancer in Queensland are doing quite well overall; however, there is still room for improvement in a few key areas of public health importance. In line with the social-ecological model, resources need to be targeted at all levels of support including personal, social, health care and broader organisational, community, policy and media levels. In particular, the following recommendations are made:

1. Assistance with the particular reported unmet psychological and physical/daily living needs is a priority. Support services should be tailored to the identified groups of survivors who had higher odds of unmet needs, both in terms of development of written materials that reflect these groups' circumstances and implementation of programs or workshops specific to these groups. In particular, the development of a number of programs or workshops are recommended that discuss the specific psychological and physical/ daily living outcomes of women who a) live with cancer, b) live with children after cancer treatment, c) live with

lymphoedema, d) have had treatment-related menopause or e) are unable to work due to illness, and how and where women can get help with managing these. These programs should be implemented by support organisations in the period closely following treatment completion and should consider technologies such as video-conferencing to reach women who are in rural and remote areas.

2. More specific written information for cancer survivors about things they can do to help themselves get well is needed, in lay-person friendly format. This information should address the value of particular dietary items, complementary therapies and types of physical activities that are safe and beneficial to cancer survivors' quality of life.
3. An evidenced-based physical activity intervention, targeting overweight and obese gynaecological cancer survivors is recommended, to reduce the weight issues of this population.
4. To facilitate the triage of cancer survivors to appropriate health care information and other support initiatives, cancer survivors' awareness of the Queensland Cancer Fund needs to be raised substantially. Practitioner education and discharge planning directives are recommended to ensure information about the Queensland Cancer Fund is disseminated.
5. To address the substantially unmet information and physical/ daily living needs specific to lymphoedema sufferers, it is recommended that self-management information and referral information for suppliers and services for lymphoedema management be given to women in high lymphoedema risk groups, as part of the hospital discharge procedure, as well as when symptoms are diagnosed, to ensure a continuum of care is maintained.
6. Clinical practice guidelines for cancer care and, correspondingly, support programs, need to expand from acute care to managing the long-term psychological, physical and sexual health consequences.

Several topics for research are likely to be important in the future, including more specific research into why uterine cancer survivors reported higher odds of unmet psychological needs and yet were less likely to use support services, what specific help women with unmet needs would prefer, the effects of lower limb lymphoedema on survivors' quality of life, and why there isn't greater use of existing support services, especially among women with morbidity such as lymphoedema and issues associated with treatment-related menopause.

STATEMENT OF ORIGINALITY

The work contained in this thesis has not been previously submitted for a degree or diploma at this or any other higher education institution. To the best of my knowledge and belief, this thesis contains no material previously published or written by another except where due reference is made.

SIGNATURE: _

DATE: _

ACKNOWLEDGMENTS

Diana Battistutta, you are my mentor, my dear friend, my principal supervisor, my second mother, my confidant, my teacher and my source of much positivism for life and learning. I have and always will enjoy your company and your mind. Thanks for joining me for a second round of thesis writing! Equally, I extend great gratitude to my husband John Beesley, who lights up my day when my energy is low, who makes my heart melt with kindness and consideration and who understands me completely. John, your support and encouragement gives me the strength to succeed with joy.

I am also very grateful to have received much guidance and support in the study design, analysis and production of my thesis, from a number of researchers and organisation staff. In particular, I thank my associate supervisor Elizabeth Eakin for her very detailed and constructive feedback at all stages of the project and Beth Newman for her guidance and facilitation in my all-round learning. Also, sincere thanks goes to Joanne Aitken (QCF), Jeff Dunn (QCF), Monika Janda (QCF), Suzanne Steginga (QCF), Andreas Obermair (RBWH), Sandi Hayes (QUT), Penny Webb (QIMR), Alex Crandon (RBWH), Dan Jackson (RBWH) and John Gower (GCS), for helping me along the way.

I was also fortunate to work with some great project staff including: Jessica Howie, Neil Swift, Loretta McKinnon, Shirley Neill and Dianne Swift. Thank you for all your attention to detail and hard work. Thanks also to the administrative staff within Public Health – QUT, for all your help. I was blessed to be situated in such a wonderful work environment. A-wing Public Health, was always a lively, fun and friendly place to hang out. Thanks to everyone there for making it this way. I also acknowledge that many of my friends and family played a large role, as always, in showing me the love! In particular, thanks Nicola Mitchell, Dave Loveridge, Mum, Dad and Barb Bradshaw for your frequent encouragement and checkups.

This study was made possible by funding support from the Queensland Cancer Fund and access to participants *via* the Queensland Gynaecological Cancer Registry at Royal Brisbane and Women's Hospital. Thanks to these organisations for their support and to the staff that made navigation through the system possible. Thanks also to all Queensland gynaecological oncologists who approved access to their patients and to the many cancer support organisations who extended their co-operation with information provision, key informant interviews and allowing their inclusion within this questionnaire. Furthermore, a special thanks is extended to the women who participated in this survey, without whom this study would not have been possible.

Finally, I would like to acknowledge the lively spirits and kind hearts of my two dear friends and colleagues Beau Martin and Carla Patterson, as well as granddad Dick Horeston, who passed away during my candidature.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS AND KEY WORDS

ARIA	Accessibility/Remoteness Index of Australia
BMI	Body Mass Index
CAT	Complementary and Alternative Therapies
CI	Confidence Interval
CNQ	Cancer Needs Questionnaire
CPNQ	Cancer Patient Needs Questionnaire
EWB	Emotional wellbeing
FACIT	Functional Assessment of Chronic Illness Therapy
FACT	Functional Assessment of Cancer Therapy
FWB	Functional wellbeing
GCR	Gynaecological Cancer Registry
GCS	Gynaecological Cancer Society
HRT	Hormone Replacement Therapy
LLL	Lower Limb Lymphoedema
N	Number of cases
NESB	Non-English Speaking Background
OR	Odds Ratio
PWB	Physical wellbeing
QCF	Queensland Cancer Fund
QCR	Queensland Cancer Registry
QIMR	Queensland Institute of Medical Research
QLQ-C30	The European Organization for Research and Treatment of Cancer quality of life questionnaire
QOL-CS	Quality of Life – Cancer Survivors (survey instrument)
QUT	Queensland University of Technology
RBWH	Royal Brisbane and Women's Hospital
RRMA	Rural, Remote and Metropolitan Area Classification
SCNS	Supportive Care Needs Survey
SD	Standard Deviation
SEIFA	Socio-Economic Indexes of Areas
SFWB	Social/family wellbeing
SPSS	Statistical Package for Social Sciences
SPWB	Spiritual wellbeing

Lymphoedema	Refers to secondary lymphoedema that develops in the lower limbs as a result of gynaecological cancer treatment.
Service use	Refers to the use of community support services and/or support organisations.
Survival phases	Refers to Mullin's (1990) survival phases defined by time post-diagnosis. However, it is acknowledged that individual variability in illness experience is likely and may not always have the same time-line trajectory.

1 INTRODUCTION

"The end of cancer treatment is not the end of the cancer experience" (Lance Armstrong, 2004)

The impact of cancer diagnosis and treatment can remain long after treatment has ceased. Some survivors continue to find day-to-day life difficult and the issues of survivorship can be challenging. Current psychosocial care in Australia is offered reactively, in a state of crisis (Girgis & Boyes, 2005). In 2003, clinical practice guidelines for psychosocial care of adult cancer survivors in Australia were developed (National Breast Cancer Centre and National Cancer Control Initiative, 2003). These guidelines were developed for use by members of the diagnostic and treatment team to ensure a continuum of care throughout the treatment process. However, they do not consider survivors post-treatment and the many valuable community services and other activities which are perhaps more appropriate to this group as they proceed beyond treatment. These guidelines are generic to all cancer survivors. In addition to the common issues that accompany any cancer diagnosis, gynaecological cancer survivors may also deal with impaired fertility, treatment-related menopause, diminished sexual response, lower limb lymphoedema, and relationship concerns that are specific to this disease (Auchincloss, 1995). For some of these issues little is known about the type of help women would like to receive.

It is important that we begin to consider the needs of cancer patients who are post-cancer treatment. It is also pertinent that the specific supportive care needs of gynaecological cancer survivors are understood to better tailor health care initiatives and services to assist the physical and emotional recovery of women diagnosed with this disease. Given that support organisations have a limited budget for provision of services and resources, services need to be tailored to those patients who require them (Hutchison *et al*, 2006). Identification of both specific needs and groups of survivors with these needs is possible using needs assessment surveys.

To date, needs assessment in the gynaecological cancer population has not been conducted in Australia. The relevant international needs research is limited to one or two areas of need and uses non-validated, non-standardised measures. Many support services exist in Queensland that cover a range of functions. However, it is unknown how well these services meet the needs of gynaecological cancer survivors or even, in fact, whether women in need are utilising the services.

In addition to support services, there is a growing body of research which suggests a significant proportion of the population is utilising lifestyle activities such as healthy diets, dietary supplements and other complementary therapies, and physical activity to promote quality of life and longevity. Only one other Australian study has considered the prevalence of complementary therapy use within a gynaecological cancer population, and this study is yet to publish their findings (Webb *et al*, 2004). Furthermore, a unique opportunity exists to compare the uptake of dietary and physical activity guidelines of the Queensland gynaecological cancer population with the general female population in Queensland, with the implementation of a population-based survey within the same timeframe (DiSipio *et al*, 2006). A direct comparison would allow some insight into the differences in supportive health behaviours between cancer survivors and the general population.

Accordingly, this current study aimed to:

1. Establish prevalence of some of the site-specific morbidities that result from the gynaecological cancer experience.
2. Determine what support survivors are receiving or utilising.
3. Determine what unmet support needs existing within this community of cancer survivors in Queensland.
4. Determine which groups have higher levels of unmet need and service use.

In Queensland more than eight hundred new cases of gynaecological cancer are diagnosed each year (Queensland Cancer Fund, 2004). Most gynaecological cancer diagnoses, except ovarian cancer, are associated with good survival rates and these are generally increasing with every year (Youlden *et al*, 2005). Considering this, research concerning the prevalence of site-specific morbidity issues, and supportive care needs and use, is of public health importance. It will supply service providers and health care professionals with specialised knowledge of this particular group of cancer survivors and will inform recommendations for the development of tailored resources and interventions.

The current project is a cross-sectional survey of Queensland gynaecological cancer survivors three months to five year post-diagnosis. The project derived its sample from a near population-based registry, to capture a representative view of unmet needs and supportive care use Queensland-wide. For clarity, the details of the research have been divided into the following chapters. A literature review is presented in Chapter two. Chapter three details the research design, development of the questionnaire, data collection, and analysis procedures. Chapter four discusses the sample characteristics, as well as health outcomes and supportive care used. Chapter five looks specifically at the burden of existing unmet need and the correlates of reporting support needs and service use. A discussion of results is proffered in chapter seven, along with specific recommendations for service providers, health professionals and suggested further research directions.

2 LITERATURE REVIEW

2.1 INTRODUCTION

In Australia, cancer is the leading cause of death, accounting for over one quarter of all deaths (Australian Bureau of Statistics, 2004). In Queensland, there were 16,448 cancers diagnosed (males 8883, females 7565) in 2000 (Baade & Coory, 2002), the most common being colorectal, breast, prostate, melanoma, lung and gynaecological carcinomas. Five-year survival rates indicate that more and more people are living with cancer and for longer periods of time (Youlden *et al*, 2005). Long-term and late effects of cancer or its treatment can occur many years after treatment ends (National Cancer Institute *et al*, 2004). The effects include but are not limited to physical, psychological and social issues. The needs stemming from these issues can go undetected and unmet (National Breast Cancer Centre and National Cancer Control Initiative, 2003). Meta-analyses have shown that patients receiving psychological therapies, psycho-educational or psychosocial interventions have improved rates of emotional adjustment, social functioning, treatment and disease-related symptoms and overall improvement in their quality of life (Devine & Westlake, 1995; Meyer & Mark, 1995). After survival, quality of life end points are most important to cancer survivors. The assessment of availability and quality of healthcare interventions and services is imperative when considering the morbidity of cancer survivors. Furthermore, it is important that we do not assume to know what the unmet supportive care needs of a specific population are. Given limited health care funds, it is imperative that supportive care is targeted to meet cancer patients' needs (Girgis *et al*, 2000).

Current Australian research on cancer survivors' unmet supportive care needs in the post-treatment phase is limited. Available research focuses on breast (Girgis *et al*, 2000; Thewes *et al*, 2003; Thewes *et al*, 2004b; Thewes *et al*, 2005), prostate (Steginga *et al*, 2001), melanoma (Bonevski *et al*, 1999) and colon cancer (Hancock *et al*, 2002) or on studies with a mix of cancer sites (Sanson-Fisher *et al*, 2000; McLachlan *et al*, 2001). In Australia, gynaecological cancer is the sixth most common cancer site with 3881 new cases of gynaecological cancer diagnosed in 2001: 252 vulval; 62 vaginal; 735 cervical; 1537 uterine; 1248 ovarian; and 47 other miscellaneous female genital organs (Australian Institute of Health and Welfare, 2001). In Queensland in 2002, there were 841 new cases of gynaecological cancer diagnosed; 42 vulval; 148 cervical; 309 uterine; 289 ovarian; and 53 other miscellaneous female genital organs (Queensland Cancer Fund, 2004).

Specific sites of cancer and specific treatments may produce unique adaptation difficulties (Molassiotis *et al*, 2002) and result in site-specific supportive care needs. Gynaecological cancers are associated with special adaptation needs, although little attention has been diverted to this area of survivorship (Molassiotis *et al*, 2002). This is mainly because of the poor prognosis of some gynaecological cancers such as ovarian cancer (as most patients present to the doctor at an advanced stage of their disease) and the recent research concentration on the needs of breast cancer survivors; breast cancer being the most common female cancer. However, advances in treatment of gynaecological cancers are currently improving and survival rates are steadily increasing, with the exception of ovarian cancer (Molassiotis *et al*, 2002). With the substantial number of gynaecological patients in Queensland who are experiencing greater durations of survival, it is pertinent that these gynaecological cancer survivors be assessed for their supportive care needs. It is only with this information that healthcare interventions or services can be targeted to meet their needs and improve their quality of life.

2.2 GYNAECOLOGICAL CANCER

Gynaecological cancers include cancers of the cervix, endometrium or uterus (womb), ovary, vulva, vagina, perineum or fallopian tubes. While gynaecological cancers are regularly pooled in reports and research, each distinct site has its own causal factors, symptoms, diagnosis and treatment. Therefore, gynaecological cancer survivors will have site-specific morbidities. These morbidities need to be further stratified by stage of disease, which will determine treatment type (Bos-Branolte, 1991). Psychological effects are also dependent on age, personal history, phase of life and characteristic coping methods (Derogatis, 1980). In general, the possible effects of the disease and treatment are wide ranging, affecting physical, psychological and social/cultural functioning. A diagnosis of gynaecological cancer may elicit disturbances to body image; feelings of helplessness, dependency, shame, guilt and vulnerability; a sense of loss of femininity and motherhood; and sexual difficulties (Bos-Branolte, 1991).

2.2.1 TREATMENT OF GYNAECOLOGICAL CANCER

Treatments for gynaecological cancers vary according to the site and stage of disease (Bos-Branolte, 1991). Patients often receive a combination of surgery, radiotherapy, and/or chemotherapy. Most Queensland gynaecological cancer patients will complete their treatment regimes by three months post-diagnosis (Obermair, 2004). However, each of the treatment modalities comprises interventions that differ considerably in terms of the potential structural and functional deficits, and hence the range of psychosocial reactions that may last years after the treatment is complete (Rieger *et al*, 1998).

2.2.1.1 *SURGERY*

Surgery occupies a predominant role in the treatment for gynaecological cancer. Hysterectomy combined with removal of the ovaries constitutes a common surgical procedure for gynaecological malignancies, raising issues of loss of child-bearing capacity and the management of surgically induced menopausal symptoms, in addition to the psychological reactions associated with cancer surgery in general (Rieger *et al*, 1998). Other surgical procedures such as pelvic exenteration (i.e., removal of the vagina, uterus, bladder and/or rectum, and the creation of a stoma) and radical vulvectomy (i.e., removal of the entire vulva including the clitoris), involve a marked challenge to body image (Knapp & Berkowitz 1986). The latter procedure, as well as radical pelvic surgery including extensive lymphadenectomy, is usually accompanied by removal of the groin lymph nodes, with the disruption in lymphatic drainage possibly resulting in varying degrees of chronic leg oedema, and consequently, curtailed activities (Rieger *et al*, 1998). After gynaecological surgery sexual dysfunctions are also commonly reported, even in patients with complete response (Schover *et al*, 1989; Corney *et al*, 1993). Fortunately, surgical techniques have improved over the past years, most notably with the introduction of laparoscopic surgery in Queensland in 2003 (Obermair, 2004). This operative procedure is performed using minimally invasive surgical technique for exposure that avoids traditional incision and hence should impact less on the quality of life of the survivor (Obermair, 2004).

2.2.1.2 *RADIOTHERAPY*

External and/or internal radiotherapy also features prominently in the treatment of gynaecological cancers (Karlsson & Andersen, 1986). Depending on site or disease stage, radiotherapy may be used either as primary treatment or in combination with surgery or chemotherapy (Greimel & Freidl, 2000). External radiation therapy involves brief daily treatments similar to having an x-ray, to the pelvic region extending over five or six weeks, whereas internal radiation (otherwise known as brachytherapy) typically involves one or more treatments of a metal devise containing radioactive material being planted in the vagina or uterus for 48-96 hours (Rieger *et al*, 1998). Delayed effects such as cystitis (inflammation of the urinary bladder) (Karlsson & Andersen, 1986) and long term sexual dysfunction (Andersen & van der Does, 1994; Bergmark *et al*, 1999) are reported. Following radiotherapy there is an increased tendency for scar tissue to form, which can result in narrowing and shortening of the vagina making sexual intercourse difficult (Gynaecological Cancer Society, 2000).

2.2.1.3 *CHEMOTHERAPY*

Chemotherapy is a medication that is administered either through a drip into the vein, by oral tablet or occasionally by injection into a body cavity (Gynaecological Cancer Society, 2000). It is often given following surgery to try and “mop up” any residual cancer cells (Gynaecological Cancer Society, 2000). Chemotherapy causes high levels of psychological distress and multiple side-effects (Bergmark *et al*, 1999). Depending on the specific cytotoxic agents employed, significant side effects such as hair loss, nausea and vomiting, fatigue, anorexia, alopecia, and peripheral neuropathy may occur following treatment (Holland & Lesko, 1989).

2.2.2 SEQUELAE OF GYNAECOLOGICAL CANCER

Even after completion of treatment, women with gynaecological cancer still face a lot of challenges on the way to recovery. As mentioned in the previous section, some site-specific concerns may include impaired fertility, treatment-related menopause and diminished sexual response. These treatment outcomes can often result in sexual problems, affective disturbances, family issues, and lymphoedema (Rieger *et al*, 1998).

2.2.2.1 *AFFECTIVE DISTURBANCE*

Studies have shown that women with gynaecological cancer worry more about their condition than patients with cancer in general (Corney *et al*, 1992) and that their sense of psychological well-being is poorer than that of patients with chronic illnesses and healthy individuals (Greimel & Freidl, 2000). Depression and anxiety are the most frequent types of affective disturbance in gynaecological cancer patients, although anger, confusion, and guilt are also common (Andersen & Turnquist, 1989). Gynaecological cancer patients have been reported to have a high prevalence (23-30%) of major depression (Evans *et al*, 1986; Zabora *et al*, 2001). For most women the severe initial distress returns to normal levels 6 to 12 months after treatment (Coyne *et al*, 2000; Greimel & Freidl, 2000). Depression, anxiety and adjustment disorders are often a result following loss of fertility, sexual difficulties, family issues or the onset of lymphoedema symptoms.

2.2.2.2 *TREATMENT RELATED MENOPAUSE AND LOSS OF FERTILITY*

Many women treated for cancer are already in menopause, while other younger patients, with normal ovarian function at diagnosis, will go into early menopause due to surgery or chemotherapy or the need for radiotherapy to the pelvic region (Biglia *et al*, 2004). With this early menopause comes loss of fertility which can be devastating for some women. Motherhood and fertility are strongly tied to a sense of being a women and for some women, losing their ability to have children can be as difficult to accept as their cancer diagnosis (Wain *et al*, 2004).

It is very unlikely that women post-treatment for gynaecological cancer are still pre-menopausal. Exceptions are patients with vulval cancer because the ovaries are not involved (Obermair, 2004). Iatrogenic menopause worsens the quality of life of apparently healthy women after treatment of malignancies in fertile years (Biglia *et al*, 2004). The sudden onset of menopause can be both physically and emotionally difficult to handle (Wain *et al*, 2004). Adjustment is required not only to changing levels of hormones, but to the fact that symptoms belong to women of an older age group and signify the end of childbearing (Wain *et al*, 2004).

The most commonly associated symptoms with menopause are: hot flushes, night sweats, vaginal dryness, mood swings, fuzzy thinking and forgetfulness, and problems with sleep (Wain *et al*, 2004). However, following surgical menopause, 30-50% of women also experience loss of sexual desire, decreased arousal, dyspareunia, difficulty with, or failure to achieve, orgasm (Rako, 1996). This is related to the typical drop of 50% of pre-surgical testosterone levels occurring after bilateral oophorectomy. In addition to the hormonal problem, the effect of surgery on sexual activity must also be taken into account, especially when surgery is aggressive (as in the case of vulval and vaginal cancers) and the anatomical changes become obviously predominant.

2.2.2.3 *SEXUAL DIFFICULTIES*

Elevated rates of sexual morbidity have been well documented among gynaecological cancer patients (Weijmar Schultz *et al*, 1992a; Andersen, 1993; Andersen & van der Does, 1994). The physical mechanisms underlying the female sexual response may be impaired by surgery, radiotherapy, and chemotherapy. These treatment modalities may result in atrophy of the vaginal mucosa, inadequate lubrication, vaginal irritation, the formation of vaginal adhesions, or an alteration in the depth of the vagina, each of which may result in dyspareunia (Weijmar Schultz *et al*, 1992b). A change in cortical sensory input may occur, resulting in reduced genital or pelvic sensitivity, while anorgasmia may result following a radical vulvectomy (Andersen & Hacker, 1983; Weijmar Schultz *et al*, 1992b). Physical changes not specific to genital or reproductive functioning (e.g., fatigue, leg oedema, the presence of an ostomy, or hot flushes) may also result in sexual difficulties (Schover & Jensen, 1988).

In addition to physical mechanisms, psychological factors may have an adverse effect on sexual functioning. Psychological reactions contributing to sexual difficulties include disturbances of gender identity (e.g., following a loss of child-bearing capacity); poor body image (e.g., following disfiguring surgical procedures or alopecia resulting from chemotherapy); impaired intimacy (e.g., following a disintegration of established patterns for achieving physical pleasure or misinformation about sexual behaviour in relation to the disease such as the belief that radiation may be contagious); or affective disturbances (e.g., anxiety, depression, or anger) (Weijmar Schultz *et al*, 1992b).

2.2.2.4 FAMILY ISSUES

Family members have been described as "second-order patients" (Rait & Lederberg, 1989), with the experience of cancer extending beyond the individual patient to impact on the family as a whole (Germino & Funk, 1993; Lewis, 1993). For example, adjustment problems are common in the spouses of women diagnosed with cancer, with a high correlation between partners level of distress (Ey *et al*, 1998; Fang *et al*, 2001). Moreover, such distress may extend from one to two years after the diagnosis as spouses attempt to support their partners, deal with their own emotional reactions, and manage disruptions to daily routines (Northouse & Peters-Golden, 1993). The importance of providing assistance to family members in general and spouses in particular is emphasized by the fact that, firstly, social support has been found to be associated with cancer patients psychological adjustment and, possibly, length of survival (Rowland, 1989a; Blanchard *et al*, 1995) and, secondly, spouses are often the preferred source of emotional support for cancer patients (Rowland, 1989a).

2.2.2.5 LOWER LIMB LYMPHOEDEMA

Lower limb lymphoedema (LLL) is a major source of morbidity following surgery for the treatment of gynaecological cancer involving removal of lymph nodes and/or radiotherapy (Ryan *et al*, 2003b). The condition of LLL presents as swelling of the leg(s), generally within the first 12 months, and once developed becomes chronic (Ryan *et al*, 2003b). Lymphoedema can lead to distortion of size, shape and function of affected extremities (Ryan *et al*, 2003a).

There are very few studies that focus on LLL. Ryan *et al* (Ryan *et al*, 2003b) found that 36% (177) of Australian women treated for gynaecological cancer reported swelling of their legs however, only half of these were clinically diagnosed with LLL. The women most at risk for developing LLL were those who had treatment for vulval cancer with removal of lymph nodes and follow-up radiotherapy (Ryan *et al*, 2003b). For this subgroup the prevalence was 47%. Women with cancer at other gynaecological sites also experience lymphoedema: 7% (10) of ovarian cancer survivors, 18% (25) of uterine cancer survivors and 18% (21) of cervical cancer survivors developed LLL (Ryan *et al*, 2003b). Another study undertaken over a 45 year period reported 9% of women developed LLL from a total of 415 who had treatment for vulval cancer (Cavanagh *et al*, 1990). Another study examined the incidence of LLL in 54 women following treatment for cervical cancer and found 41% incidence of LLL when classified by measurement (unilateral increase in volume of 5% or more in one leg) and 22% of the 54 women had lymphoedema that was severe enough to cause symptoms (Werngren-Elgstrom & Lidman, 1994). A Norwegian study reported 20% of 92 patients with cervical cancer and vulvar cancer had symptoms of lymphoedema of the lower limbs (Nesvold & Fossa, 2002). Other publications present case reports that describe the management of LLL and the eventual outcome (Matthiesen & Simonsen, 1990; Araujo *et al*, 1997; Abang *et al*, 1999). The experience of having LLL from the women's perspective is reported by (Ryan *et al*, 2003a). The majority of research on lymphoedema is that which develops on the upper limb following breast cancer treatment. Much less is known about LLL as an outcome of gynaecological cancer treatment. The management of upper limb lymphoedema is not directly transferable to LLL. Researchers can only hypothesise that lymphoedema in one or two legs will encroach on a women's quality of life and supportive care needs.

2.3 THE STUDY OF NEEDS

Comprehensive care of cancer patients involves not only curative efforts, but also attention to psychosocial needs of patients and their families (Miller *et al*, 2003). The importance of psychosocial aspects of cancer care is becoming increasingly evident due to a rising number of long-term survivors and the diversity of treatment effects (Miller *et al*, 2002). Good quality of care must be based on an understanding of the needs, desires and expectations of patients (Nelson & Niederberger, 1990).

Research identifying cancer patients' unmet psychosocial needs has revealed deficiencies in a variety of areas: dealing with emotions; obtaining information from physicians concerning prognosis, treatment, and side effects; communicating with their families about death; dealing with caregiver fatigue and/or need for assistance; and sexual functioning problems (Houts *et al*, 1986; Houts *et al*, 1988; Houldin & Wasserbauer, 1996; Sanson-Fisher *et al*, 2000). Others have pointed out that the psychosocial needs of patients can include spiritual concerns (Sheehan, 1997; Thiel & Robinson, 1997; Fitchett, 1999). Addressing needs is crucial for the long-term wellbeing of patients.

2.3.1 WHAT ARE NEEDS?

The term "need" has been used interchangeably within the psychosocial literature with concepts as diverse as "wants", "demands", "concerns" and "problems" (Foot, 1996). In the context of purchasing for health or social care, needs have been defined as the populations ability to benefit from specific services relating to specific problems (National Health Service Management Executive, 1991). This definition focuses on the outcomes of care interventions for population needs, not the individual. It assumes an ability to improve health through effective provisions, and implies that needs are inextricably linked with services provision. There is evidence that education programs can increase knowledge about cancer and provide support networks for cancer patients and families (Narsavage & Romeo, 2003). However, needs can also be broadly defined and thus go beyond what are typically thought of as cancer-specific supportive care services. For example, cancer survivors may need support for regular exercise or a healthy diet to feel well and/or reduce fatigue (Demark-Wahnefried *et al*, 2005). Moreover, the definition implies that needs result from a specific problem and does not consider that need can result from the broader cancer experience. Foot (1996) has defined "needs" as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being.

2.3.2 SUPPORTIVE CARE DEFINED

Foot's (1996) definition of needs is in-line with the comprehensive definition of supportive care (see below) which is inclusive of health services and other related activities. This is a more appropriate definition, with wellbeing as the outcome, and the acknowledgement of actions or resources, service and beyond, as the means of addressing the needs. Recognising the need to provide comprehensive care to all patients at any stage of their illness, Whelan *et al* (1997) have defined supportive cancer care as "those health services and related activities designed to help patients and their families with their cancer experience during the diagnostic, treatment, follow-up and palliative phases". Thus supportive care includes not only issues of physical or symptom support, but other domains, such as instrumental and social care, the need for information, psychological support and spiritual needs. Supportive care differs from palliative care as it addresses patients at all stages of a disease and not just those with an active, progressive, far advanced disease with minimal prospect of cure. Another difference between these definitions of care is that supportive care is also for the families and friends of patients who act in a care-giving role.

2.3.3 UNMET NEEDS

An approach to assessing the adequacy of supportive care, derived from the gerontological literature is to assess patients' need for services as well as whether those needs are being met (Fillenbaum, 1988; Mor *et al*, 1988; Steinwachs, 1989). It explicitly defines patients' needs on the basis of health-related functional deficits. Unmet need is present only if the patient cannot perform, or has difficulty performing, needed tasks independently, and if the individual's existing family network and/or formal services are insufficient to meet the patient's need (Mor *et al*, 1991). Therefore, unmet need is conceptualised as a function of both the physiological effects of disease and treatment and the associated support pressures.

Unmet needs have been conceived as an important quality of life indicator as it represents the interaction of physical illness and the social support necessary to meet daily living needs (Mor *et al*, 1991; Kane & Boult, 1998). The concept of unmet need has been operationalised in several ways. Some studies define unmet needs as lack of access to formal health care services (Biegel *et al*, 1989; Vinton *et al*, 1997; Thomas & Payne, 1998; Katz *et al*, 2000). Other studies concentrate less on the specific services needed and more on the limitations in activities of daily living and the availability or adequacy of assistance with these tasks (Allen & Mor, 1997; Montoya *et al*, 1997; Sanson-Fisher *et al*, 2000). The latter focus is more appropriate in survivor research as it concentrates on activities of daily living which the person must resume. This focus is also more holistic as, in-line with supportive care, it takes into account the adequacy of health services and other dimensions of support.

2.3.4 UNMET NEEDS AND GYNAECOLOGICAL CANCER

The diverse morbidities including psychological issues, sexual dysfunction, reproductive impact, body image concerns, relationship problems, financial or vocational difficulties, that can emerge in the context of gynaecological cancer highlight the importance of assessing unmet supportive care needs. There is a growing body of research focusing on psychosocial aspects of gynaecological cancer; however, these studies do not distinguish between 1) patients having a problem and 2) patients having a problem and a desire for assistance (Miller *et al*, 2003). A MEDLINE, CINAHL, PsycARTICLES and PsycINFO title search using the words “gynaecological cancer” or “gynecological cancer (American spelling)” and “needs” revealed six studies (Corney *et al*, 1992; Bourgeois-law & Lotocki, 1999; Gamel *et al*, 2000; Stewart *et al*, 2000; Jefferies, 2002; Miller *et al*, 2003). The available studies are not Australian and limit their focus to one or two areas of needs. In particular, Corney *et al* (1992) found women treated for cervical or vulval cancer in the previous five years would have liked to have had more information on the after effects of the operation, including physical, sexual and emotional aspects, and the opportunity for emotional support and counselling during treatment. While this study identified some important current issues, such as the fact that a high proportion of the 105 women interviewed were still depressed and anxious and the majority reported chronic sexual problems (Corney *et al*, 1992), in terms of needs assessment for the treatment phase, the retrospective method of questioning could be seen as being affected by recall bias or an approach with the benefit of hindsight. While many studies have shown women have questions about the effects of treatment during the diagnosis and treatment period, other research indicates women have difficulty in hearing and comprehending any information provided because of the shock of diagnosis (Gamel *et al*, 2000).

In addition to Corney *et al’s* (1992) research, a few other studies highlighted the expressed need for information about the effects of gynaecological cancer on sexuality. In a Canadian study of 73 women attending clinics for follow-up treatment, Bourgeois-law and Lotocki (1999) found about half of respondent had received little or no information on sexuality and cancer, only half of the remainder were satisfied with the information they received, and almost 60% said they would have liked more information. In a review article by Gamel *et al* (2000), a Dutch study was translated and findings summarised. As reported in Gamel *et al* (2000), the Dutch study found that information about sexuality was needed at multiple phases along the disease trajectory: the diagnosis and treatment period; recovery and first intercourse; followed by the period of rebuilding sexual life. Accordingly the information needs varied across theses phases. In the diagnosis and treatment period, the main desired information pertained to effect of treatment on sexuality. During the second identified phase, women expressed desire for information about normal symptoms during first intercourse post-treatment and how to manage complications such as incontinence, vaginal shortening and dryness. During the phase of rebuilding sexual life, women wanted to know how to manage problems such as use of a dilator to widen the vagina and minimise scar tissue build up. Bourgeois-law and Lotocki (1999) examined two time periods in the disease trajectory and found 46% of women reported they would have preferred information before treatment, 42% reported after treatment, and 12% indicated both. Overall, the following sexuality information needs were expressed by participants in order of priority: effect of treatment on sexuality; effect of cancer on sexuality; dealing with feelings regarding illness; and dealing with partner's feelings and reactions (Bourgeois-law & Lotocki, 1999).

Examining information needs more broadly, Stewart *et al* (2000) found that Canadian women with ovarian cancer overwhelmingly endorsed a desire for detailed information at every phase of their illness; approximately two-thirds of these women sought both physical and psychological information about their illness. In fact they expressed greater preference for information than has been reported in most studies of breast cancer and prostate cancer. Jefferies (2002) noted that 34% of English ovarian cancer patients in their study said they did not receive any written information and 31% indicated that the information they received only answered a few of their questions. However, the generalisability of these findings is questionable even in England due to a very small sample size of 24 women, who were all from the same ethnic group. Moreover, this study failed to determine whether patients actually had a desire for more information. Jefferies (2002) also considered sources of emotional support, ie. family, friends, health care professionals and support groups; however, didn't determine if these emotional support sources were meeting patients' needs.

Miller *et al* (2003) found that most American gynaecological cancer patients stated that they had needed help dealing with their emotional response to being a cancer patient. The most common emotional problems were feeling nervous, being worried, being afraid, needing someone to talk to, sadness and loss of control. Although most of the physical symptoms after surgery or radiation therapy are resolved after 6-12 months (Cella *et al*, 1993; Klee *et al*, 2000b), Miller *et al*'s (2003) results indicated that feelings of fear lasted longer in a significant percent of patients. This is similar to findings reported by Fitch *et al* (1999) in patients with ovarian cancer.

Studies of gynaecological cancer survivors' support needs typically draw on qualitative research methods or small sample sizes. They have been valuable in identifying the need for more information (Corney *et al*, 1992; Bourgeois-law & Lotocki, 1999; Gamel *et al*, 2000; Stewart *et al*, 2000; Jefferies, 2002) and emotional support during treatment (Corney *et al*, 1992; Miller *et al*, 2003). There is still much potential to explore these support domains and others in a population-based study both during and after treatment completion.

2.3.5 UNMET NEEDS AND CANCER

In the broader cancer context, some aspects of cancer patients' needs are better documented than others. Practical/ daily living (Siegel *et al*, 1991; Maguire *et al*, 1999), informational (Meredith *et al*, 1996; Jenkins *et al*, 2001), social support (Taylor *et al*, 1986) and psychological needs (Greer, 1994) are popular foci of research. However, social and identity needs are less frequently addressed (Liang *et al*, 1990; Whelan *et al*, 1997). Many studies of needs of people diagnosed with cancer have attempted to thoroughly understand one particular area of need. However, more recently, with the recognition that cancer causes multiple issues as a results of many interacting influences, there has been increasing awareness of the importance of taking a "holistic" view of the needs of a person diagnosed with an illness, seeing their medical, information, psychosocial, and other needs in a complete picture (Boberg *et al*, 2003).

2.3.6 UNMET NEEDS IN AUSTRALIA

As unmet needs have been linked to available healthcare (Biegel *et al*, 1989; Vinton *et al*, 1997; Thomas & Payne, 1998; Katz *et al*, 2000), and adaptation across cancer diagnosis and treatment may include many common themes (Molassiotis *et al*, 2002), it is necessary to review more broadly other research on cancer patients' needs in the Australian context. In the past ten years, Australian research on cancer patients' unmet supportive care needs has been productive and is considerably stronger in comparison to international research. An Australian supportive care needs survey was developed and the following research has utilised this survey to examine needs from five categories: psychological; health system and information; physical and daily living; patient care and support; interpersonal communication or sexual needs.

2.3.6.1 *STUDIES WITH A MIX OF CANCER SITES*

A study of a consecutive series of patients, with a variety of types of cancer, across varying times since diagnosis, at one of two major cancer centres in a metropolitan region of New South Wales revealed substantial prevalence of unmet needs for issues relating to provisions of health information, psychological adjustment and improved patient care and support (Foot & Sanson-Fisher, 1995). However, this study over-represented female patients, patients aged younger than 65, and those from the diagnostic group of breast cancer. A study of a consecutive series of patients from nine treatment centres, collectively accounting for approximately 20% of all surgical oncology in the state of New South Wales in 1997, showed that patients with a variety of types of cancer, across varying times since diagnosis, had high levels of unmet needs in the psychological, health system and information, and physical and daily living supportive care domains (Sanson-Fisher *et al*, 2000). Limiting their New South Wales study to just patients undergoing treatment for cancer, Newell *et al* (1999) found that the physical and psychosocial domains showed the greatest level of need, with 30% and 23% of participants, respectively, reporting some needs in these areas. Further limiting their study to patients undergoing radiation in three major public cancer treatment centres in New South Wales, Perkins *et al* (2002) found that the highest needs for help were in the physical and daily living needs and psychological needs domains. A study sampling only patients with advanced, incurable cancer found the main unmet needs were in the psychological or emotional domain and the medical communication/information domain (Rainbird *et al*, 2002). This study's patients came from the clinics of 44 medical specialists in the Sydney and Hunter regions of New South Wales and hence is not necessarily representative of the Queensland population.

2.3.6.2 *SITE-SPECIFIC STUDIES*

There have been a handful of cancer-site-specific Australian studies examining patients' unmet needs. A New South Wales study found that 6 of the 10 highest-ranked needs of melanoma patients, across varying times since diagnosis, concerned health information (Bonevski *et al*, 1999). They also identified needs in other domains, such as psychological concerns and problems with health care providers, in addition to disease-specific needs. Girgis *et al* (2000) found that New South Wales women diagnosed with breast cancer had the highest level of needs in the information domain, with 10 of the 15 highest moderate or high unmet needs relating to this domain. This study mainly included women three or more years post-diagnosis. A study of prostate cancer self-help groups in Queensland found that there were moderate to high unmet needs reported by a third of men in the domains of sexuality, psychological concerns and health systems and information (Steginga *et al*, 2001). They identified health system and information needs as a priority area for prostate cancer patients, which included men from a range of educational backgrounds, across major urban and regional geographical areas with relevance to the general community. A New South Wales study of breast cancer survivors in remission 6-24 months after completion of their hospital-based treatment found many unmet psychosocial needs (Thewes *et al*, 2004a). This study further examined site-specific issues for recent breast cancer survivors, and found the area of highest unmet need was in the information and medical communication needs domain. Unmet needs for help with coping with breast cancer were also prevalent (Thewes *et al*, 2004a). A New South Wales study of people within three to six months diagnosis with colon cancer found that the highest level of needs concerned professional support and information (Hancock *et al*, 2002). Also people with a colostomy bag had high levels of unmet needs in the psychological and physical/daily living domains (Hancock *et al*, 2002).

2.4 FACTORS ASSOCIATED WITH UNMET NEEDS

The above studies indicate that there is much variability in the levels and domains of unmet needs across cancer populations sampled. These studies' sampling frames differed by phase of the cancer experience, cancer site, cancer stage, types of treatment and geographical location; all likely to be associated with unmet needs. When considering the correlates of supportive care needs, Sanson-Fisher *et al* (2000) included the following variables in a regression analysis: when the patient was first told that he or she had cancer; the primary site of cancer; the current cancer site; whether the cancer was in remission; the type of treatment ever received; the type of treatment received in the last month; when the patient was last admitted to hospital for treatment of the cancer; the treatment centre; and the patient's age, gender and marital status. Sanson-Fisher *et al* (2000) found within the psychological needs domain that age, gender, treatment centre and whether the cancer was physically diminishing were associated with unmet needs. Age, type of treatment received last month, and whether the cancer was diminishing were associated with health system and information needs. Gender, date of last administration for treatment, treatment centre, and whether the cancer was diminishing were associated with physical and daily living needs. Age, gender, type of cancer, when patient was told of cancer diagnosis, treatment centre, and whether the cancer was diminishing were associated with patient care and support needs. The significant correlates of sexuality needs were age, gender and type of treatment received in the last month. Sanson-Fisher *et al* (2000) study included participants with a mix of cancer sites who were receiving treatment. The support needs of cancer survivor in the treatment phase are likely to be different from those who have completed treatment and are attempting to return to previous levels of physical, as well as psychosocial function. Also the site-specific support needs of cancer survivors may be concealed in this research which pools all sites together.

Molassiotis *et al* (2002) states that needs of gynaecological cancer patients are shaped by site, treatment type, demographic characteristics, social backgrounds of patients, personality traits and previous experience with stressful events and coping. Cultural values and ethnic background may also influence needs as they affect every aspect of the experience of health and illness, ultimately affecting the perception of satisfaction with life, well-being, and quality of life (Marshall, 1990). Several intrapersonal variables have been found to be associated with poor adjustment to cancer, including a psychiatric history, substance abuse, and certain coping styles (Rowland, 1989b). Recent interest has grown in spirituality as a factor affecting adjustment to cancer. However, while this interest is evident in media reports and descriptive studies (eg self-reported use of spirituality by patients), few empirical studies have examined the link between spirituality and psychosocial adjustment to cancer (Gioiella *et al*, 1998; Holland *et al*, 1999; Mytko & Knight, 1999). Chan *et al* (2001b) found that gynaecological cancer patients at risk of psychosocial maladjustment included those who are without religious beliefs, as well as those who are treated surgically and less educated. No studies have examined the impact of spirituality on patients' unmet needs. Identifying correlates of unmet needs may enable service providers to develop interventions that target and assist the groups of people with higher levels of unmet needs, to manage their distress.

2.4.1 CANCER PHASE

Individual reactions and psychosocial needs vary at each phase of disease post-diagnosis (Rumsey & Harcourt, 1998). Mullin (1990) described three phases post-diagnosis on the life trajectory. The first phase, the period from diagnosis through to first year, which generally includes treatment, is referred to as acute survival. The second phase, or extended survival, is from the end of the first year following diagnosis until approximately three years later. The third phase, permanent survival, extends from three years out, when the probability of recurrence diminishes for most cancers. Mullin (1990) categorises disease phases according to time since diagnosis. Other research has reserved the word 'phase' to refer to stages in the disease trajectory that are more strictly characteristic of a similar symptom or life experience. For example, Clipp *et al* (2001) capture developmental phases of illness including crisis, early chronic, late chronic and terminal. Andersen *et al* (1989b) define "islands" of disruption that occur at particular points in the cancer trajectory. Stanton *et al* (2005) focus on the period immediately following the diagnosis and treatment phase, known as the reentry phase. In the consideration of the cancer care continuum, Hudson (2005) defined two phases for intervention considerations; primary interventions for patients undergoing diagnosis and treatment, and secondary interventions for cancer-free survivors. In this study it is acknowledged that individual variability in illness experience is likely however, Mullin's (1990) survival phases were used to capture broad differences in needs and morbidity outcomes over an extended period of time.

2.4.1.1 *CANCER IN GENERAL*

Bloom (2002) summaries the quality of life cancer research within the three survival phases and notes that, emotional distress, especially depression and anxiety are early effects of diagnosis and treatment of cancer but seem to dissipate by the end of the first year. Other acute phase effects are energy reduction, decrease in physical functioning and symptom distress (Fobair *et al*, 1986). Bloom (2002) notes that within the extended survival phase problems such as continued energy reduction, decrements in physical functioning and body image changes typically exist, as well as interpersonal issues such as returning to work, re-establishing parenting roles and the increasing salience of issues of sexual function/dysfunction. In the third phase, permanent survival, Bloom (2002) summaries that permanent loss of energy and relationship issues continue to be reported. Also issues such as reintegration into society, resuming prior activities, such as jobs and recreational activity, and the late effects of therapy become prominent concerns in the third phase (Gotay & Muraoka, 1998).

2.4.1.2 *PHASES IN GYNAECOLOGICAL CANCER*

Although adjustment to cancer is an ongoing process, few studies have assessed the health-related quality of life of gynaecological cancer patients over an extended period. Of the studies that have done so, findings consistently suggest that gynaecological cancer patients experience significant psychological and social effects of disease and its treatment up to six months after completion of treatment (Andersen *et al*, 1989b; Klee *et al*, 2000a; Chan *et al*, 2001a). This period of significant effects approximates the first survival phase, with treatment usually taking about three to six months to complete and the first survival phase stretching to one year post-diagnosis. After the approximated first survival phase (from 6 to 24 months after treatment), scores remained the same on the global health status and functional scales (including physical, role, emotional, cognitive and social functioning) for quality of life (Chan *et al*, 2001a). Hence, in Chan *et al*'s study phase was significantly correlated with global health status and all functional scales when comparing women who were pre-treatment to six month after treatment, to women who were 6 to 24 months after treatment.

A qualitative study of seven female cancer patients, five breast and two gynaecological malignancies, found that narrative responses supported the notion that the period after treatment may be viewed as a crisis that brings with it anxiety and uncertainty (Arnold, 1999). Arnold (1999) recommended that additional research be conducted so that services and programs can better meet patients' needs by playing a critical role in helping women make the transition from cancer patient to cancer survivor.

2.4.2 TYPE OF CANCER

Variation in support needs across types of cancer is not surprising, as different cancers require different treatment options, and therefore, survivors are faced with different side-effects, losses or equipment with which they have to deal. While gynaecological cancers are regularly grouped together, each distinct site has its own causal factors, symptoms, diagnosis and treatment and probably most important from a survivors perspective, site-specific morbidities outcomes.

Vulval cancer survivors experience significant sexual dysfunction and alteration in body image, whatever the extent or type of surgery (Green *et al*, 2000). Vulval numbness can hinder sexual arousal, and possible removal of the clitoris alters body image as a result of scarring and perceived disfigurement (Lancaster & Nattress, 2005). Loss of perineal fat and vulval swelling can also cause pain or discomfort (Lancaster & Nattress, 2005). Vulval cancer survivors have a much higher risk of developing lower limb lymphoedema compared to other gynaecological cancer survivors due to their treatment that often involves lymph node removal and follow-up radiation (Ryan *et al*, 2003b).

Cervical cancer is primarily caused by the human papilloma virus or warts virus, and patients with this cancer deal with the stigma of the disease being sexually transmitted (Corney *et al*, 1992). Also, because cervical cancer is one of the more easily detected gynaecological cancers (*via* the Pap test), patients tend to be diagnosed at a younger age, which results in many of the cervical cancer survivors having to deal with loss of fertility and early menopause (Biglia *et al*, 2004).

Ovarian cancer patients have a very different disease trajectory, they have poorer prognosis as most patients tend to present to the doctor at an advanced stage of their disease (Molassiotis *et al*, 2002). Studies have shown that ovarian cancer patients' awareness of having a more severe disease is associated with greater psychological distress (Pignata *et al*, 2001). Miller *et al* (2002) found that among cervical, uterine and ovarian cancer survivors who were at least six months after treatment, all scores (physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing and total quality of life) were lowest in patients with ovarian cancer. However, Chan *et al*'s (2001a) longitudinal study of cervical, uterine, ovarian, vulval and other gynaecological cancer survivors did not completely replicate this finding. It was reported that type of gynaecological cancer was associated with physical, cognitive and social function but not role and emotional functioning or global health status (Chan *et al*, 2001a). Parameter estimates were not presented for subscales and hence it was unclear as to which types of cancer had higher functioning scores.

2.4.3 STAGE OF DISEASE

Gynaecological cancers are diagnosed as one of four stages, depending on their severity, or recurrent disease (Gynaecological Cancer Society, 2003). Recurrent cancer is cancer that has recurred after it was treated (Gynaecological Cancer Society, 2003). Studies have found stage of disease to have no relation to long-term overall quality of life in gynaecological cancer patients (Chan *et al*, 2001a; Chan *et al*, 2001b). However, stage was associated with the physical and cognitive functioning of gynaecological cancer survivors (Chan *et al*, 2001a). Supportive care needs research has either not collected stage information (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001) or not reported stages' correlation value (Newell *et al*, 1999). However, regarding stage of disease, the prevalence of depression in cancer patients has been found to be positively correlated to severity of illness (Massie, 1989; McDaniel *et al*, 1995).

2.4.4 TREATMENT AND REMISSION

Treatments for gynaecological cancers vary depending on the site and stage of disease (Bos-Branolte, 1991). The effects of treatment on patients have been discussed in Section 2.2.1 Treatment of Gynaecological Cancer. Chan *et al* (2001a) found that treatment type for gynaecological cancer patients was significantly correlated with global health status and role functioning. As indicated by the parameter estimates for factors affecting global health status, patients who had surgery had the highest global health scores compared with radiotherapy (which was next highest) and chemotherapy. Treatment type was not associated with physical, emotional cognitive or social functioning (Chan *et al*, 2001a). Assessing a mix of cancer types, for patients attending surgical, radiation or medical oncology departments, Sanson-Fisher *et al* (2000) reported that the type of treatment received in the last month was significantly associated with health system/ information needs and sexuality needs, but not psychological needs, physical/ daily living needs or patient care/ support needs. However, the frequency of cases within the significant treatment types being compared to the referent were generally small (1, 3, 125, 5). The only convincing significant association was that patients who had chemotherapy in the last month (n=125) were 1.88 times (CI=1.23-2.86) as likely to report sexuality needs as patients who had other/multiple treatments in the last month.

Within the supportive care needs research that tested remission status as a correlate of five supportive care needs domains, cancer survivors not in remission reported a greater need for help within the psychological needs domain (Sanson-Fisher *et al*, 2000), health system/ information domain (Sanson-Fisher *et al*, 2000) and patient care/ support domain (Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001). In both of these studies, remission status was not associated with physical/ daily living needs or sexuality needs.

2.4.5 AGE AND GENDER

Unmet needs differ by age and gender, with a greater likelihood of unmet needs in younger compared to older and female compared to male patients (Girgis *et al*, 2000). In the case of the younger patient, for example, one of the major challenges of gynaecological cancer and its treatment may relate to its feared or actual association with diminished attractiveness or loss of child-bearing capacity and hence the ability to establish or maintain a sexual relationship (Brock & Perry, 1995). Thewes *et al* (2002) found that younger women who have survived breast cancer had more psychological needs than older women and older women had significantly higher needs for help with information and medical communication than younger women. Moreover, it was observed that female patients were three times as likely as males to report moderate/high levels of perceived needs (Newell *et al*, 1999).

2.4.6 GEOGRAPHICAL LOCATION

Another potentially critical issue that has received less attention in the needs literature is the impact of place of residency. Patients living in rural compared to urban areas may be more likely to have unmet needs due to geographical isolation and difficulty accessing health services. Men with prostate cancer who resided in major urban centres surrounding the capital city of Queensland reported more psychological needs then did men living in regional centres (Steginga *et al*, 2001). A study of breast cancer patients in New South Wales revealed that women living in a rural location reported two and a half times more needs in the physical and daily living domain compared to women living in an urban location (Girgis *et al*, 2000).

2.4.7 CULTURAL NORMS AND ETHNIC BACKGROUND

While culture has not been assessed for its effect on supportive care needs, Ashing-Giwa *et al* (2004) found ethnicity, cultural beliefs and cultural practices dictated the level of cancer related burden in a group of multiethnic cervical cancer survivors in America. In countries with a history of immigration, there is an emphasis on ‘culturally appropriate care’ (Markovic *et al*, 2004). In Australia, the concept of culturally sensitive care is applied also to the indigenous population. Australian studies have shown that the cancer experience of the Aboriginal population is very different from other Australians. Typically Indigenous women are reluctant to participate in screening and treatment and therefore experience delayed diagnosis and later-stage symptoms (McMichael *et al*, 2000). In the Aboriginal, Asian and Latina culture, it is unacceptable to expose women’s genitalia or discuss sexual health concerns, especially in the company of a male (McMichael *et al*, 2000; Ashing-Giwa *et al*, 2004). This poses a barrier for women of these origins to the health care system of Queensland, as currently there are five gynaecological oncologists, all of whom are male (Obermair, 2004).

Some immigrant women may also be reluctant to utilise the health care system due to the different diagnostic and treatment practices compared with the country they were born. Women of eastern descent, particularly those more recently immigrated, may have a belief in the superiority of alternative medicine (home remedies, herbs) over Western modern medicine (Ashing-Giwa *et al*, 2004). Also disclosure practices worldwide can include full, partial or non-disclosure of diagnosis (Markovic *et al*, 2004). Immigrant women in Australia, like other Australians experience full disclosure of their diagnosis (Markovic *et al*, 2004) and this potential difference in cultural norm may affect immigrant women and their family's support needs differently than Australian born women, as their cultural community may not be used to facing the reality of their diagnoses.

Culture also affects how survivors cope with their illness. The culture of care within indigenous and immigrant populations is also different from white Australians. For example the Indigenous culture has always relied on the Indigenous women as family and community carers (Kirk *et al*, 1997). When aboriginal women are sick they typically seek the support of their “Indigenous sisters” (Kirk *et al*, 1997), whereas many white Australian women rely on partner support or seek support services or groups with other patients of the same illness (Pistrang & Barker, 1995; Pistrang & Barker, 1998). Ashing-Giwa *et al* (2004) also found in an American sample, that women of colour in particular relied on faith and god for comfort, strength and healing and many believed their faith determined the cancer outcome. While culture may be associated with supportive care needs, it may also be a barrier to support service use. However, Indigenous and immigrant women may feel they have adequate support from their community and/or spiritual beliefs.

2.4.8 SPIRITUALITY

There appears to be consistent evidence that religious/spiritual beliefs may aid in psychosocial adjustment to cancer (Jenkins & Kl., 1995; Musick *et al*, 1998; Schnoll *et al*, 2000). Higher levels of existential and religious beliefs have also been associated with lower rates of anxiety and depression among patients with cancer (Kaczorowski, 1989; Fehring *et al*, 1997). Moreover, a higher level of spiritual/religious beliefs was associated with higher levels of psychological, social and family adjustment (Fernsler *et al*, 1999; Schnoll *et al*, 2000).

Research has suggested that spirituality is an important aspect of quality of life for cancer patients (Ferrell *et al*, 1992; Ferrell *et al*, 1995b; Wyatt & Friedman, 1996a; Wyatt & Friedman, 1996b). Brady et al (1999) showed that spirituality, as measured the FACIT-Sp, was found to be associated with quality of life to the same degree as physical well-being, a domain unquestioned for it's importance to quality of life. The significant association between spirituality and quality of life was unique, remaining after controlling for core quality of life domains and other possible confounding variables. Furthermore, spiritual wellbeing was found to be related to the ability to enjoy life even in the midst of symptoms (Brady *et al*, 1999), making this domain a potential important clinical target.

2.4.9 SOCIAL SUPPORT

Social support has been claimed by many authors to have positive effects on cancer patients physical health, mental well-being, and social functioning (Funch & Mettlin, 1982; Wortman, 1984; Goodwin *et al*, 1991; Waxler-Morrison *et al*, 1991; Leiberich *et al*, 1993b). It may be a valuable resource to coping with the disease and assume the function of meeting a variety of supportive care needs.

Social support researchers have increasing recognised the role of different types of support in various contexts. For example, Hoskins *et al* (1996) reported a strong positive relation between disclosure of feelings to friends and relatives and adjustment, and found that the need for support increased over time (from one month to a year post surgery, implying that a need for social support lasts well beyond the initial period of diagnosis and treatment. Courtens *et al* (1996) reported that breast cancer patients in the Netherlands were supported by small, dense networks, consisting mostly of family members and that the size of these networks as well as the amount of emotional support showed some decrease over time. Moreover, a tendency was found to indicate that patients with deterioration in quality of life perceived a larger decrease in emotional support than patients with a positive course (Courtens *et al*, 1996). Pistrang and Baker (1995) found that satisfaction with partners helping was associated with greater psychological wellbeing among women with breast cancer, with helping from other network members failing to substitute for effective spousal support. It is likely that women who feel less supported socially will have more supportive care needs.

2.5 FACTORS AFFECTING SUPPORTIVE CARE USE

Implicit in the assessment of unmet supportive care needs appears to be the assumption that patients' needs are not being met because the support care does not exist. However, this may not be the case. Survivors' lack of awareness and barriers to use of supportive care may be where the supportive care system breaks down. An Australian study of breast cancer survivors reported that, already having enough support from family and friends (43%), not knowing about services (23%), and not thinking services would be useful (20%), were the main reasons for women not using breast cancer support services (Rankin *et al*, 2004). In an American study, the most commonly reported barriers to using support services were: already having adequate support; lack of awareness of services; and lack of provider referral (Eakin & Strycker, 2001).

When considering supportive care provision it is important to go beyond identified unmet needs and consider awareness of and referral to support services, as well as other psychosocial and demographic correlates of supportive care use. This approach will enable services to determine whether they need to develop a higher profile within the community and/or whether they need to target subgroups that may require a greater need for help. It has been identified that higher education, having a physician referral, having higher levels of social support and lower levels of spirituality are important influences on the use of some psychosocial cancer support services (Eakin & Strycker, 2001).

2.6 EXISTING SUPPORT SERVICES

There are a variety of community support organisations and services available to gynaecological cancer survivors and their caregivers. These organisations may provide support to all types of cancer patients or they may provide support specifically to women diagnosed with gynaecological cancer, or they may provide morbidity-specific support such as for lymphoedema sufferers. The following is an outline of the main support organisations in Queensland and what services they provide.

2.6.1 GENERAL CANCER SUPPORT ORGANISATION:

The Queensland Cancer Fund (QCF) was established 1961 and currently provides services that are both general and targeted to supportive care needs, cancer types and age, gender and geographical subgroups. The table 2.1 outlines QCF services.

TABLE 2.1 QUEENSLAND CANCER FUND SUPPORT SERVICES UNDER SUPPORTIVE CARE NEEDS DOMAINS, (STEGINGA, 2002).

Practical	Informational	Psychosocial
Accommodation: Brisbane; Townsville; Rockhampton	Booklets and Brochures: that explain about different types of cancer, cancer treatments and ways to manage side effects of treatment.	Peer support: breast cancer; prostate cancer; brain tumours; teenagers with cancer; young women with breast cancer.
Wigs and Turban	Educational Sessions: understanding cancer and its treatment; nutrition; stress management	Psycho-educational sessions: for cancer in general and breast cancer
Home Equipment		
Financial Assistance: accommodation; transport.		

Note: Services are run from the following regional centres: Brisbane, Gold Coast, Sunshine Coast, Cairns, Rockhampton, Toowoomba, and Townsville.

Queensland Cancer Fund in conjunction with Griffith University also established the Cancer Support Centre in Brisbane in 2002, which provided professional counselling by psychologists for cancer patients and their families coping with diagnosis, treatment or life after cancer (Pinchen *et al*, 2002). However, this service was closed in early 2006.

The Sunshine Coast has a locally established cancer centre, the Bloomhill Cancer Help Centre in Buderim. It was established in 1997 and is a non-government funded charity. On becoming a member, it provides initial assessment by a registered nurse or counsellor, access to support groups, a respite care and companionship volunteer service, a 24 hour phone service for urgent enquires, a patient travel subsidy scheme, access to a library, relaxation and meditation, and a number of other subsidised therapies including counselling, massage, reflexology and reiki (Bloomhill Cancer Help, 2005).

2.6.2 GYNAECOLOGICAL SPECIFIC SUPPORT ORGANISATIONS:

The Queensland Centre for Gynaecological Cancer was established in 1982 and is responsible to Queensland Health for the provision of gynaecological cancer services for the State of Queensland. The centre located at Royal Women’s Hospital in Brisbane, provides an inpatient and outpatient clinic-based social work service. In addition, a gynaecological oncology support group for patients and their carers is held monthly at the Hospital. The centre also runs a physiotherapy service for both inpatient and outpatient care to the women who attend the Royal Women’s Hospital or District Health Service. A large part of this service involves lymphoedema management and prevention for women who have had lymph node dissection and/or radiation therapy. (Queensland Centre for Gynaecological Cancer, 1997)

In 1997 the Gynaecological Cancer Society of Queensland was established in response to the need for more comprehensive site-specific services for gynaecological cancer patients. The society has an “Information & Education Programme”, which covers a broad range of issues related to gynaecological cancer. The Society offers emotional support and practical advice to patients, their carers and close family members, through its “Emotional Support Helpline”, which is staffed by specially trained gynaecological cancer past-patients. The Gynaecological Cancer Society hosts an online electronic mail discussion group (talk@gcsau.org) and also has the ability to provide financial assistance to patients and their carers currently experiencing severe hardship and distress. (Gynaecological Cancer Society, 2000)

The National Ovarian Cancer Network (OvCa Australia) is specific to ovarian cancer patients and provides information leaflets, an information telephone line and events throughout the year. This organisation is dedicated to raising the profile of ovarian cancer. (OvCa Australia, 2005)

2.6.3 MORBIDITY SPECIFIC SUPPORT SERVICES:

Women who develop lymphoedema as a result of gynaecological cancer treatment can also seek specific support through the Lymphoedema Association of Queensland. This association provides telephone contact and support services, regular meetings with invited speakers on relevant topics and opportunities for informal exchange, and currently active support groups in Brisbane, Gold Coast, Toowoomba, Bundaberg, Mackay and Sunshine Coast. (Lymphoedema Association of Queensland, 2003)

A small proportion of women with gynaecological cancer may be fitted with a stoma as a result of having a bowel resection. These women are supported by the Australian Council of Stoma Associations. This body represents, at a national level, the interests of all 22 regional Stoma Associations in Australia. These associations provide information and support *via* stomal therapy nurses, as well as the stomal appliances required after a colostomy. (Australian Council of Stoma Associations, 2003)

2.6.4 MAPPING EXISTING SUPPORT SERVICES WITH SUPPORTIVE CARE NEEDS

It can be deduced by the types of support that the above services provide, that a variety of support needs are being addressed. Table 2.2 maps the type of support each agency provides for survivors (post-treatment) to the supportive care domains outlined earlier. In general, information needs seem to be well addressed by existing services. While most services indicate that they address psychological and patient care/ support needs, it must also be recognised that these services are often limited to the south-east region of Queensland. Some physical/ daily living needs are being addressed. The least directly targeted needs appear to be sexuality needs, however it is recognised that some of these sensitive issues will be brought up in forums such as support groups, counselling/social work sessions or within email discussion lists. Furthermore it is acknowledged that need domains are correlated and other services will also meet multiple needs.

TABLE 2.2 MAPPING EXISTING QUEENSLAND SUPPORT SERVICES WITH SUPPORTIVE CARE NEEDS DOMAINS

	Psychological needs	Sexuality needs	Physical and daily living needs	Patient care and support needs	Health system and information needs
Queensland Cancer Fund	Psycho-educational sessions, telephone counselling		Home equipment, respite care	Peer support, support groups, relaxation and meditation	Booklets, brochures, library and educational sessions
Cancer Support Centre	Counselling service				
Bloomhill Cancer Help Centre	Counselling		Respite care	Support groups, companionship volunteer service, relaxation and meditation	24 hour phone service, library
Queensland Centre for Gynaecological Cancer	Social work service		Physiotherapy service	Support group	
Gynaecological Cancer Society	Emotional support helpline	Sexuality issues information and supporting partners programme			Booklets, brochures, website, email list
National Ovarian Cancer Network (OvCa Australia)					Leaflets and information phone line
Lymphoedema Association				Support groups	Website information
Stoma Association			Stomal appliance	Stoma therapy nurse	Booklets, brochures, website

Overall, Queensland gynaecological cancer survivors appear to be well provided for. However, the question is whether these services are adequate across Queensland and are specific enough to meet gynaecological cancer survivors' needs. During key informant interviews in a prior arm of this study (see appendix 1: Qualitative pilot study report), it was stated that *"There are no specific support groups for gynaecological cancer patients. Other support groups such as the lymphoedema support group talk about many issues that are breast cancer specific and hence are not relevant for gynaecological cancer patients."* This quote raises a few support issues. Firstly, do existing support services require further tailoring to address gynaecological specific issues? Secondly, does awareness of available support need to be increased, as in fact the Queensland Centre for Gynaecological Cancer do provide a gynaecological oncology support group.

2.7 LIFESTYLE SUPPORT

A substantial number of reports suggest that cancer survivors adopt lifestyle changes in the hope of achieving improved health (Demark-Wahnefried *et al*, 2005). After recovery of treatment setting and achieving life-long healthy living goals is important to many cancer survivors (Brown *et al*, 2003). Healthy behaviours such as consuming adequate fruits and vegetables, stopping smoking, limiting alcohol intake, participating in sufficient physical activity, achieving or maintaining appropriate weight, and utilising complementary therapies, are an important part of supportive care. Cancer survivors may initiate these lifestyle changes themselves or they may become involved in behavioural interventions.

In a survey of 978 cancer survivors, with a mean of 3.2 years since diagnosis (SD±1.6), it was reported that there was a strong interest in health promotion programs aimed at healthier diets, exercise and smoking cessation (Demark-Wahnefried *et al*, 2000). Demark-Wahnefried *et al* (2005) identified many interventions targeting these interest that showed promise for improving survivors' health-related outcomes.

Patterson *et al* (2003) reported that about two-thirds of cancer patients diagnosed up to two years previously reported making changes in diet, physical activity and/or supplement use, and that these patients overwhelmingly thought that these lifestyle changes improved their health and well-being. Demark-Wahnefried *et al* (2000) found that 42% ate five or more daily serves of fruit and vegetables and 58% reported routine exercise, with a mean score among routine exercises indicating frequencies of approximately four times per week at moderate intensity for roughly 40 minutes per session.

2.7.1 COMPLEMENTARY AND ALTERNATIVE THERAPIES

Complementary and alternative therapies (CAT) appear to be widely used by cancer patients in many parts of the world. A systematic review of relevant published data (Ernst & Cassileth, 1998) located 26 surveys of CAT use by cancer patients conducted in 13 countries. The average prevalence of CAT use in a adjunctive or supplementary fashion, across all studies was 31%, indicating that nearly one-third of cancer patients used CAT for cancer reasons. However, the percentage varied greatly across studies from 7% to 64% depending on which type of cancer the patients had, which country the studies were conducted in, whether therapies were used in an adjunctive mode and/or as “curative” treatment, and how the studies defined CAT. Some studies defined CAT so broadly as to include all treatments receive outside of hospital, thus including counselling, support groups and other activities more appropriately counted as conventional support. According to this meta-analysis, the regimens used most often include dietary treatments, herbs, homeopathy, hypnotherapy, imagery/visualization, meditation, megavitamins, relaxation, and spiritual healing (Ernst & Cassileth, 1998).

A handful of studies have been conducted specifically with gynaecological cancer patients (Beaufort *et al*, 1988; Munstedt *et al*, 1996; Uwe *et al*, 1999; Von Gruenigen *et al*, 2001; Powell *et al*, 2002). These studies have been conducted in Germany and America, and found the prevalence of complementary therapy use ranged from 31% to 66%. Unpublished data from a Queensland study with ovarian cancer patients found that around 40% of patients use complementary and alternative medicine to help with their cancer (Webb *et al*, 2004). Studies generally indicated that younger age, female gender, and higher education and income are associated with use of alternative medicines (Eisenberg *et al*, 1993; Eisenberg *et al*, 1998; Ernst & Cassileth, 1998; Burstein *et al*, 1999; Boon *et al*, 2000; Richardson *et al*, 2000; Sollner *et al*, 2000).

While some patients use alternative therapies as a cancer treatment, most patients generally believed that complementary and alternative therapies helped to improve their quality of life through more effective coping with stress, decreasing the discomforts of treatment and illness, and giving them a sense of control (Sparber *et al*, 2000). Therapies used for these purposes play a part in supportive care for cancer patients. Randomised control trials have demonstrated the usefulness of many complementary therapies for relieving treatment related symptoms. In particular, hypnotherapy has proven valuable for anxiety, pain and nausea; relaxation therapy, music therapy and massage were effective in controlling anxiety; and acupuncture was effective in relieving nausea (Vickers & Cassileth, 2001). These trials were conducted during the treatment phase. For cancer survivors post-treatment, these therapies may still be relevant as anxiety and pain can be ongoing symptoms.

In addition to addressing cancer-related symptoms, complementary therapies fulfil an important psychological need for some patients (Holzner *et al*, 2001). Fear of the cancer spreading or returning was the most prevalently reported need for help within the supportive care needs literature (Sanson-Fisher *et al*, 2000). Cancer survivors may utilise CAT and lifestyle factors such as diet and exercise to protect against recurrence. Dietary treatments, herbal medicinal products and various food supplements are currently being promoted as ‘cancer cures’ but none of these treatments are backed up by convincing clinical evidence; however, the evidence is sufficiently encouraging to warrant further research (Ernst, 2000). Cancer patients in remission may utilise these therapies for their potential protective effect on cancer recurrence.

2.7.2 PHYSICAL ACTIVITY AND BODY MASS

Convincing data does exist that obesity is associated with breast cancer recurrence, and evidence on obesity and other prognoses is also accumulating for other cancers (International Agency for Research on Cancer, 2002). Physical activity has been associated with weight loss and weight maintenance among healthy individuals (Wing, 1999; Irwin *et al*, 2003), and recent studies have shown a favourable effect of exercise on body weight among cancer survivors (Rock & Demark-Wahnefried, 2002; Irwin & Ainsworth, 2004). Women with endometrial cancer seem to have the highest incidence (39%) of overweight or obesity compared to other types of cancer (Boyle *et al*, 2003). They have a three fold increase risk of developing this cancer when they are in the overweight (25-29) or obese (≥30) Body Mass Index (BMI) categories (WHO/FAO, 2003).

Physical activity and exercise participation are important considerations in management of acute and long-term care for cancer patients. Exercise is considered to be highly effective in relieving side effects of cancer such as mood swings, weight gain, sleep problems, poor body image and fatigue (Schain *et al*, 1994; Mock *et al*, 1997; Pinto *et al*, 2002). In populations other than cancer patients, exercise has been shown to have positive effects against anxiety, depression, and self image (Pappas *et al*, 1990; King, 1991), probably through a combination of direct and psychosocial effects. A lack of physical activity in adult oncology patients is related to diminished physical fitness, reduced functional status, impaired cognition, and diminished quality of life (Drake *et al*, 2004). Exercise-intervention trials have comprised the majority of the behavioural interventions conducted among cancer survivors. Despite the evidence suggesting that regular physical activity can protect against weight gain, decrease cancer risk, and potentially improve cancer prognosis, efforts to encourage physical activity are not a routine part of the cancer treatment or rehabilitation process.

2.7.3 FRUITS AND VEGETABLES

Within the gynaecological cancers, the WCRF/AICR (1997) report found there is possible evidence that fruits and vegetables reduce the risk of ovarian cancer, cervical cancer and endometrial cancer development. A more recent review article on ovarian cancer, with publications up to 2004, found the protective effect to be confined to vegetable intake alone (Schulz *et al*, 2004). Many potential mechanisms have been proposed to account for cancer protection by vegetables and fruits however; it is likely that the various vitamins, minerals and other phytochemicals in these whole foods act in synergy to reduce cancer risk (Brown *et al*, 2003).

For cancer survivors, the impact of dietary change on ultimate end points of disease progression and recurrence has yet to be determined (Demark-Wahnefried *et al*, 2005). Dietary interventions have been largely effective in increasing the intake of fruits and vegetables (Pierce *et al*, 1997; Pierce *et al*, 2004). Nutrition interventions have the potential to maintain energy, weight and activities of daily living in cancer survivors (Kalman & Villani, 1997). Dietary interventions to date have been delivered within individualised counselling sessions by nutritionist, trained volunteers or commercial institutions (*i.e.* weight watches), or by telephone counselling (Demark-Wahnefried *et al*, 2005). These can be resource intensive.

2.7.4 ALCOHOL

It is now generally accepted that drinking alcohol increases the risk of developing mouth, pharyngeal, laryngeal, oesophageal and liver cancers (WCRF/AICR, 1997). In people who have already received a diagnosis of cancer, alcohol could also affect the risk for new primary cancers (Brown *et al*, 2003). There are many alcohol related medical problems that are important in the consideration of cancer recovery and quality of life. Evidence suggest that women can develop these problems at lower levels of consumption than men, probably reflecting women's lower total body water, gender differences in alcohol metabolism, and effects of alcohol on postmenopausal oestrogen levels (Bradley *et al*, 1998). Higher levels of alcohol consumption by women are associated with increased menstrual symptoms, hypertension and stroke, increased infertility, spontaneous abortion and adverse fetal effects (Bradley *et al*, 1998).

2.7.5 CIGARETTE SMOKING

Tobacco smoke contains around 43 carcinogenic (cancer-causing) substances (U.S. Department of Health and Human Services, 1989). There is convincing evidence that smokers have significantly increased risks for developing cancers at various sites. It is estimated that 40% of vulval cancers and 19% of cervical cancers are attributable to smoking (Winstanley *et al*, 1995). Apart from cancer, smoking is strongly associated with cardio-vascular disease, stroke, emphysema, a range of other respiratory diseases such as asthma and bronchitis, hypertension, peptic ulcer, eye cataracts, macular degeneration (which can lead to blindness), Crohn's disease, impotence, back pain and premature facial wrinkling (The Cancer Council NSW, 2002). To improve quality of life, survival and diminish risk of cancer recurrence and the development of other major health problems, smoking cessation is imperative. Programs for cancer patients that aid this cessation are an important part of supportive care.

2.8 ASSESSMENT OF PATIENT MORBIDITY OUTCOMES FOR SUPPORTIVE CARE REQUIREMENTS

2.8.1 SHIFT OF FOCUS OF MORBIDITY OUTCOMES

Traditionally, the effectiveness of cancer care has been assessed using biomedical endpoints such as tumour shrinkage, survival and length of remission (Boyes *et al*, 2002). Izsak and Medalie (1971) suggested that although survival rates are important, they do not reflect how well individuals have survived. Emphasis on quality of survival was first seen in the works of Mayer (1975) and Veronesi and Martino (1978). Mayer (1975) introduced the concept of "rehabilitation" in partnership with traditional treatment modalities, so that the focus of treatment included the consideration of a persons ability to function day-to-day following treatment. Veronesi and Martino (1978) were the first to examine the social/cultural context of cancer after treatment and how that effects quality of life. In the early 1980s studies began to focus on psychological reactions (eg. depression, anxiety) to cancer and their relationship to adjustment and well-being (Holland, 1982; Derogatis *et al*, 1983). Few studies reported psychosocial outcomes amongst adults who had completed treatment (Kennedy *et al*, 1976; Maher, 1982).

With continued improvements in the control of cancer and increased survival rates among diagnostic groups, in the last twenty years the focus of health professionals has expanded beyond the biomedical model which focused on treating the disease, to include issues relating to morbidity outcomes of cancer in the psychological, social and physical context of each individual patient, thus encompassing a broader biopsychosocial perspective (Foot & Sanson-Fisher, 1995). Gustafson (1991) has suggested that this shift in patients' responsiveness is essential in order to ensure the important non-physiological needs of patients are recognised, and services appropriately modified or developed to address the impact of disease on the whole person.

In line with this philosophical shift, a body of research has evolved to explore the morbidity sequelae of cancer. Three primary methodologies have been applied in the study of morbidity outcomes for cancer patients: quality of life, patient satisfaction and needs assessment (Ware *et al*, 1978). Quality of life evaluations have gauged the ramifications of disease for different aspects of life experience (Gustafson, 1991; Lehr & Strosberg, 1991; Gustafson *et al*, 1993; Skeel, 1993). Patient satisfaction surveys have more closely focused on perceived quality of care issues (Ware *et al*, 1978). In contrast, needs assessment spans both quality of life and quality of care issues when the impact of disease on patients' needs is assessed (Bonevski *et al*, 2000).

2.8.2 QUALITY OF LIFE MEASURES ON ONCOLOGY

By mid-1990s, the term "quality of life" appeared to have supplanted "adaptation" and "psychosocial adjustment" as the psychosocial outcome of patients' and survivors' health and wellbeing (Zebrack, 2000). This ascendance of quality of life as a primary outcome measure in psychosocial oncology (as well as health service research, acute care, clinical trials, and chronic illness) has coincided with economic changes as pressure forces health care providers to reconcile quality of care and cost effectiveness (Zebrack, 2000). The United States National Cancer Institute recommends quality of life assessment in all clinical trials (Kiebert & Kaasa, 1996). Quality of life is a multidimensional, dynamic concept that encompasses psychological, social and physical aspects associated with a particular disease or its treatment (Guyatt *et al*, 1993). Questionnaires measuring quality of life can be either generic, to measure the health status for any disease and compare to different populations, or specific for patients with a given disease (Jones *et al*, 2006). Specific-disease quality of life instruments should be more sensitive to change in health status because they contain items from relevant patient groups (Streiner & Norman, 1995).

2.8.3 PATIENTS' SATISFACTION IN ONCOLOGICAL CARE

During the past decades, increasing attention has been paid to monitoring and improving the quality of health care services. In this respect there is a growing consensus that patient satisfaction with care is an important outcome parameter (Zastowny *et al*, 1995). Patient satisfaction is an indicator of care quality and its assessment provides feedback to clinicians and to services. It is also considered as an outcome measure, allowing one to assess the superiority of one treatment, program of care, health care organisation or system, over another (Bredart *et al*, 2003). Assessment of health-service-users' satisfaction fulfils a number of valuable functions. Satisfaction research can describe health services from the users' point of view, identify strengths and weaknesses in service provision and contribute to a strategy of health care-evaluation (Sitzia & Wood, 1998).

The issue of patient assessment of quality of care is particularly salient in the field of cancer. Cancer patients are often confronted with continued dependence on health care providers for lengthy treatments, medical follow-up or rehabilitation. They commonly experience unpleasant or debilitating side-effects of treatment, which may undermine continued compliance. They often have to face considerable emotional strain. This requires particular attention and interpersonal competence from health care providers, specifically for dealing with patients' concerns about nature, course and prognosis of disease. In this context insufficient quality of healthcare interventions or services can contribute to further deterioration of patients' quality of life. (Bredart *et al*, 1998)

2.8.4 NEEDS ASSESSMENT IN ONCOLOGY

In the oncological setting, needs assessment was first utilised for both patients and their families in the early 1980s. Stengle and Eckert (1983) reviewed an existing cancer foundation's ability to meet the continuing care needs of colorectal cancer survivors *via* its service provision. This study (Stengle & Eckert, 1983) looked at the type of services requested and provided for colorectal cancer survivors, in an effort to reconcile survivors unmet supportive care needs. On the other hand Blumberg (1983) used qualitative formative evaluation to develop educational materials for adolescence with cancer, a need the National Cancer Institute identified themselves and ask patients and their families to determine the relevance, importance and usefulness of materials being developed. Both studies utilised very different approaches to needs assessment, in terms of the study method, the inclusiveness or exclusiveness of types of needs (informational *vs* social, psychological and other) and the parameters of what resources patients may suggest as useful to meet their needs. While these studies state they are using needs assessment outcomes, it is possible Stengle and Eckert (1983) are assessing patient satisfaction and Blumberg (1983) is purely developing a resource without actually assessing needs first.

2.8.5 COMPARING MORBIDITY OUTCOMES

Although the distinction of three methodologies to explore morbidity outcomes has been made, morbidity measures have often been subsumed into the term 'quality of life' (Foot, 1996). In addition, the term 'needs assessment' has frequently been cited in the literature in relation to both patient satisfaction surveys and quality of life evaluations (Foot, 1996). This merging of constructs may be due to the way in which morbidity terms are defined. The definition of the perception of quality of life for cancer patients has been reviewed by Montazeri *et al* (1996) and was defined in two ways: conceptual and operational. Conceptually, quality of life refers to well-being, quality of survival, human values and satisfaction of needs, and operationally, it refers to a patient's evaluation of their own health compared with what they expect to be possible or ideal.

Needs assessment has been conceived as an important quality of life indicator (Mor *et al*, 1991; Kane & Boult, 1998) and has been defined as the process undertaken to measure patient perceptions of issues with which they require help for optimal health and quality of life outcomes (Foot & Sanson-Fisher, 1995). Satisfaction has been defined as the extent to which patients' expectations, desires or needs are felt to be met (Linder-Pelz, 1982). All three constructs measure from a patient's perspective, satisfaction of needs compared with what they expect to be possible or ideal well-being.

Although the concepts underlying satisfaction surveys and needs assessment are interrelated (as both measure dimensions of patients' perception of their disease experience and aim ultimately to improve quality of patient care (Till, 1991)), satisfaction measures are restricted to measuring the efficacy of existing support whereas, needs assessment measures consider what support ought to be provided (Foot, 1996). It is the difference between asking "were you satisfied with this?" and "what would you find satisfying?". Hence, the scope of evaluation in needs assessment is conceptually less restrictive (Foot, 1996).

In relation to the quality of life concept, Mor *et al* (1991) argued that unmet needs were related to needs for assistance and thus to health-related quality of life. However, some differentiation of the two approaches was made on the basis of functionality (Foot, 1996), *i.*e. unmet needs were functionally based because unlike quality of life measures, they intrinsically assessed a social support factor. To some extent this is true, as needs assessment allows the respondent to answer whether they had no need because the item was not applicable or because they were satisfied. This satisfaction response option may be a reflection of an individuals social support network meeting that need or it could be that other forms of supportive care (*i.*e. services, complementary therapies, lifestyle changes) are satisfying these needs. Quality of life assessment on the other hand, measures perceived problems without accounting for whether the patient indeed requires help (Foot, 1996) or if they are already supported, socially or otherwise.

2.8.6 JUSTIFICATION FOR NEEDS ASSESSMENT

Although quality of life measures have provided important insights into the problems experienced by patients, and patient satisfaction surveys have revealed the less satisfying aspects of patients' experiences of care, both methods fail to link patients' experience directly with service desires (Bonevski *et al*, 1999). Thus both measurements require a conceptual leap to determine patients' service needs. Moreover, neither measurement reveals what patients ideally want from the health care system or the extent to which their needs are being satisfied.

Of the three appraisal areas (quality of life, patient satisfaction and needs assessment), needs assessment is considered to be the most useful for evaluating supportive care, as it directly assesses and identifies specific issues of need for patients, as well as perceived magnitude of those needs (Sanson-Fisher *et al*, 2000). It can measure both met and unmet needs (Boberg *et al*, 2003). It enables individuals and subgroups of patients with higher levels of needs to be identified and targeted with appropriate interventions (*eg*. Counselling of young women to help with fears), and this method also makes it possible to identify and prioritise aspects of health services that need improvement (Spiegel, 1994).

2.8.7 NEEDS ASSESSMENT MEASUREMENT TOOLS

A review of the psychometric properties of needs assessment tools used with oncology populations and published between 1985 and 1995 revealed that a lack of quality tools. Approximately one-fifth of studies lacked face validity, other studies employed poor methods involving objective and/or retrospective assessment of patients needs. Remaining subjective studies involved labour intensive methods, such as interviews, card sorts or focus groups. No self administered needs assessment tool was located with empirical evidence of its capacity to provide a reliable, valid and comprehensive assessment of prevalence and magnitude of unmet needs in the cancer population. (Foot, 1996)

2.8.7.1 *CANCER PATIENT NEEDS QUESTIONNAIRE*

In the absence of an existing comprehensive, reliable and valid needs assessment instrument for adult oncology patients, the Cancer Patient Needs Questionnaire (CPNQ) (also referred to in the literature as the Cancer Needs Questionnaire (CNQ)) was developed by Foot and Sanson-Fisher (1995). A principle component factor analysis provided evidence for construct validity of the following five factors, which together accounted for 69% of the total variance (Foot & Sanson-Fisher, 1995):

1. Psychological needs: assessing patients' perceived need for help with psychological and emotional issues, including counselling and support.
2. Health information needs: information needs pertaining to diagnosis, investigative test, psychologic issues, family issues and financial issues.
3. Physical and daily living: physical needs and adjustment tasks, including coping with physical symptoms and side effects of treatment, performing usual physical tasks and activities of daily living and self-management of medical treatment routines and health care at home.
4. Patient care and support: support needs of cancer patients in relation to family, friends and health care professionals.
5. Interpersonal communications: interpersonal relationships and the interaction skills and communication styles of health care providers.

The internal reliability of all five factor-based scales was found to be substantial, with Cronbach's alpha co-efficient being in excess of 0.90 on factors one to four, and 0.78 on factor five (Foot & Sanson-Fisher, 1995).

2.8.7.2 SUPPORTIVE CARE NEEDS SURVEY LONG-FORM

Bonevski *et al* (2000) adapted the Supportive Care Needs Survey (SCNS-LF59) from the CNQ following consultation with health professionals and people with cancer, although, their reasoning as to why the CNQ needed to be modified was unclear. Bonevski *et al* (2000) stressed the importance that needs assessment instruments provide demonstrable evidence of sound psychometric properties. As has just been outlined above the CNQ had adequately demonstrated validity and reliability. Never the less, on the basis of patient and expert responses some items from the CNQ were made redundant or rephrased and some new items were included. This successor instrument was then validated in a sample of a consecutive series of patients from nine treatment centres, collectively accounting for approximately 20% of all surgical oncology in the state of New South Wales. A principal components factor analysis identified five factors with eigenvalues greater than one, which together accounted for 65% of the total variance (Bonevski *et al*, 2000). Cronbach alpha reliability coefficients of all five factor based scales were found to be substantial, ranging from 0.87 to 0.97 (Bonevski *et al*, 2000). Four of the five constructs (see below) are similar to those underlying the Cancer Needs

Questionnaire. The issue of sexuality was a new construct that may have reflect changing attitudes towards aspects of patient morbidity (Bonevski *et al*, 2000).

The SCNS-LF59 classifies needs into the following domains:

- Psychological: needs related to emotions and coping.
- Health system and information: needs relating to the treatment centre and obtaining information about the disease, diagnosis, treatment and follow-up.
- Physical and daily living: needs related to coping with physical symptoms and side effects of treatment and performing usual physical tasks and activities.
- Patient care and support: needs related to health care providers showing sensitivity to physical and emotional needs, privacy and choice.
- Sexuality: needs related to sexual relationships.

2.8.7.3 *SUPPORTIVE CARE NEEDS SURVEY SHORT-FORM*

To enhance the practical utility of the SCNS-LF59 further psychometric development of a short-form was undertaken in 1998 and 2002. This was done by consecutively removing the item that correlated the least with the remaining items in the domain until all correlations resulted in coefficients of 0.57 or greater. In addition the frequency distribution and clinical significance of each item was considered using data from the validation of the SCNS-LF59. The Supportive Care Needs Survey – Short-Form 34 (SCNS-SF34) was developed and has a total of 34 items which make up five domains, identical to the long-form. The five factors accounted for 72% of the total variance. The Cronbach's alpha ranging from 0.87 to 0.96. The SCNS-SF34 is recommended for all new activities. (McElduff *et al*, 2004)

2.8.7.4 *SUPPORTIVE CARE NEEDS SURVEY SUPPLEMENTARY MODULES*

A number of supplementary modules have been developed in conjunction with the SCNS-LF59 and SCNS-SF34. The modules provide more detailed information about perceived needs of specific cancer patient populations and primarily assess issues related to specific cancer sites, stages of disease and types of treatment (Boyes *et al*, 2002). Modules are currently available for: breast cancer, melanoma, prostate cancer, colostomy, access to services and long-term survivors of cancer. Modules are currently under development for patients with advanced incurable cancer and women who experience lymphoedema following breast cancer treatment (McElduff *et al*, 2004).

2.8.8 QUALITY OF LIFE MEASUREMENT TOOLS

The inclusion of a quality of life measure in this survey was also considered, so as to provide a second, more widely accepted (compared with needs assessment) measure of cancer morbidity and allows the direct comparison to other cancer studies of quality of life. The inclusion of a quality of life measure also provided the opportunity to compare statistically the association between measures (quality of life and supportive care needs). Furthermore, quality of life tools incorporated some gynaecological-cancer-specific measures of morbidity. Three cancer specific measures of quality of life were considered: the Quality of Life – Cancer Survivors (QOL-CS) (Ferrell *et al*, 1995a); The European Organization for Research and Treatment of Cancer quality of life questionnaire (QLQ-C30) (Aaronson *et al*, 1993) and; the Functional Assessment of Cancer Therapy (FACT) (Cella *et al*, 1993). These three measures are validated and reliable tools used widely within cancer populations. The FACT questionnaire was selected because of its use in a general population study (DiSipio *et al*, 2006) that this study will compare to, as well as for its gynaecological cancer site-specific subscales and spiritual wellbeing subscale.

The Functional Assessment of Cancer Therapy – General (FACT-G) has 28 items for four subscales: physical (PWB); social/family (SFWB); emotional (EWB); and functional well-being (FWB). It uses a five-point ordinal Likert type response format. The scale is sensitive to stage of disease, performance status and change in patients' condition over time. The coefficients of reliability and validity have been shown to be high. Cronbach's alpha for each subscale has been reported (Cella *et al*, 1993) as follows in patients receiving cancer treatment with mixed cancer diagnoses: PWB, 0.82; FWB, 0.8; SFWB, 0.69; EWB, 0.74; and total FACT-G, 0.89. Test-retest reliability at three to seven days was 0.92 for the total scale with reliability for subscales ranging from 0.82 to 0.88 (Cella *et al*, 1993).

There are also cancer site-specific subscales that can be added to the FACT-G. Those specific to gynaecological cancers include the FACT-Cx for patients with cervical cancer, the FACT-O for patients with ovarian cancer, the FACT-V for patients with vulval cancer and the FACT-En for patients with endometrial cancer.

Currently, reliability and validity data is only available on the FACT-O and the FACT-V. The internal consistency and test-retest reliabilities for the validation of the FACT-O are as follows. The FACT-O total score, and PWB, EWB, and FWB subscales all showed very good reliability with cronbach's alphas and test-retest correlations greater than 0.80 (Basen-Engquist *et al*, 2001). The SWB and ovarian subscale had Cronbach's alphas and test-retest correlations between 0.70 and 0.80 indicating adequate reliability (Basen-Engquist *et al*, 2001). For the FACT-V, Cronbach alpha scores for PWB, FWB, the vulva subscale, and the FACT G and FACT-V were ≥ 0.80, while the EWB and SWB subscales had adequate internal consistency with scores of 0.75-0.77 (Janda *et al*, 2005).

In addition to the cancer-specific subscales a spiritual wellbeing scale is available. The Spiritual Well-Being Scale (FACIT-Sp) has been demonstrated to be a psychometrically sound measure of spiritual well-being for people with a mix of cancer diagnoses. The reliability of the scale was evaluated and found the alpha coefficient was quite good (cronbach's $\alpha = 0.87$) (Peterman *et al*, 2002). There were moderate to strong spearman correlations between total FACIT-Sp score and quality of life, as measured by FACT-G (0.58) and its subscales (0.25-0.55) (Peterman *et al*, 2002).

2.9 MODELS IN CANCER MORBIDITY RESEARCH

Many theories or models in cancer morbidity research have provided a framework in which to consider the functions of psychological, physiological, social and other variables and the pathways through which they might directly or indirectly affect health outcomes. In earlier cancer research, outcomes such as the constructs of quality of life and supportive care needs mentioned above were not considered. The concepts of coping and adjustment were really the first to evolve. However, a natural progression from these earlier concepts to the outcomes of current research occurred as the understanding of interacting influences on multiple needs and quality of life domains developed. The evolution of theoretical frameworks evolved in conjunction with the development of these morbidity constructs and the growing understanding of interacting influences on them.

2.9.1 STRESS, COPING AND HEALTH BEHAVIOUR MODELS

Throughout the late 1980s and early 1990s, a stress coping paradigm (Kessler *et al*, 1985) formed the foundation for investigations of individuals' psychological responses to cancer. According to coping theory (Lazarus & Folkman, 1984), coping is the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual. Coping theory focusses on identifying and measuring observable outcomes like coping response, adaptation, psychosocial adjustment, or psychosocial functioning (Kessler *et al*, 1985). Studies conducted within this paradigm advanced the knowledge of physical, emotional, sexual, social, vocational, and economic implications of living with, or beyond, a cancer diagnosis and treatment. However, coping theory and research has so far been of limited practical use in that it has failed to bridge the gap between research and the devise of effective interventions (Brennan, 2001). One of the difficulties in applying stress and coping theories to needs assessment is the focus on the psychological dynamics that occur inside the mind without reference to an individual's social support or evaluation of the importance of resources available to them (Harpur, 2002).

The primary proposition in coping theory studies is that patients' beliefs about symptom reporting in cancer is a critical determinant of how they cope with these symptoms (Ward *et al*, 1998). For example, in the research surrounding coping with pain in cancer patients, when patients have fear of addiction to medication, in spite of safe and potent analgesic medication, or fatalism about the possibility of pain control, these belief barriers result in them using inadequate potency levels of analgesic relative to the level of pain and their suffering continues compared to those patients who do not have these belief barriers (Ward *et al*, 1998). However, this model does not consider other factors that may contribute to, or relieve the perceived pain, such as having help around the house or at work to minimise onset or severity of pain. Furthermore, this stress-coping model does not contextualise the impact of this continued suffering on a person's quality of life. In addition to a model that considers social and environmental influence, a more inclusive model that links beliefs to coping behaviour and then to relevant outcomes such as quality of life or supportive care needs, would be more meaningful for both service provider and patient understanding.

Meta-models have served to define the components of stress and coping for a broader understanding of problem-specific outcomes such as pain or distress. For example, a problem-specific meta-model for adaptation to distress among cancer survivors includes personal factors (*e.g*. beliefs about cancer), environmental factors (*e.g.* health care providers, family members), and event-related factors (*e.g.* number and type of physical symptoms after treatment, presences or absence of side effects, ability to obtain health insurance) (Somerfield *et al*, 1999). While this approach broadens its view from the earlier stress and coping models, to consider multiple levels of factors that may influence a survivor's coping, it is limited to the study of a single, cancer-related problem and only the variables that relate to this problem. In reality, cancer survivors typically have multiple issues, which are the results of many interacting influences, and will therefore require a more holistic model with multi-dimensional outcomes such as supportive care need and quality of life domains.

2.9.2 SOCIAL COGNITIVE THEORY

Unlike coping theorists, who focus on how people respond to crisis, social cognitive theorists are more interested in the broader social and cognitive changes required of an individual and their social network in such circumstances (Brennan, 2001). In the context of gynaecological cancer, physical and mental health has been recognised to have implications for both the woman and her partner. Together couples encounter many potential losses, such as threat of death, change in the relationship, loss of income, employment, health and the activities of daily life (Harpur, 2002). A social-cognitive model (Lepore *et al*, 1996) emphasises the interpersonal contexts of recovery, and describes the way in which modification of social norms can impact on beliefs or behaviour (Nutbeam & Harris, 2004). This is important, as talking about trauma may facilitate the processing of adjustment by providing opportunities for understanding what is normal, and enabling people to find meaning in the experience (Brennan, 2001). However, disclosure may be met with responses that inhibit processing and increase distress. For example, some studies of social support have witnessed significant others reacting with fear or feelings of aversion towards cancer patients, resulting in patients feeling abandoned or rejected (Wortman & Dunkel-Schetter, 1979). It is important that both patients and their partners are informed about the disease and its sequelae, so that they develop realistic self-efficacy.

Social cognitive theory has evolved with input from several researches over the past fifty years; the most influential has been Albert Bandura (Nutbeam & Harris, 2004). Bandura (1986) developed self-efficacy theory within the framework of social cognitive theory. The theory provides an analysis of behaviour change, and states that a person's belief can be formed through information. Self-efficacy theory is advantageous for use in psychosocial intervention because influencing the development of sources of self-efficacy or belief provides direction of effective coping behaviours (Lev, 1997). That is, with acquired understanding and management techniques of the effects of gynaecological cancer, through evidence based interventions, women should believe in their ability to adjust and achieve quality of life again. This concept has been applied in the scenario of adjustment being facilitated by meeting patients' information needs. Galloway and Graydon (1996) found colon cancer patients who perceived more uncertainty in their illness placed more importance on having information to help manage after hospital discharge than patients with less uncertainty. This information would help them to formulate a realistic picture of what is likely to occur, and make it easier for them to evaluate any changes. Without such interventions, self-efficacy has been found to decrease over time with consequent decrease in adjustment to cancer (Lev, 1997).

Social cognitive theory, including the self-efficacy component, has also been identified as a useful framework for the design of health behaviour interventions. Within cancer populations, interventions based on social cognitive theory have been effective in increasing physical activity (Courneya *et al*, 2000; Rogers *et al*, 2004; Rogers *et al*, 2005). The application of self-efficacy theory within interventions improves a person's confidence in their ability to perform a certain behaviour, and outcome-expectancy further considers the impact of the value of the expected outcome on an individual's behaviour (Bandura, 1986). For example, those patients who believe they could be successful in exercise during treatment and who expect exercise will make them feel better or improve survival, will be more likely to participate in this behaviour. However, social cognitive theory does not recognise medically related barriers as part of the self-efficacy measure for ability to perform health behaviours (Rogers *et al*, 2004). Barriers such as fatigue, nausea and general malaise are likely to affect ability to increase physical activity, and thus confound the correlates of the uptake of this health behaviour.

Social cognitive theories are limited to the social and personal systems of adjustment, as they provide a basic understanding between behaviour and the social environment. While Bandura (1986) also formed a third part to this relationship by determining a range of personal cognitive factors that describe the way in which an individual, their environment and behaviour continuously interact and influence each other, the theory fails to recognise the biological impact on health behaviours or outcomes, as well as a full range of other environmental influences.

2.9.3 BIOPSYCHOSOCIAL MODEL

The current follow-up of oncological patients is based on the biopsychosocial model, where in addition to psychosocial change, functional impact of the illness on the patient is considered (Morales Lopez *et al*, 2002). This model emerged to incorporate biomedical impacts on health outcomes, as well as the psychological and social impacts recognised by social cognitive, and stress and coping theories (Astin *et al*, 2003).

In cancer research, the biopsychosocial model has been applied to the study of stress, coping and immune function in breast cancer patients (Luecken & Compas, 2002), predicting depressive symptoms in breast cancer patients (Wong-Kim, 2000), cancer treatment-related pain (Syrjala & Chapko, 1995), assessment of sexual dysfunction in oncology patients (Dobkin, 1991), and emotional expressions in cancer onset and progression (Gross, 1989).

In the context of assessing cancer patients' supportive care needs, the biopsychosocial model requires that assessment occurs across the following areas for each patient: physiological, demographic characteristics of patient and caregiver, psychological, available social support systems (human, financial, institutional, transportation, structural, accommodation), spiritual, and legal and advanced directives (National Cancer Institute, 2002). Furthermore, biopsychosocial intervention/options should take into account: places for care, possible team members for delivery of care, available programs, legal and/or advanced directives, pharmaceutical support, nutrition, and need for special devices (National Cancer Institute, 2002).

Foot (1996) developed a hypothetical biopsychosocial model of patients' adaptation to cancer to illustrate the role of needs assessment in influencing morbidity outcomes in oncology care. The model integrates some of the widely accepted biological, developmental, psychosocial and cognitive theories, with theories of coping and morbidity outcomes. The processes outlined in Foot's (1996) hypothetical model describe the steps that must be worked through in order to fulfil patient unmet needs, enhance coping, and improve perceived quality of life and satisfaction of people with cancer. The model proposes that when appropriate resources are available and utilised, the chances of problem resolution will be optimised, and prevalence and intensity of unmet needs will be reduced. However, the model in its entire complexity has not been tested in the context of research.

As suggested earlier, at the individual level, unmet supportive care needs may differ according to type of cancer, phase of the cancer experience, age, and gender of patients. Furthermore, survivor's individual condition and personal disposition play major roles in the need and use of particular supportive care (Foot, 1996), However, it is also acknowledged that other indirect factors, for example geographical location, existing healthcare, current policy, funding support, have an influence on the types of supportive care used (National Cancer Institute, 2002) and possibly needed. These factors sit within the broader systems of our environment and may serve to buffer or exacerbate the impact of disease upon the individual. The biopsychosocial model does not take into account that the use of supportive care by people diagnosed with cancer is influenced by a hierarchical of multi-level factors, that go beyond medical, personal and social levels of influence. Therefore, in the context of understanding the whole picture of influences on supportive care use and needs, it is necessary to consider a multi-level model of influence on multi-morbidity-domain outcomes.

2.9.4 SOCIAL-ECOLOGICAL MODEL

Previously discussed models have been developed to explain the effects of a stressor, such as life-threatening illness, on an individual; however, Bronfenbrenner's (1979) social-ecological model moves further to study the relationship of human beings to the settings and contexts in which they are actively involved (Shapiro *et al*, 1998). The social-ecological model organises the earlier mentioned frameworks including stress and coping, social cognitive, and biopsychosocial models, into a holistic framework that recognises the interactions of people and their illness experience within an ever-broadening range of contexts that exist in a person's environment (social, healthcare, community/work and political/cultural).

Needs assessment may be best understood within the context of Bronfenbrenner's (1979) ecological theory of human behaviour and development. Research during the late 1970s increasingly pointed to the use of the ecological model to understand service delivery systems, due to the model's consideration of nested influences (Crittenden, 1992). According to Bronfenbrenner (1979), the social-ecological conceptual model has four types of systems that influence an individual's development: 1) "microsystems" of individuals with whom a person has direct contact, such as family members, friends, co-workers and professionals; 2) "mesosystems" of which a person is not a member but that directly affect that person, such as supervisors who influence the course of therapy without meeting the client; 3) "exosystems" of bureaucratic structures that have impact on groups without the knowledge of the specific individuals affected, for example legislative bodies that make funding decisions and administrators who decide what services to offer; and 4) "macrosystems" of cultural influences that affect individuals and institutions through values, traditions and role expectations.

Patients' support needs may be directly related to biological, psychological social or environmental factors. In addition to these direct influences, it is postulated that un-met supportive care needs are a result of a nested hierarchy of influences, including cultural, political, community, family and individual factors (Kazak, 2001). The ecological model, unlike other frameworks, includes an emphasis on characteristics of the built environment and geographical location, such as community design, access to elements important to health behaviours, and the impact of technology such as television or other media (Patrick *et al*, 2005). The delivery of information, services or interventions to target unmet needs may be influenced by these indirect factors, recognised only by the ecological framework.

Bronfenbrenner's (1979) social-ecological model was originally intended to shed light on mental health issues in children; however, it has also been applied to adults and other illness populations. Applications of social-ecological theory have been made to chronic childhood disease and disability (Nihira *et al*, 1981; Crnic *et al*, 1983; Kazak, 1989; Kazak, 2001). Crittenden *et al* (1992) utilised the social-ecological model to analyse the service system for maltreated children in America. Shapiro *et al* (1998) applied the model to caregiver adaptation in mothers of child cancer patients, and Patrick *et al* (2005) applied the framework to cancer information communication methods. The social-ecological approach has also been utilised in healthy populations to identify correlates of physical activity (Blanchard *et al*, 2005) and to increase fruit and vegetable consumption (Peterson *et al*, 2002; Sorensen *et al*, 2004). A social-ecological perspective was considered conceptually in the assessment of cancer patients unmet needs by Foot (1996) however, when it came to implementing the model only the biopsychosocial levels of influences were tested for their association with unmet needs.

To evaluate supportive care systems in Queensland, the social-ecological perspective needs to be applied both conceptually and practically to assess the degree of fit between cancer survivors' biological, behavioural and sociocultural needs and the environmental resources available to them, ie. whether the existing supportive care system is meeting cancer survivors' needs. To assess the influences on patients' unmet supportive care needs, the following model has been adapted from Bronfenbrenner's (1979) social-ecological model to be applicable to the context of cancer and supportive care needs and use. Some constructs within the personal, social and healthcare levels of influence were transposed onto this model from the biopsychosocial model. That is, the physiological, demographic characteristics, psychological, and spiritual constructs were extracted from the National Cancer Institute's (2002) biopsychosocial framework for supportive care and inserted into the personal level of influence of the social-ecological model. Both the National Cancer Institute's (2002) biopsychosocial framework and Bronfenbrenner's (1979) social-ecological model note the importance of human social support for supportive care. Microsystems of individuals with whom a person has direct contact, such as family members, friends and co-workers have been included within the social support level of the model. The National Cancer Institute's (2002) application of the biopsychosocial model to interventions acknowledges the importance of taking into account geographical location, care delivery professionals, available support programs, pharmaceutical support, nutrition, and special devices that may be needed. These have been added to the model within the appropriate systems level. Several other constructs have been added to the health care level of this model based on the literature of what cancer survivors are utilising for support of their health (see sections 2.6 Support Services and 2.7 Lifestyle Support). The remaining constructs within the media/ policy/ culture and worksite/ organisational/ community levels of the model are based on the original version of Bronfenbrenner's (1979) social-ecological model.

The following model is complex and testing the whole model is beyond the scope of this PhD. Constructs highlighted in red will be considered within this research project. Constructs not included were not easily measurable, such as the media/policy/cultural levels of influence, as well as organisational administration, or not typically within the post-treatment phase of interest of this study such as, special devises, care delivery professionals, pharmaceutical support. A measure of exercise was included within the health behaviour construct and hence was not measured separately as a mode of health care. While spiritual belief was not measured, a measure of spiritual wellbeing was included within the wellbeing disposition construct and this was believed adequate to cover the influence of spirituality.

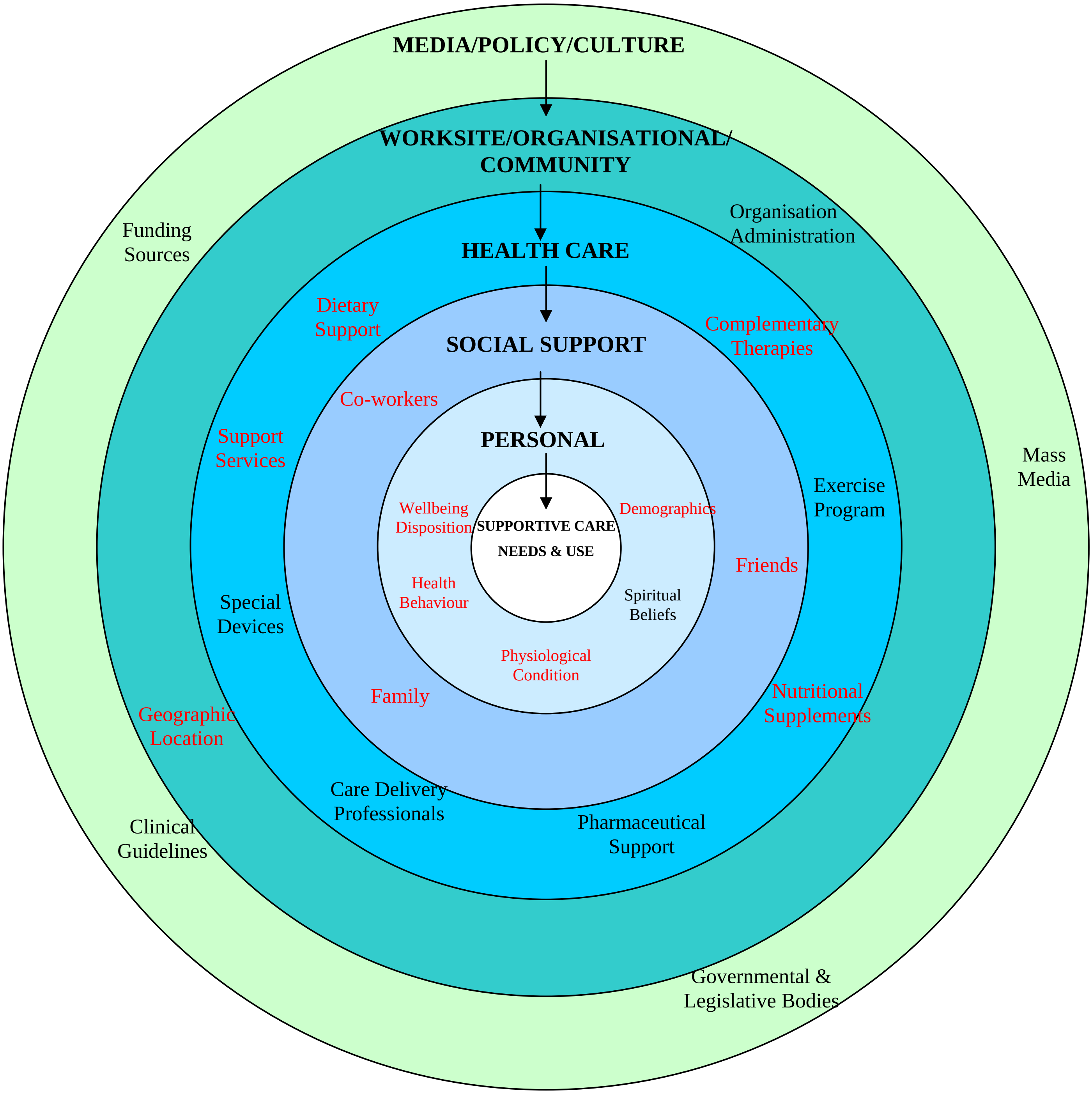


FIGURE 2.1 SOCIAL-ECOLOGICAL MODEL OF LEVELS OF INFLUENCE ON CANCER SUPPORTIVE CARE, ADAPTED FROM (BRONFENBRENNER, 1979)

2.10 SYNTHESIS

The impact of a gynaecological cancer diagnosis and treatment may present many challenges to both short- and long-term survival. Each particular gynaecological cancer site has its own sequelae and side-effects of treatment. Addressing the specific support needs these women is crucial to their quality of life. Needs assessment should enable the identification of existing unmet needs and the groups of cancer survivors that have higher levels of need, so service delivery can target these groups.

There is a growing body of research focusing on psychosocial aspects of gynaecological cancer survivors, however, these studies measure the patients' quality of life, which does not distinguish between patients having a problem and having a desire for assistance, as does the study of needs (Miller *et al*, 2003). World-wide, only six studies (Corney *et al*, 1992; Bourgeois-law & Lotocki, 1999; Gamel *et al*, 2000; Stewart *et al*, 2000; Jefferies, 2002; Miller *et al*, 2003) have examined specifically gynaecological cancer patients needs, and these studies are not Australian, they limit their focus to information and emotional needs and they use non-validated needs assessment measures.

Needs assessment of other cancer types in the Australia context has been abundant over the past ten years; however, the theoretical framework in which most studies have been constructed has been limited to the biomedical approach. Consequently, identified correlated of unmet need have been limited to disease and treatment variables and patient demographic characteristics. This approach excludes social, health care and broader community and cultural factors that may influence needs either directly or indirectly.

More recently, a "holistic" view has been taken of the needs of a person diagnosed with an illness, seeing their medical, information, psychosocial, and other needs in composite (Boberg *et al*, 2003). This view of needs assessment may be best understood within the context of Bronfenbrenner's (1979) social-ecological model (see figure 2.1), which extends the commonly researched biomedical perspective to study the relationship of human beings to settings and contexts in which they are actively involved. This includes consideration of health care and community factors that may be particularly important to cancer survivors who are beyond the treatment phase and attempting to return to previous levels of physical, as well as psychosocial function.

At this point, the extent to which existing supportive care meet the specific needs of gynaecological cancer survivors is unknown. There are a wide variety of support services provided by support organisations. Cancer survivors are also utilising complementary therapies and lifestyle-focused behaviours or interventions (ie, physical activity and diet) for supporting or improving their general health and wellbeing, although existing research on this topic is not specific to gynaecological cancer and it is not in the Australian context.

Hence, the aims of this research project were to explore: quality of life and some of the site-specific morbidities that result from the gynaecological cancer experience; the support that survivors are receiving or utilising; what unmet support needs exist within this community of cancer survivors in Queensland, and; the groups of women with relatively higher levels of supportive care needs and use. These aims acknowledge an interconnected picture of supportive care issues, needs, and use. To contextualise this interconnected picture, the social-ecological framework was adopted. Multi-level outcomes were examined, reflecting the multi-level nature of the model. These included outcomes that are influential on a personal level, such as an individual's perceived level of quality of life, their health behaviours, and the physiological conditions such as lymphoedema and sexual dysfunction with which some gynaecological cancer survivors chronically deal. The study examined the adequacy of social support which represents the second layer of influence of the social-ecological model. Beyond individual and direct factors to the individual, at the health care level of influence, the use of services and complementary therapies were examined. This multi-level conceptual model was also considered in the assessment of correlates of needs and use.

3 METHODS

3.1 RESEARCH DESIGN

3.1.1 METHODOLOGY AND RESEARCH QUESTIONS

This research used a quantitative approach applied to population-based data. The project was designed as an observational, cross-sectional, study that used self-administered mailed surveys to obtain patient information. This research project had six research questions that were derived from the literature review. The research questions were specifically targeted to gynaecological cancer survivors three months to five years post-diagnosis and were as follows:

1. What is the perceived level of quality of life?
2. What is the prevalence of diagnosed and symptomatic lymphoedema?
3. What is the prevalence of sexual dysfunction?
4. What is the prevalence of supportive care use (including community support services/ organisations, complementary therapies, health behaviours and social support) for support of wellbeing?
5. What is the prevalence of unmet supportive care needs?
6. What factors within the social-ecological model correlate with service use and supportive care needs?

Gynaecological cancer type and survival phase are two factors that may have had a significant relationships with the outcomes of interest in this study. While the initial intention was to pool data across cancer types and survival phases, if these variables proved to be effect modifiers, subgroup analyses were conducted.

3.2 TARGET POPULATION AND SAMPLE

3.2.1 STUDY DESIGN

As survival phase of the cancer experience has been identified as an important factor affecting patients' quality of life (Chan *et al*, 2001a) and needs (Rumsey & Harcourt, 1998), the ideal design for this study would have been a longitudinal, repeated-measures study following a cohort of gynaecological cancer patients through the different phases of survival. However, due to time and resource limitations within the PhD program, it was not possible to adopt this type of design and so stratified sampling has been used.

The design chosen for this study was a cross-sectional mail survey of Queensland gynaecological cancer survivors who were between three months and five years post-diagnosis. With the study's focus on cancer survivors and their community support, the choice of three months post-diagnosis was chosen to allow for surgical treatment to be completed and the patients to move into the survival phase. As three years is the point at which the probability of recurrence diminishes (Mullin, 1990), and the patients' support needs are likely to differ before and after this point, it was decided that a sample of patients up to five years post-treatment was suitable to determine if needs differ across survival phases of cancer. Stratified sampling by cancer survival phase was conducted to ensure sufficient numbers per phase for anticipated subgroup analysis. Phases of 3-12 months, 1-3 years and 3-5 years post-diagnosis were selected to reflect Mullin's (1990) classification of survival phases of cancer.

With regards to the study of patients' needs, compared to the other cancer sites gynaecological cancer has received less attention. Needs are likely to differ across types of gynaecological cancer. Thus the decision was made, in this early stage research, to be broadly inclusive of women diagnosed with cancer of all gynaecological sites. The sample was stratified by cancer site (ovary, cervix, uterine and all other gynaecological cancers) to ensure sufficient numbers per cancer site for the anticipated subgroup analyses. Vulval cancer survivors made up the majority of the "other" subgroup and therefore where sufficient data existed, vulval cancer survivors were also reported.

3.2.2 SAMPLING FRAME

Utilisation of a population-based sampling approach was used to maximise the generalisability of results. The original research plan was to recruit patients through the Queensland Cancer Registry (QCR) which is a population-based sampling frame. However, during the development of the design of this study, this sampling frame became unavailable due to a government procedural change blocking direct access by researchers to QCR patients and an extended moratorium ceasing all research occurring *via* this registry.

At the time, the sampling frame most closely approximating the QCR for gynaecological cancer patients, was the Gynaecological Cancer Registry (GCR), based at the Queensland Centre for Gynaecological Cancer. This Centre is responsible to Queensland Health for the provision of gynaecological cancer services for the State of Queensland. It is also the largest such service in Australia, centred at the Herston campus at the Royal Brisbane and Women's Hospital, with subcentres at the Mater Hospital, South Brisbane, Gold Coast Hospital, Southport, John Flynn Hospital, Coolangatta and The Townsville Hospital, covering most of Queensland. This registry has been maintained since 1982.

A comparison between the Queensland Cancer Registry data, which is a population-based registry, and the Gynaecological Cancer Registry data from 2001 (the mid year of our sampling frame i.e. women diagnosed between 1999 – 2004 and the latest available comparison data), found that approximately 85% of Queensland gynaecological cancer patients were registered on the Gynaecological Cancer Registry. A breakdown of the main cancer sites, for which there are registry comparison data, showed that approximately 64% of ovarian patients, 95% of cervical patients, 100% of uterine patients and 85% of all other gynaecological cancer patients were registered in 2001 at the GCR (see table 3.1). The comparison also shows that age and regional location were distributed similarly between registries in most subgroups, except in ovarian cancer survivors. In ovarian cancer survivors, women aged 30-39 and 40-49 were under-represented in GCR, with approximately two times less women in this age group and women aged 80+ were under-represented in GCR, with five times less in this age group, whereas the other ovarian age groups were similar in distribution. Moreover, ovarian cancer survivors who lived in North Queensland were under-represented in GCR, with approximately two times less women in this region, whereas the other Queensland regions were only under-represented in ovarian cancer survivors by approximately one and a half times less within the GCR. Therefore, generalisability of the ovarian cancer subgroup to the broader ovarian cancer population will be exercised with caution in relation to these characteristics. Information about cancer variables were not available to compare between registries.

The registry comparison (described above and in Table 3.1) uses the mid year of our sample as QCR does not have data beyond 2001 available and hence a comparison of the whole sampling time frame was not possible. The earlier years (1999 and 2000) with available data were not included in this comparison because indications show that the GCR each year becomes closer to population coverage. An earlier registry comparison was conducted in 1997 and found that approximately 60% of Queensland gynaecological cancer patients were registered with the Gynaecological Cancer Registry in that year (Queensland Centre for Gynaecological Cancer, 1997).

TABLE 3.1 QUEENSLAND CANCER REGISTRY *VS* QUEENSLAND GYNAECOLOGICAL CANCER REGISTRY, CANCER INCIDENCE IN 2001 BY SITE, AGE AND GEOGRAPHICAL AREAS.

Diagnosis	C56 Ovary		C54 Corpus Uteri		C53 Cervix Uteri		C51, C52, C55, C57, C58, Other Female Genital Organs		Total	
	QCR	GCR	QCR	GCR	QCR	GCR	QCR	GCR	QCR	GCR
AGE (years)										
Under 20	1	1	0	0	0	0	0	0	1	1
20-29	11	10	1	1	12	8	0	0	24	19
30-39	20	10	4	5	31	30	1	2	56	47
40-49	44	23	32	28	45	50	12	14	133	115
50-59	54	47	84	83	28	26	13	15	179	171
60-69	58	45	81	84	15	20	15	14	169	163
70-79	46	30	58	53	10	11	11	8	125	102
80+	35	7	33	25	9	9	21	9	98	50
GEOGRAPHICAL AREAS										
North QLD	46	23	37	38	24	20	10	4	117	85
Central QLD	117	71	130	115	60	56	35	31	342	273
South QLD	105	70	125	111	65	63	28	24	323	268
Non QLD	1	9	1	14	1	11	0	3	5	37
Unknown	0	0	0	1	0	4	0	0	0	5
Total	269	173	293	279	150	154	73	62	**785**	**668**

* *The primary site of cancer was coded to the international classification of diseases (ICD). Ovary = C56, Corpus Uteri = C54, Cervix Uteri = C53, Vulva = 51,Vagina = C52, Uterus unspecified = C55, Fallopian Tube= C57 and Placenta = C58.*

3.2.3 INCLUSION AND EXCLUSION CRITERIA

Patients with tumours classified to have borderline malignancy were not included, as they were likely to be viewed as non-cancerous by the women being approached to be in this cancer study. The cancer types that were included were: cancer of the Retroperitoneum, Peritoneum, Bartholins Gland, Vulva, Vagina, Endocervix, Ectocervix, Cervical Stump, Cervix (not otherwise specified), Corpus Uteri, Ovary, Fallopian Tube, Genital Tract (not otherwise specified), Urethra, Perineum, Rectovaginal Septum and Peritonii.

In line with ethical conduct, patient eligibility criteria included being at least 18 years old, and being physically and mentally able to complete a written questionnaire. For logistic purposes, patients also had to be able to speak and write English; although with this later criteria they were given the option of completing the survey over the phone if they were capable of comprehending and speaking English, but not reading and writing.

3.2.4 SAMPLE SIZE

As this study was descriptive in its aims, sample size was calculated to ensure reasonable confidence intervals around prevalences and point estimates. Sample size was calculated using the precision of proportion equation (Kirkwood, 1989) for the aims assessing prevalence. For example, Patterson *et al*'s (2002) reported that more than 70% of cancer patients use complementary therapies (which is one of the outcomes this research question addresses, for which there is evidence of prevalence in the cancer population). It was calculated that a total of 323 patients would be required to assess 70% prevalence, with ± 5% precision (95% confidence interval). While the prevalences of the other outcome variables could be quite different from 70%, the same equation calculates that 385 patients were the most cases required to assess prevalence with ± 5% precision (*i.e.* using 50% prevalence).

The two proportions equation (Kirkwood, 1989) was used to calculate the sample size needed for the testing of research question six. To detect a 15% difference between any two groups, with 90% power, where the referent group reported a 40% prevalence of some needs, 199 patients would be required per group. Given the expected stratified analysis by cancer type or survival phase, it was calculated that approximately 200 women per type or phase stratum would be required to test this research question with adequate power. Furthermore, as the intended purpose of this research question was to inform the reorientation of support services to address unmet needs, the conservative level of 15% differences between groups was considered reasonable for making confident recommendations. However, as there are no data to indicate what is a meaningful group difference or effect size, it is acknowledged that the minimal important differences may be much smaller in a public health sense. Therefore, it was determined that the sample size of approximately 200 women per stratum, required to test research question six, would also be ample to report prevalence of all outcomes with precision.

3.2.5 SAMPLE SELECTION

To ensure subgroup analyses of research questions by cancer type and survival phase were carried out with reasonable precision, 200 patients per cancer type and survival phase stratum were randomly selected from the available patient records at the Gynaecological Cancer Registry. If there were less than 200 patients in the stratum, the total number was included in the study sample (see table 3.2).

After selection, the sample size shrank by 53 cases due to a number of women having two gynaecological cancer diagnoses resulting in their being counted in the database as two separate cases. Table 3.2 more appropriately shows women classified by their most recent diagnosis. However, during data analysis, these women were coded as having an “other” type of gynaecological cancer, due to their likely differences in outcomes from those with only one diagnosis. It was also identified that: five women had doctors of unknown identity and therefore couldn’t be part of our study as ethical procedures stipulated that first contact for this study must come from the doctor; two women were under 18 and couldn’t be part of our study due to ethical issues regarding consent of minors and; nine women did not want to be approached by this study as they were already involved in the Ovarian Cancer Study being conducted by the Queensland Institute of Medical Research. All patients involved in the Ovarian Cancer Study had been informed about this study and been given the option not to be contacted. In the end a total of 1774 eligible patients were mailed out a survey.

TABLE 3.2 PATIENTS SAMPLED AND INCLUDED IN THE MAIL-OUT, BY TYPE OF CANCER AND SURVIVAL PHASE

Post-diagnosis	Ovarian	Uterine	Cervical	All other gynae cancer
3-12months 30-04-04 to 1-08-03	83 (all patients)	163 (all patients)	84 (all patients)	56 (all patients)
1-3years 31-07-03 to 1-08-01	198 (Random sample from 325 patient records)	198 (Random sample from 521 patient records)	200 (Random sample from 234 patient records)	123 (all patients)
3-5years 31-07-01 to 1-08-99	183 (Random sample from 294 patient records)	192 (Random sample from 497 patient records)	196 (Random sample from 291 patient records)	98 (all patients)

3.3 QUESTIONNAIRE DESIGN

A questionnaire was designed to include measurements of the descriptive outcomes, including services used, health behaviours, complementary therapies, social support, support needs, quality of life, lymphoedema and sexual dysfunction. Furthermore, to be able to test research question six, within the social-ecological context, a model was derived from the literature, mapping identified or potential correlates of supportive care needs and use with the levels of influence of the social-ecological model (see model 3.1).

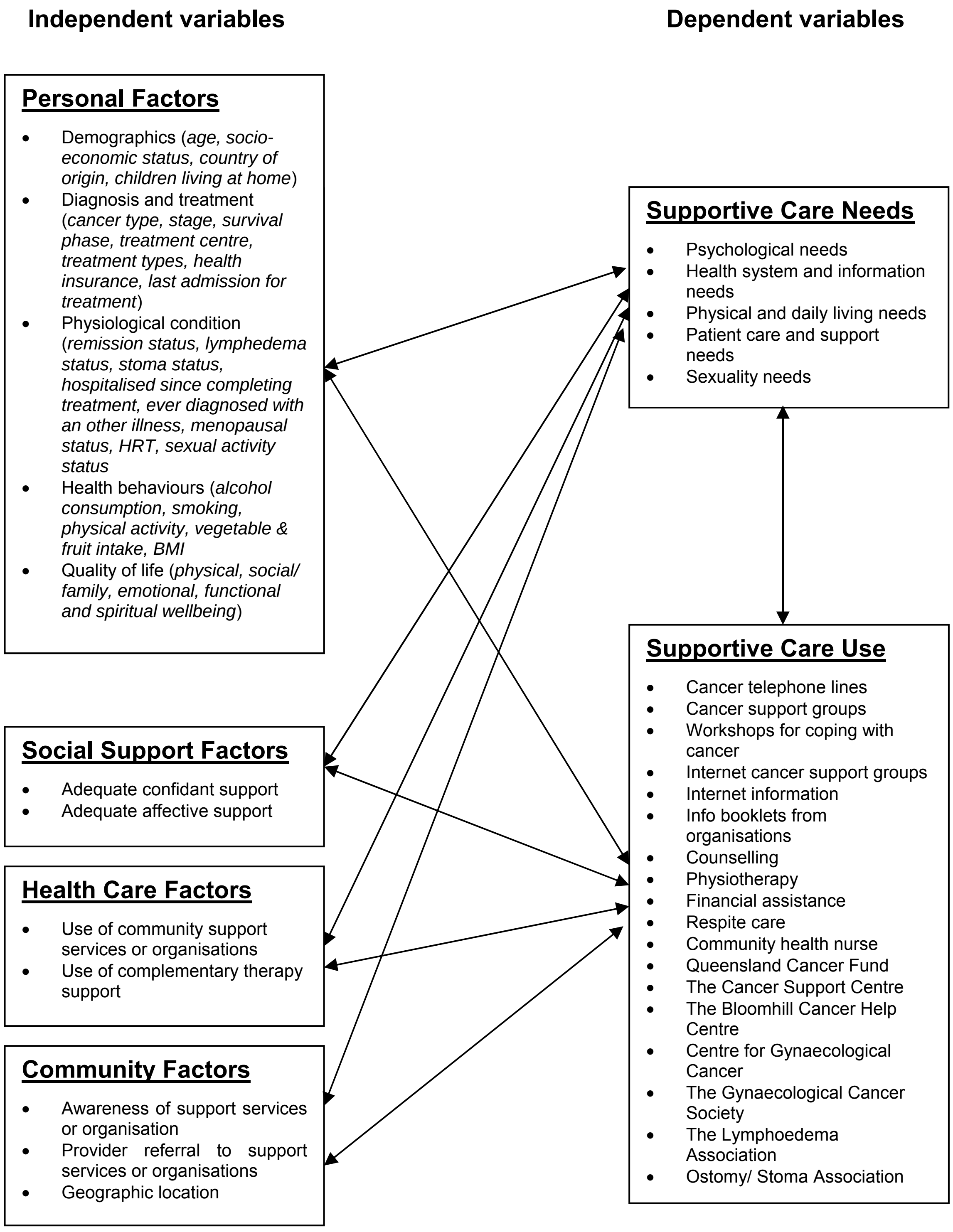


FIGURE 3.1 MODEL FOR ANALYSIS OF RESEARCH QUESTION SIX

To collect data on all of the outcome variables within the six research question, as well as the independent variables identified in the above model, a questionnaire was designed to include the following 11 sections:

- Section 1: Your Medical History
- Section 2: Problems with your Lower Limbs
- Section 3: Your Support Needs
- Section 4: Your Use of Community Support Services
- Section 5: Your Complementary Therapy Support
- Section 6: Your Lifestyle Support
- Section 7: Your Support From Others
- Section 8: Your Quality of Life
- Section 9: Your Gynaecological History
- Section 10: General Information
- Section 11: Survivorship Concerns

These sections consist of standardised and validated instruments when available including the Supportive Care Needs Survey – Short Form 34 (SCNS-SF34) (McElduff *et al*, 2004), the Functional Assessment of Cancer Therapy – General (FACT-G) (Cella *et al*, 1993), the Active Australia Survey (Australian Institute of Health and Welfare, 2003a) and the Duke-UNC Functional Social Support Questionnaire (Broadhead *et al*, 1988), as well as commonly used questions, and newly developed questions. Clip art and Illustrations by Susan Spangler were also included throughout the survey. Permission was sought and granted by the artist to use these illustrations (with thanks).

3.3.1 STANDARDISED AND VALIDATED INSTRUMENTS

The Supportive Care Needs Survey is the only validated measure of needs assessment within the cancer population. This study utilised the SCNS-SF34 (McElduff *et al*, 2004) which has 34 items, that can be classified into five supportive care needs domains. Also used was the pre-existing validated “access to health care and ancillary support services” supplementary module however, the first five questions relating to the facilities within the hospital were omitted as the focus of this study and the sampling frame was beyond the treatment phase (*i.e.* patients more than three months post-diagnosis).

The Functional Assessment of Cancer Therapy – General (FACT-G) (Cella *et al*, 1993) and four cancer site-specific subscales including, (FACT-Cx) for patients with cervical cancer, (FACT-O) for patients with ovarian cancer, (FACT-V) for patients with vulval cancer and (FACT-En) for patients with endometrial cancer, were included in this survey. The Spiritual Well-Being subscale (FACIT-Sp) (Peterman *et al*, 2002) was also included.

The questions assessing physical activity in this study were the standard eight core questions from the Active Australia Survey (Australian Institute of Health and Welfare, 2003a). These questions were also chosen because of their use in the Queensland Cancer Risk Study (DiSipio *et al*, 2006) enabling comparison data to the Queensland population.

Several measures were considered to measure social support including, the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991), the Interpersonal Support Evaluation List (ISEL) (Cohen and Hoberman 1983), The Social Support Questionnaire (Sarason *et al*, 1987) and the Duke-UNC Functional Social Support Questionnaire (Broadhead *et al*, 1988), all of which have been used in the cancer population. The DUFSS was chosen to measure social support in this questionnaire as it is a short standardized tool that has been validated in a gynaecological cancer patient population. Wenzel *et al*'s (2002) study of ovarian cancer survivors showed the Cronbach's alpha was 0.85 for confidant support and 0.88 for affective support subscales.

3.3.2 COMMONLY USED QUESTIONS

Most medical and some demographic questions were taken from a questionnaire on the supportive care needs of men with prostate cancer (Steginga *et al*, 2001). This was to allow the direct comparison of correlates (measured the same way) of supportive care needs between studies. Other demographic questions including, residential postcode, ethnic origin, level of education, occupational status, number of children and adults in the household, gross/annual household income, number of dependents on this income, private health insurance, were taken from the Queensland Cancer Risk Survey (DiSipio *et al*, 2006).

To assess health behaviours, the same questions were used in this study as in the Queensland Cancer Risk Survey (DiSipio *et al*, 2006), making the comparison of health behaviours between samples possible. These questions have been used regularly in other population-based research.

To measure sexual activity and dysfunction, a question about sexual activity status and reasons for sexual inactivity was taken from the Ovarian Cancer Survivorship Study (Wenzel *et al*, 2002). Also a ten part question was included about the women's sexual feelings and experiences; these questions also came from the Ovarian Cancer Survivorship Study and are presented in the format of the FACT.

3.3.3 NEWLY DEVELOPED QUESTIONS

3.3.3.1 *MEASURING LYMPHOEDEMA*

A battery of questions was developed in this study to capture the experience of having lower limb lymphoedema (LLL). Based on the qualitative findings of Ryan *et al*'s (2003a) study, questions about patients symptoms in lower limbs, triggers that preceded the appearance or worsened the lymphoedema symptoms, when informed about the potential risk of developing LLL, and lymphoedema treatments used, were developed to refect reported responses to these domains presented in Ryan *et al*'s (2003a) study. In addition, severity of symptoms in the last month were assessed using a graded scale (mild, moderate and severe), as was difficulty with performing daily tasks (no difficulty, mild difficulty, moderate difficulty, severe difficulty and unable to perform daily tasks); based on response options from the "Disabilities of the Arm, Shoulder and Hand" outcome measure (Beaton *et al*, 2001). Also questions about the area's swelling is experienced, LLL diagnosis and diagnosis date, when LLL symptoms began, and a five point likert effectiveness scale where 0=not effective and 4=very effective, for the treatments patients used, were developed.

A module to measure these specific needs of women with lymphoedema symptoms was also developed in this study. The newly developed lower limb lymphoedema module was based mainly on the existing questions from the colostomy supplementary module of the Supportive Care Needs Survey, as it was thought that both these conditions are similar in that they require ongoing management and they precipitate body image issues. Five of the eight items in the colostomy module were used in the lymphoedema module by substituting "lymphoedema symptoms" for "colostomy bag" and removing the references to "the first days after having surgery/ after going home from hospital" as lymphoedema symptoms may develop long after treatment. The question about controlling embarrassing odours was omitted as it is not relevant to lymphoedema. The question about “dealing with emotional reactions of family and friends” was substituted with the question about “dealing with your partner's reaction” (which is a question from the survivors of breast cancer modules) as loss of interaction and intimacy with partners as a result of appearance and swollen legs was reported, while family and friends reactions was not specifically mentioned (Ryan *et al*, 2003a). The question about “being informed about how to manage the colostomy bag” was substituted with “being informed about the causes, preventions and treatment of lymphoedema”, which was a more specific question to lymphoedema from the recent survivors of breast cancer module. A question about “finding a support group which addresses your particular lymphoedema needs” was added from the survivors of breast cancer modules with the additional word lymphoedema being added to the question. A question about “pain or discomfort” was also added from the recent survivors of breast cancer module. This question was altered to “in the legs and groin”. Two additional questions were also added about “doing daily activities around the home” and “cost of having lymphoedema” as it was reported that a majority of women altered their daily activities because of swollen legs, and that having LLL created extra expenses (Ryan *et al*, 2003a).

3.3.3.2 *MEASURING AWARENESS, REFERRAL, USE OF AND SATISFACTION WITH SUPPORT SERVICES*

To measure the awareness, referral, use of and satisfaction with support services, a table was developed with support services and organisations listed in the first column. The above constructs were presented in question format at the top of each preceding column, with corresponding yes or no response options or a satisfaction rating of 0-4 in the rows. The list of support services was constructed from groupings of types of services used in a similar question in Eakin and Strycker’s (2001) study. The list of support organisations was developed from a comprehensive search of journal articles, books, the internet, cancer newsletters and pamphlets, as well as a filtered search of OnCall (the Queensland Cancer Fund software package that tracks phone inquiries and lists support services) for services most commonly referred to gynaecological cancer patients. Yes or no response options, rather than a tick if yes option, were included to ensure missing data was quantifiable. The satisfaction scale was based on a similar response scale from the validated

Functional Assessment of Cancer Therapy scales where 0 = Not at all and 4 = Very much.

3.3.3.3 *MEASURING COMPLEMENTARY THERAPY SUPPORT USE AND SATIFACTION*

A table was also developed to measure complementary therapy use and satisfaction. Above the table women were given the option to tick a box and proceed to the next section of the questionnaire if they had never used any complementary therapies or alternative therapist for coping with cancer or reducing the risk of it spreading or returning. Within the first column of the table, CAT is segregated into; alternative medicine providers; diet and nutrition and; mind body therapies. These groupings are in line with the format of questioning used by both Patterson et al (2002; 2003) and Webb (2004) who grouped complementary and alternative therapies into the same three domains. These domains are further grouping of the National Centre for Complementary and Alternative Medicine’s five major domains: alternative medical systems, mind-body interventions, biological based treatments, manipulative and body based methods and energy therapies (Patterson *et al*, 2002). Under each of these heading, the most prevalently used therapies (determined in Patterson et al (2002) study) were listed. Several lines were also left under each heading with “other, please specify” response options to capture the less prevalent therapies. The second column asked “for all the complementary therapies and alternative therapists you have ever utilised to cope with cancer or reduce the risk of it spreading or returning, please rate how much the therapy improved your health and wellbeing on the 0 - 4 scale where: 0 = no improvement and 4 = great improvement”. Women were further instructed to circle NA if they had not used the therapy listed.

3.3.3.4 *MEASURING CHANGE IN HEALTH BEHAVIOURS*

Four health behaviour change questions about fruits and vegetables, physical activity, smoking cigarettes and drinking alcohol were also included. These questions asked “are you ……the same amount now as you were recently before your cancer diagnosis”. This question was modelled on a question from the Central West Nutrition Survey, (1999) which asked “Are you eating the same amount of fruits and vegetables now, as you were about 12 months ago?”. The comparison of the question has changed from “about 12 months ago” to “recently before your cancer diagnosis" so it can be determined whether or not having been diagnosed with cancer had changed the health behaviour of participants.

3.3.3.5 *MEASURING MENOPAUSAL STATUS*

The survey included questions to determine menopausal status. Questions measuring menopausal were based on those used in the Ovarian Cancer Survivorship Study (Wenzel *et al*, 2002) and the Queensland Midlife Women's Health Survey (Anderson *et al*, 2004) to enable the classification of cancer survivors into pre- or peri-menopause, natural menopause, surgical menopause pre-cancer treatment or iatrogenic menopause. Consultation with Dr Debra Anderson (a menopause researcher and senior lecturer at Queensland University of Technology), suggested that many women do not understand what the word "menopause" refers to specifically. Therefore, all wording was changed to ask about menstrual periods and not menopause.

3.4 ETHICS

3.4.1 SEEKING APPROVAL

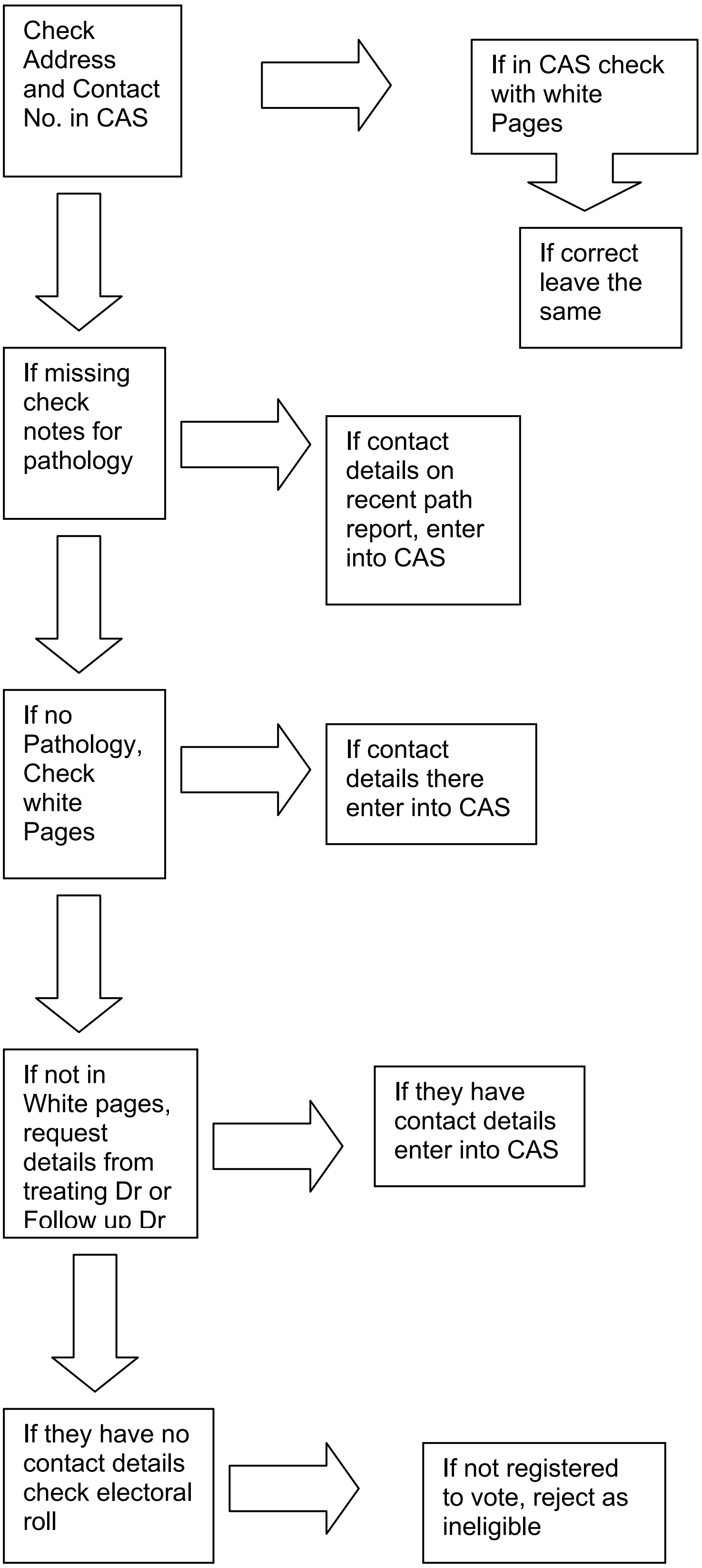
Recruiting patients *via* the Gynaecological Cancer Registry required multi-hospital ethical clearance from all treating hospitals of registry patients. Ethical protocols were submitted and approved by Human Research Ethics Committees at the Mater Hospital, Royal Brisbane and Women's Hospital (RBWH), The Wesley Hospital and John Flynn Private Hospital. Ethical protocols were also submitted to Brisbane Private and The Townsville Hospital and ethical clearance was granted once approval was given by other major Queensland Health institutions. Ethical clearance was also sought and approved by the Queensland University of Technology Human Research Ethics Committee.

3.4.2 MAIN ETHICAL CONSIDERATIONS

The main ethical considerations for this study included ensuring patients were contacted in an appropriate way which did not breach patient confidentiality or raise sensitive issues in a distressing way. That is, the first point of contact came from their treating doctor. Ethical considerations also concerned maintaining confidentiality of data *via* keeping a locked filing cabinet with the stored survey data and having a de-identifiable database with identification codes separating collected data and personal and medical history data. It was also important to ensure before contacting patients that all death notifications and mailing addresses were up to date.

3.4.3 ENSURING UP-TO-DATE PATIENT RECORDS

As the Gynaecological Cancer Registry had been without a data manager for eight months between July 2003 – March 2004, a research assistant was appointed to update and check all patient records in this research sampling frame. All doctors were sent a fax or letter asking for information about address changes or death notifications for registry patients. Addresses were further checked for accuracy using the procedure outlined in figure 3.2. Patient contact details within the clinical administration system were reconciled against firstly, contact details on white pages, then pathology reports, doctors' records and finally the electoral role. If confirmation of details was not possible *via* any of these avenues, patients were classed as ineligible for participation in this study.



*CAS = Clinical Administration System

FIGURE 3.2 PATIENT INCLUSION IN THE STUDY

3.5 DATA COLLECTION PROCEDURES

Both pilot and main studies were conducted using the same sampling frame and similar data collection and follow-up methods. A database of selected patients, their identifying information, date of birth, tumour site, stage, date of diagnosis, date of treatment, type of treatment and name of their doctor was obtained from the Gynaecological Cancer Registry, with appropriate ethical approvals. After treating doctors were approached and gave permission to contact their patients (see appendix 2), patients who were selected from stratified sampling were sent a letter (see appendix 3), signed by their doctor, asking them to participate in the study. A study information sheet and consent form (see appendix 4), and a questionnaire (see appendix 5) was enclosed with the letter and patients were asked to sign the consent form and return it with the completed questionnaire to the researcher. Patients also received a packet of forget-me-not daisy seeds as an incentive and thank you for completing the questionnaire (see appendix 6). A follow-up letter (see appendix 7) was sent two to three weeks from the initial questionnaire mail-out. One and a half weeks after the reminder letter was sent, a telephone follow-up of non-respondents was conducted (see appendix 8 for telephone protocol). Phone calls were made during and after office hours, and up to three attempts were made at different times, to make contact with the women.

The telephone follow-up was the final follow-up stage for the pilot study. In the main study however, two weeks after the telephone follow-up finished, a final reminder letter was sent to those patients who indicated they may return the survey (see appendix 9). Also, the whole initial questionnaire package was sent again to those patients with whom no contact was established due to no number, wrong number, disconnected or no answer after three attempts (see appendix 10 for final letter and appendix 4 and 5 for other contents). This follow-up procedure is illustrated below in figure 3.3 and was based on Queensland Cancer Registry's standard protocol for optimising response rates. The procedure is also in-line with Dillman's (Dillman, 1978) recognised protocol for tailored design methods.

Approximately eight months after the data collection phase, women who participated in the survey were sent a thank you letter which shared some of the preliminary results (see appendix 11). This letter was also shared with gynaecological oncologists involved in the project, the Queensland Cancer Fund and the

Gynaecological Cancer Society for their interest. Further preliminarily descriptive results were provided to the Queensland Cancer Fund and the National Breast Cancer Centre to help inform respectively the production of a DVD they were making specifically for gynaecological cancer survivors, and the design of a supportive care needs survey of ovarian cancer survivors. Further feedback of the results of this study, to the cancer survivor and general population, has been disseminated in both the Gynaecological Cancer Society and Queensland Cancer Fund newsletters and the QUT newspaper and “Best of Health” publication (see appendix 12).

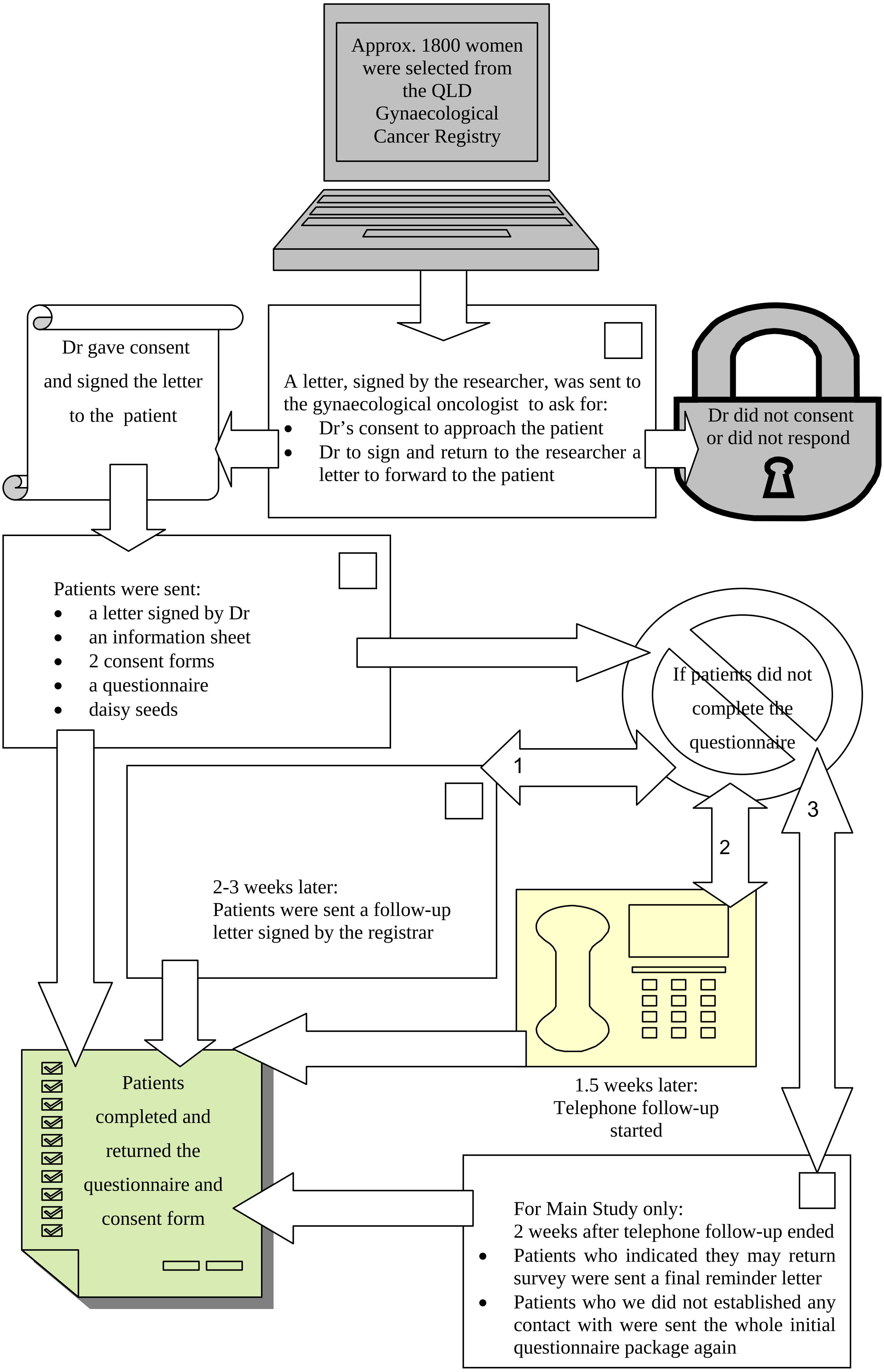


FIGURE 3.3 ADMINISTRATIVE PLAN FOR DATA COLLECTION

3.6 PILOT STUDY

3.6.1 GOAL AND PROCEDURES

The pilot aimed to determine the clarity of instructions and questions, repetitiveness and sensitivity of questions, coherence of format and layout, and if the length was appropriate. Some new measures were developed and included in the questionnaire, as there were no existing validated or commonly used tools to measure these constructs. These measures' psychometric properties were not formally evaluated. However, they were evaluated for content validity *via* review by cancer support experts in Queensland, and for face validity during pilot testing. The pilot also served as a test drive for the process of recruitment and allowed the response rate to be assessed.

Forty-eight women from the Queensland Gynaecological Cancer Registry were included in this pilot (four per each stratum of sampling frame) to ensure saturation of feedback was achieved. These 48 women were selected the same way as the main study patients, that is, equal numbers across cancer sites (four sites include: ovary, uterine, cervix and all other gynae cancers) and survival phase (three phases include: 3-12 months, 1-3 years and 3-5 years post-diagnosis). Selection within these subgroups was random.

As mentioned above, the pilot was administered under similar protocol conditions to the main study, however the cover letters to the doctors and patients was altered to inform that this was a pilot study to assess the appropriateness of the enclosed questionnaire. Participants were asked to: firstly read the one page checklist about the questionnaire (see appendix 13) so that they knew what they were assessing when they reviewed the questionnaire; secondly to complete the questionnaire and make comments in the questionnaire margin and; finally, to complete the one page checklist about the questionnaire.

3.6.2 PILOT RESPONSE RATE

Of the 48 women selected in the pilot sample, three were not contacted: two as the registry notified us that they were deceased prior to mail out and; one as the gynecological oncologist notified us that they were deceased prior to mail out. Hence we attempted to contact 45 women. Of these 45, ten were removed from the denominator of the response rate calculation as: two were deceased; one reported never being diagnosed; five were uncontactable as their mail package was returned to sender *via* Australia Post and; two moved out of QLD, thus leaving 35 eligible women to complete the pilot study who met the inclusion criteria. Overall about a half of women participated (49%, 17/35), about a quarter (23%, 8/35) refused to participate and 29% (10/35) never replied.

Other cancer studies that have been conducted *via* the Queensland Cancer Registry have typically achieved a 70% response rate. The 49% response rate in the pilot was most likely due to the inclusion of patients well beyond the treatment phase, *i.e.* up to five years post-diagnosis, who are harder to both motivate to participate, and to follow-up. The pilot did not include the final recruitment phases where final reminder letters and questionnaire packages are resent, nor did it carry out electoral role address verification. These improvements were made to the main study to maximise response rates.

3.6.3 PILOT FEEDBACK

The pilot demonstrated the need to reduce the length of the questionnaire. Responses showed that the questionnaire took on average an hour to complete, and that many women found it long but bearable. Also five women in the telephone follow-up implied they were getting around to completing the questionnaire but never did.

Women were asked specifically to make comments about Section 4 “Your Use of Community Support Services” and Section 5 “Your Complementary Therapy Support” as these sections were newly developed and included particularly detailed tables. Some women said they were too long and confusing, and consequently these questions were reduced and simplified. Completion patterns of the tables helped to inform this process.

To further reduce the size of this survey, questions in sections 2 "Problems with lower limbs" and 6 "Your lifestyle support" were trimmed by one page each. It was considered important to keep parts of these sections so that the holistic model of support was not compromised. Only the crucial items were retained.

Overall readability, sensitivity and repetitiveness were OK for compliers. However, two women commented that they did not consider themselves as “ill” (as they were disease-free) and were quite upset by the use of the term “your illness” (which is used in FACT). To address this issue it was decided to insert a statement before the FACT stating “Section 8 is a standard questionnaire used widely in research. You will note the word "illness" mentioned many times. We realise that some women completing this questionnaire are long past the diagnosis and treatment phase of their gynaecological cancer and that they are no longer ill. In this case please view the word "illness" in reference to your cancer diagnosis. Please answer the questions in reference to your well-being during the past week”. Also several women reported that the section on sexual relationship was not applicable as they were single, divorced, widowed, too old or their partner had physical problems which made sexual relations difficult. Therefore, a question that asked “Do you currently engage in sexual activity?” was included and if they answered ‘yes’, they completed the section on sexual relationships; if ‘no’, they were asked to specify why not.

3.7 MAIN STUDY PROCEDURES

3.7.1 DATA COLLECTION

After having made changes to the questionnaire based on pilot feedback, a research assistant conducted the main study data collection. The initial package was mailed out on the 31st of August 2004 to 1774 eligible women. The data collection process has already been outlined in section 3.5.

3.7.2 DATA STORAGE

Hard copies of the data collected were kept in a locked filing cabinet. All collected data underwent a de-identification procedure for electronic entry. Two data files were kept, one containing patient identification information (names, addresses, phone numbers) and a barcode, the other containing barcodes and collected information about patients. These were kept on a personal drive which was password protected, with only the principal researcher and research assistant having access.

3.7.3 DATA QUALITY

3.7.3.1 *DATA ENTRY AND VERIFICATION*

A master copy of the survey was assigned comprehensive codes and then data were entered *via* a trained data entry person into SPSS. Initially seven surveys were entered and visually assessed to determine if the data entry person was interpreting the variable entry the same way as was the researcher. With three incorrect entries out of 3402 variable entries, it was determined that a 10% random sample verification of the total data would be sufficient, rather than a complete double entry verification protocol. Eighty surveys (486 variables per survey) randomly selected were verified using the SPSS module "Data Entry Builder". An error log was recorded and found that the original data entry contained 95 errors in 38880 cells (*i.e.* 99.8% accurate).

3.7.3.2 *DATA CLEANING*

Frequency distributions were run for all variables in the data file and checked against the coding protocol to determine any invalid values. Frequencies were also checked for duplicated identification numbers.

Any extreme values identified in the frequencies were discussed to determine plausibility and what to do if they were implausible. For example, in the questions that ask "on average in the last month, how many serves of [food type] have you eaten each day….", some people had answered as high as 90 serves of fruit or 90 serves of vegetables. It was clearly not possible that they ate this many serves in a day and must have misinterpreted the question. In this scenario, consultation with a dietitian established that 15 serves per day of fruit and 15 serves per day of vegetables was a reasonable maximum cut off and all data above 15 serves per day were recoded as missing.

From the earlier seven survey entry verification exercise, it was identified that some women circled "no need" or "not applicable" at the top of the page in Section 3: Your support needs. It was unambiguous that these women were indicating that they meant all the answers to the questions on the page were not applicable, hence the research assistant checked all surveys for this and recoded the data appropriately.

3.7.3.3 CONSISTENCY CHECKING

Consistency checking was performed between registry data and survey data, and also within survey data. Firstly, using matched identification numbers between files, demographic and disease variables (age, cancer type, survival phase, cancer stage, surgery type, chemotherapy, radiotherapy and lymph node removal) were matched to quantify the level of agreement between registry records and survey data. Secondly, within survey consistency checks were defined to determine as many as possible of the discrepancies that might occur on crosstabulating variables and to ensure questionnaire branching had been appropriately followed. A full report of results from the defined checks is included in appendix 14.

3.8 VARIABLE DEFINITIONS

This section demarcates variables and their definition within each research question. Research questions were outlined earlier in section 3.1.1.

3.8.1 OUTCOME (DEPENDENT) VARIABLES

In research question one, quality of life was the outcome variable. Quality of life was made up of five subscales including physical; social/family; emotional; functional and spiritual well-being. In addition there were four site-specific subscales including cervical cancer, ovarian cancer, vulval cancer and endometrial cancer. Raw continuous scores were calculated for each subscale by reversing negatively stated items scores then summing the items within the scales. When there was missing data, subscale scores were prorated as long as there were more than 50% of items answered. Overall quality of life was calculated as a continuous score by adding physical, social/family, emotional, and functional wellbeing subscale. Overall quality of life scores were accepted as long as overall item response rate was greater than 80%. Furthermore, four site-specific quality of life scales were calculated by adding physical, social/family, emotional, functional wellbeing and the site-specific subscale. These four site-specific subscales included only women with a particular type of gynaecological cancer and were only valid as long as the overall item response rate was greater than 80%.

In research question two, lymphoedema status was the outcome variable. This was a categorical variable with three mutually exclusive categories of interest: diagnosed with lymphoedema, symptomatic of lymphoedema but not diagnosed (*i.e.* lower limb swelling) and non-symptomatic of lymphoedema (*i.e.* no lower limb swelling).

In research question three, sexual dysfunction was the outcome variable. This was a dichotomous, categorical variable defining women whose cancer had made sexual relations too difficult or too uncomfortable to be able to engage in sexual activity, or all other women. For women who were sexually active, the level of desire, vagina dryness, and pain or discomfort, were also explored as symptoms that may be associated with cancer treatment.

Research question four considered supportive care use as an aggregate of several outcome variables including, use of individual community support services and organisations, meeting recommended daily intake of fruit, meeting recommended daily intake of vegetables, participating in the recommended amount of physical activity, frequency of alcohol consumption, cigarette smoking, use of individual complementary therapies for support, perceived level of social support. These were all considered inclusive elements to the term “supportive care”. They were all categorical variables except social support, which was continuously scaled.

Fifty-six need items were assessed individually as the outcome variables of research question five. These were all dichotomous, categorical variables with the response options of moderate-to-high unmet need, or no-to-low need.

Research question six included six outcome variables; service use and five supportive care needs domains: psychological, health system and information, physical and daily living, patient care and support and sexuality needs. However, the patient care and support needs domain was later dropped as an outcome, due to the low prevalence of needs and irrelevance of this domain in this group of survivors. An overall need score was not calculated so as to preserve the level of the detail of information collected consistent with the rationale and theoretical framework. For all the items in the particular need domain, if an individual responded one or two to <u>every</u> item, then the individual was categorised as having no need for that particular domain and allocated a score of zero. If an individual responded three, four or five to <u>any</u> item in the domain, that is, they indicated 'some need' to any item, then they were allocated a score of one. Supportive care need domains and use of at least one support service were defined as dichotomous, categorical variables.

3.8.2 EXPLANATORY (INDEPENDENT) VARIABLES

Research questions one to five do not have explanatory (independent) variables because they are interested in overall levels or prevalence’s. However, for research question six, there were many variables that may have explained the outcome variables according to the theoretical framework adopted in this study. These variables and their definitions are expressed in appendix 15. Within the personal level of influence in the social-ecological model, variables measuring demographic characteristics, diagnosis and treatment modalities, current physiological condition, health behaviours and perceived wellbeing, were collected. Within the social support level of influence, a number of items were collected to measure the social support construct. Variables measuring service and complementary therapy use in relation to support with gynaecological cancer, made up the independent variables for the health care level of influence. Finally, within the community level of influence of the social-ecological model, variables measuring service awareness, referral, access and geographical location, were included.

3.8.3 VARIABLE DERIVATION

A number of variables were collected in the survey in a different format to the way they were analysed. Some independent variables were recoded from continuous to categorical variables and some categorical variables were collapsed across groups. This section discusses the reasons why these transformations were made.

Age was collected continuously however, as other supportive care needs analysis presents age in 10 year grouping this analysis followed suit so that it is directly comparable to these studies. However, the first two age groupings were further collapsed into 20 – 39 years of age as the number of women within these categories was limited and was resulting in unstable modelling.

Within marital status, divorced and separated categories were combined and de facto and married categories were combined (as they are in many other analyses) because of small numbers in at least one of the categories. Similarly, within household income “$80 000 – less than $100 000” and “$100 000 +” were pooled.

Information about the type of cancer women were diagnosed with was specific to cancer site however, as type of cancer was considered a potential effect modifier, large numbers within categories were required to maximise power in the analysis. Hence, stratified sampling was conducted across the three most prevalent cancer types and all other cancer types were lumped into an “other” category. This categorisation was maintained throughout most analysis, except in the consideration of lymphoedema where vulval cancer was known to be a high risk group and thus was given its own category.

The figo staging variable originally existed with stages one through four, no stage and don’t know. As the literature generally did not find stage had an influence on quality of life or supportive care needs, this variable was collapsed into early stage (clinically recognised are stages one to two), late stage (clinically recognised are stages three to four) and no or don’t know, to reduce the degrees of freedom used up and increase power of the modelling.

The regularity of alcohol consumed was collapsed into none, <weekly, 1-4 days per week and 5-7 days per week to maximise numbers across categories and align ordinal progression. All treatment centres were listed and then those with less than 10% of survivors in them were reclassified into an “other” category.

All treatment variables including surgery type, chemotherapy, radiotherapy, hormone therapy and lymph nodes removed, were obtained from the gynaecological cancer registry. There derivatives were discussed in terms of their effect on supportive care needs and use and decided upon in consultation with a gynaecological oncologist (Obermair, 2004). Within surgery type, laparoscopic and vaginal were further collapsed as there were few women in laparoscopic only and both these classifications cause minimal scaring. Also, women who had open abdominal surgery regardless of whether or not they had had vaginal or laparoscopic as well, were all pooled together as they would have major scaring.

Lymphoedema status was categorised into three levels, no lower limb swelling, undiagnosed lower limb swelling and diagnosed lymphoedema. While information was collected on a number of symptoms that could be symptomatic of undiagnosed lymphoedema it was documented in the literature that swelling was the main symptom of lymphoedema and the rest could be related to other conditions. The lymphoedema variable was also categorised like this in Ryan *et al*'s (2003b) study.

Use of, awareness of and referral to support services was coded from a list of services and organisations which participants could answer yes or no, into one variable each which identified 1) if women used one or more support services or organisations 2) if women were aware of one or more support services or organisations 3) if women were referred to one or more support services or organisations. It was decided to pool support services and organisations together within these variables as most of the services listed were provided by the organisations listed. It was believed that women who were likely to use one services were the same women who would try other services. In a similar premise, women who were aware of or who were referred to one service would be more likely to be aware of/ or referred to other services. As services and organisations were not likely to each contribute equally to reporting supportive care needs, it was decided that a continuous score would be inappropriate for these variables; hence this was the rational behind this way of classifying use, awareness and referral. However, within awareness variable, the exclusion of awareness of Queensland Cancer Fund (QCF) was made, as this survey was administered in QCF envelopes and included the QCF logo on letters head and on the front page of the questionnaire.

Postcode was classified into 14 geographical locations. These 14 locations were originally developed for Queensland Health's zonal indicators report, and were also utilised by Queensland Cancer Funds' Cancer Risk Study (in this study they were known as CaRS). With a view for consistency this study also classified women into these 14 locations. It was believed that the Australian Standard Geographical Classification with three zones in Queensland would not be sensitive enough to pick up variation of the outcomes of interest in this study. It was also determined that the 39 zone classification in Queensland by this same body, would spread data too thinly and possible identify some individuals. In addition, a number of locality indexes (including SEIFA's, ARIA's and RRMA's) were utilised to assess the location women lived in with the outcome of interest.

3.8.4 EFFECT MODIFYING VARIABLES

As mentioned earlier, the results of research questions in this study were explored for subgroup differences within the following variables:

- Type of cancer, because after treatment women may face the following symptoms and problems, which are particular to their cancer site: infertility, premature menopause, sexual dysfunction and other problems such as lymphoedema, hence determining that each cancer type would have different supportive care needs, quality of life issues and lymphoedema outcome
- Survival phase post-diagnosis, because the literature indicates that the early effects of diagnosis and treatment seem to dissipate by the end of the first year, then as three years is the point at which the probability of recurrence diminishes, patients' support needs and quality of life issues are likely to differ before and after this point. The onset of lymphoedema symptoms (predominantly swelling of the legs) does not always present immediately after treatment. One study indicated that symptoms present generally within the first 12 months (Ryan *et al*, 2003b) and another says within the first two years (Clark *et al*, 2005). Therefore, it will be important to account for the effect of lymphoedema over survival phases.

Stratified sampling was conducted to ensure inflated numbers for reasonably powered stratified analysis across these variables should they prove to be effect modifiers.

3.8.5 CONFOUNDING VARIABLES

Many of the variables outlined in the explanatory variables section were also potential confounders of the relationship between the independent and dependent variables in research question six. These potential confounding factors have been identified within the literature review and are summarised below in relationship to the dependent variable "supportive care needs" and the listed independent variables. A multivariable model including all variables adjusted for all others covered these complex inter-relationships.

TABLE 3.3 POSSIBLE CONFOUNDERS OF THE RELATIONSHIP OF SUPPORTIVE CARE NEEDS WITH INDEPENDENT VARIABLES OF INTEREST

Independent variable	Possible confounder
Age	Household income, Physical activity, Menopausal status, Sexual activity status, Ever diagnosed with a physical or emotional illness
Marital status	Age, Awareness of 1 or more support services, Use of 1 or more community support services, Social support, Sexual activity status
Education levels	Age, Country of origin, SEIFA
Employment status	Age, Education levels, Country of origin, SEIFA
Household income	Age, Marital status, Education levels, Employment status, Country of origin, Geographic location, SEIFA
Country of origin	-
Children living at home	Age, Marital status
Type of cancer	Age
Survival phase	-
Cancer stage	Age, Type of cancer
Treatment centre	Geographic location, Health insurance
Health insurance	Age, Household income, Country of origin
Surgery	Type of cancer, Cancer stage
Chemotherapy	Type of cancer, Cancer stage
Radiotherapy	Type of cancer, Cancer stage
Hormone therapy	Type of cancer, Cancer stage
Lymph nodes removed	Type of cancer, Cancer stage
Last admission for treatment	-
Remission status	Cancer stage
Disease presence	Cancer stage
Lymphedema status	Type of cancer, Surgery, Radiotherapy, Lymph nodes removed, Survival phase
Stoma status	Type of cancer, Cancer stage, Surgery, Survival phase
Hospitalised since completing treatment for gynaecological cancer	Age, Remission status, Disease presence,
Ever diagnosed with a physical or emotional illness	Age, Alcohol consumption, Smoking, Physical activity, Fruit and vege intake, BMI
Menopausal status	Age, Surgery, Type of cancer
HRT in the past 3 months	Age, menopausal status
Sexual activity status	Age, Marital status, Type of cancer, Survival phase, Remission status, Surgery, Chemotherapy, Radiotherapy, Hormone therapy, Last admission for treatment, Lymphedema status, Stoma status, Hospitalised since completing treatment for gynaecological cancer, Ever diagnosed with a physical or emotional illness
Physical wellbeing	Age, Type of cancer, Survival phase, Remission status, Disease presence, Surgery, Chemotherapy, Radiotherapy, Hormone therapy, Lymph nodes removed, Last admission for treatment, Lymphedema status, Stoma status, Hospitalised since completing treatment for gynaecological cancer, Ever diagnosed with a physical or emotional illness, Alcohol consumption, Smoking, Physical activity, Fruit and vege intake, Use of complementary therapy support
Social wellbeing	Age, Marital status, Employment status, Geographical location, Physical activity, Use of complementary therapy support, Social support ARIA, RRMA
Emotional wellbeing	Age, Marital status, Survival phase, Cancer stage, Last admission for treatment, Remission status, Disease presence, Lymphoedema status, Stoma status, Hospitalised since completing treatment for gynaecological cancer, Ever diagnosed with a physical or emotional illness, Menopausal status social support
Functional wellbeing	Age, Type of cancer, Survival phase, Surgery, Chemotherapy, Radiotherapy, Hormone therapy, lymph nodes removed, Lymphoedema status, Stoma status
Spiritual wellbeing	Age, Education level, Use of complementary therapy support
Alcohol consumption	Age, Education levels, Smoking, Physical activity, Fruit and vege intake, Use of complementary therapy support, Physical wellbeing

Independent variable	Possible confounder
Smoking	Age, Education levels, Alcohol consumption, Physical activity, Fruit and vege intake, Use of complementary therapy support, Physical wellbeing
Physical activity	Age, Education levels, Alcohol consumption, Smoking, Fruit and vege intake, Use of complementary therapy support, Physical wellbeing
Vegetable intake	Age, Education levels, Alcohol consumption, Smoking, Physical activity, Use of complementary therapy support, Physical wellbeing
Fruit intake	Age, Education levels, Alcohol consumption, Smoking, Physical activity, Use of complementary therapy support, Physical wellbeing
BMI (Kgs/m^2)	Age, Alcohol consumption, Smoking, Physical activity, Fruit and vege intake, Use of complementary therapy support, Physical wellbeing
Social support	Age, Marital status, Country of origin, Geographic location, Survival phase, Remission status, Use of 1 or more community support services in the last month
Use of 1 or more community support services or organisations	All variables
Use of complementary therapy support	Age, Education levels, Alcohol consumption, Smoking, Physical activity, Fruit and vege intake, Physical wellbeing, Social wellbeing, Emotional wellbeing, Functional wellbeing, Spiritual wellbeing
Awareness of 1 or more support services or organisation	Age, Marital status, Education levels, Employment status, Household income, Country of origin, Geographic location, Type of cancer, Survival phase, Remission status, Treatment centre, Provider referral to 1 or more support services, Lymphedema status, Stoma status
Provider referral to 1 or more support services or organisations	Country of origin, Geographic location, Type of cancer, Treatment centre, Awareness of support services, Lymphedema status, Stoma status
Geographic location	Household income, SEIFA, ARIA, RRMA
Accessibility/Remoteness Index of Australia (ARIA)	Use of 1 or more community support services or organisations, Awareness of 1 or more support services or organisation, Provider referral to 1 or more support services or organisations, Use of complementary therapy support, RRMA
Rural, Remote and Metropolitan Area Classification (RRMA)	Use of 1 or more community support services or organisations, Awareness of 1 or more support services or organisation, Provider referral to 1 or more support services or organisations, Use of complementary therapy support, ARIA
Socio-Economic Indexes of Areas (SEIFA)	Age, Education levels, Employment status, Household income, Country of origin, Geographic location

3.9 STATISTICAL METHODS

3.9.1 REPRESENTATIVENESS

Representativeness of the sample was considered by comparing participants to the rest of the survivors within the Gynaecological Cancer Registry during the same sampling frame period (1st of August 1999 – 30th of April 2004). Participants were not compared to Queensland total population statistics as the Queensland Cancer Registry is the only registry which has total population based data and they only have data up until 2001 available. A comparison (discussed earlier in Section 3.2.2 Sampling Frame) between the Gynaecological Cancer Registry and the Queensland Cancer Registry showed that approximately 85% of Queensland gynaecological cancer patients were registered with the Gynaecological Cancer Registry and the ratio of age and regional location was distributed similarly between registries, however ovarian cancer survivors were under-represented.

As the sample selection was stratified by type of cancer and phase post-diagnosis and then randomly or consecutively selected within each stratum (as discussed in Section 3.2.5 Sample Selection), the representativeness of the participants was also compared within stratums. Age was stratified by type of cancer and then compared using boxplots between women who were participants and survivor within the sampling frame excluding participants. Age was then stratified by phase post-diagnosis and again compared between participants and the rest of the sampling frame. For the categorical variables compared (including: SEIFA, stage, disease presence, ARIA) they were stratified similarly as above however results were compared using crosstabulation and three dimensional bar charts.

Furthermore a comparison between participants and non-participants was performed to quantify any under-representations or over-representations of participants' characteristics. To do this counts and percentages of comparable characteristics were calculated and the likelihood ratio of participants over non-participants was calculated for each group within each categorical variable to determine if any group was more or less likely to participate than not. Finally, the key demographic and treatment characteristics of participating patients were presented in the form of counts and percentages.

3.9.2 PREVALENCE OF OUTCOME VARIABLES

Prevalence of diagnosed and symptomatic lymphoedema cases, sexual dysfunction due to cancer, the top ten ranked unmet supportive care needs items, individual community support services and organisations used, complementary therapies used, health behaviours including, age adjusted recommended intake of fruits and vegetables, sufficient physical activity for health, BMI, cigarette smoking and frequency of alcohol consumption, were summarised as proportions and 95% confidence intervals. As the sampling selection was stratified by type of cancer and survival phase post-diagnosis and there was not equal chance of selection within each of these stratums, the reported prevalence was weighted by each woman's chance of selection. Likewise, the level of social support and quality of life (including physical, emotional, social/ family, functional and spiritual) were also weighted and summarised as medians and minimum and maximum values. In addition, these variables were then stratified by cancer types and by phases of survival post-diagnosis leaving the weighting on.

3.9.3 ADDITIONAL DESCRIPTIVE INFORMATION

More information around the outcomes of interest in this study were presented as descriptive statistics. For those women who where diagnosed with lymphoedema, categorical information about their proximity of lymphoedema diagnosis with time since cancer diagnosis, when informed about the potential risk of developing lymphoedema, symptoms and severity, triggers that preceded the appearance or worsened the lymphoedema symptoms, lymphoedema treatments used, was presented as counts and percentages. Women also ranked effectiveness of treatments used and this information was presented as a median effectiveness score for each item.

For women who did engage in sexual activity, a list of sexual difficulties commonly experienced with gynaecological cancer treatment were rated on a scale of “not at all” to “very much”. As dysfunction was of interest, the percentage of women who responded “quite a bit” or “very much”, to these difficulties was reported.

A comparison of current health behaviours, including fruit and vegetable intake, physical activity levels, alcohol intake and cigarette smoking, to just prior to cancer diagnosis, was presented as counts and percentages of whether there was no change, an increase or a decrease in the activities.

Frequencies of the number of fruits and vegetables consumed on average each day were calculated and presented as medians and ranges. These frequencies were further categories into whether women met the national recommendations for daily intakes of fruit and vegetables. The proportions of women who met these recommendations within three age groups (20-39, 40-59, 60-75), were then compared to females in the same three age groups within the Queensland Cancer Risk study (DiSipio *et al*, 2006), a population based study, conducted in the same year as this study, that standardised its results to the 2003 Queensland population by age, sex and geographic location. Results were presented as bar charts.

Physical activity was categorised using the Active Australian Survey Manual, into women who meet the National Physical Activity Guidelines for Australians (DHAC, 1999) and participated in adequate physical activity for health benefits, women who participated in insufficient activity and women who were sedentary. Then similarly to above, the proportions of women within the physical activity categories, within three age groups (20-39, 40-59, 60-75), were compared to females in the same three age groups within the Queensland population. This comparison was also done for body mass index categories, cigarette smoking categories and frequency of alcohol consumption categories.

In addition to overall social support, two subscales, confidant and affective support were also considered. Median plus minimum and maximum values were presented.

The percentage of gynaecological cancer survivors who utilised complementary therapies or therapist for coping with cancer was presented, as well as the break down of counts and percentages for types of complementary therapy (alternative medicine providers, diet and nutrition and mind-body techniques) and the most prevalent items within each of these types. Median (and range) perceived improvement of the most prevalently used therapies was also presented.

Support services awareness, referral and use were presented across types of support service categories and organisations. Data for use were presented as counts and percentages. Furthermore, data for awareness, referral and use were presented in a bar chart to enable direct comparison of percentages across these three outcomes for each service/ organisation type.

The percentage of women who reported no unmet supportive care needs, one unmet need, two unmet needs, *etcetera* through to a possible 45 unmet needs was summarised in a bar graph. In addition to the presentation of the top ten ranked unmet supportive care needs items, need items were combined into five needs domains (psychological, physical and daily living need, health system and information, sexuality, and patient care and support need), following the Supportive Care Needs Survey Guide to Analysis (McElduff *et al*, 2004) and were assessed using counts and percentages to determine the proportion of women with needs in each domain.

3.9.4 TESTING ASSUMPTIONS FOR TESTS AND MODELS

Prior to applying bivariate and multivariable tests/models the assumptions behind these tests were checked as follows.

The chi-square test assumes:

1. The sample was randomly selected and all individuals were independent of each other;
2. Categories were mutually exclusive and exhaustive; and
3. All expected cell counts were of five or more. Please note that the expected frequency less than five is a conservative rule and that in this analysis the expected cell count of two or more was used. However, in all cases Fisher's Exact test was applied whenever computationally possible.

The sample met the random selection assumption, as participants were individuals who were not likely to experience exactly the same thing and hence did not need to be counted as the same data. The second assumption was met within the survey design. That is, the categories within the needs scores, quality of life scores and supportive care use scores were mutually exclusive and exhaustive. The third assumption was tested during the chi-square testing and if violated, discussed at the point of analysis.

Prior to applying the t-test or ANOVA to comparing means, the following assumptions were tested:

1. Normal distribution of continuous variables
2. Homogeneity of variances of the scores in each group

Normality of continuous independent variables (quality of life and social support) was tested using both a one-sample Kolmogorov-Smirnov (K-S) test and by running frequency distributions showing a normal curve to confirm all the following normality criteria were met:

- mean within 10% of median
- minimum and maximum values (observed) were approximated by the mean ± 3SD
- skewness and kurtosis both within ± 3
- a roughly symmetrical histogram.

When the conclusion from the above checking procedure did not match the K-S test, the conclusion from the second less conservative checking procedure result was used, since parametric tests are fairly robust to the assumption of normality (Tabachnick & Fidell, 2001). When the variable was not Normal, a relevant transformation (eg logarithmic or square root) was attempted to normalise the data. In some cases this worked and in some cases it did not. For consistency, non-parametric tests (Mann-Whitney or Kruskal-Wallis) were used and results were also expressed as medians with minimum and maximum values. Before these non-parametric tests were used the homogeneity of variance assumption was tested. For the “wellbeing” and “social support” continuous variables and their relationship to “needs” or “support service use”, the homogeneity of variance was tested firstly using the Levene’s test. Since this is a stringent test, when data failed to meet this assumption using this test, it was further tested by comparing for gross dissimilarities across the spread of box plots or histograms when broken up into groups of the outcome variable.

It was also considered that some of the independent variables may be measuring the same concept and hence were tested for multicollinearity to determine the degree of redundancy. Categorical variables were examined with crosstabulation of counts and percentages to consider how qualitatively similar the variables were. In addition, phi for 2x2 tables and Cramers's V for other nominal tables and Kendall's Tau-b when both variables were ordinal were used to statistically test multicollinearity. If the test statistic was above 0.9 then one of the variables would have been excluded from the bivariate and multivariable analysis, however this did not occur. The following provides a rationale as to which variables were tested and why.

The registry provided a disease-present or absent variable and women reported whether they were in remission. These variables measure a similar concept and hence were tested for multicollinearity. Lymphoedema is associated with having lymph nodes removed and radiation therapy. The strength of association between these variable was tested. It was also considered that “physical activity” and “BMI” may be highly correlated as physical activity is highly associated with weight, which is part of the BMI equation. Therefore, this association was tested. Treatment centre and geographical location may have also measured the same thing as people generally get treated at their nearest location. Therefore, this association was tested. Marital status may have been highly correlated with sexual activity and hence was tested. It was recognised that “education level”, “employment status” and “household income” cluster together to measure the concept of socioeconomic status. While in most research these variables are independent yet have an effect on each other (“education level” influences “employment status” and both “education level” and “employment status” influence “household income” (Turrell, 2004)) it was important in the context of this research question to determine if they were not measuring exactly the same concept. These three variables were also tested for their strength of association with the socio-economic-status for areas variable which was classified from their postcode.

In addition to the independent variables mentioned above, it has also been suggested in the literature that “quality of life” and “supportive care needs” measure the same concept (Mor *et al*, 1991). These outcome variables were tested using Pearson correlation as quality of life is continuous. In particular, tests were conducted between 1) physical/ daily living needs and physical wellbeing 2) physical/ daily living needs and functional wellbeing and 3) psychological needs and emotional wellbeing. If the correlation was above 0.9 or below -0.9 then they would have been deemed to be measuring the same concept; however this was not the case.

3.9.5 CRITERIA USED FOR REPORTING SIGNIFICANT ASSOCIATIONS

Statistical significance is quoted at the conventional $p < 0.05$ level (two-tailed). For the primary research question which considers “what factors correlated with supportive care needs and community support service use” clinical significance (see section 3.2.4) is also considered for meaningful effect size differences with respect to each outcome variable or separate research question.

As outlined in the FACIT Effect Size Tables (2004), a meaningful group difference of greater than eight between mean scores or an effect size of greater than 0.5 is considered clinically significant for the FACT-G score which ranges from 0-108. Hence, for continuous scales a meaningful difference between mean or median group scores of eight on a scale of approximately 0-108 was considered important. However, meaningful differences are proportional to the range. Hence, the wellbeing scores meaningful difference was much less than the FACT-G score as their range was less. For example, physical wellbeing ranges from 0-28, which is about a quarter of the range of FACT-G, so the minimal important difference was a quarter of what was important for the FACT-G (*i.e.* two).

As there was no data to indicate what was a meaningful group difference between community support services use and supportive care needs, a similar difference between groups as outlined for the quality of life research question was considered meaningful. That is, a minimal important difference of eight percent between groups was consequentially contemplated. At the multivariable level of analysis odds ratios were considered significant when they were greater than 2 or less than 0.5 with reasonable cases and confidence intervals. This effect size was chosen as it was believed to reach public health importance when one group experiences the outcome twice as much as another. Hence, this effect size is large enough to recommend targeting subgroups. Furthermore, counts and percentages of a handful of key independent variables were converted to odds ratios which showed that odds of between 1.5 and 2 reflected the clinically meaningful bivariate difference of 8% between groups.

3.9.6 TESTING FOR EFFECT MODIFICATION OF OUTCOME VARIABLES BY TYPE OF CANCER AND SURVIVAL PHASE

It was considered that the percentage of reported needs and service use, across age groups, type of surgery, chemotherapy, radiotherapy, remission status, disease status, lymphoedema status, menopause status, unmet needs, service use, service awareness, service referral and, geographic location may differ substantially by the type of gynaecological cancer women were diagnosed with. Gynaecological cancer subtype differences in these relationships have not been explored in other research. It is recognised that there could be subgroup differences across many other of the relationships of interest in this study. These particular relationships were selected as they generally had adequate cases within independent variable categories and, specific recommendations for a cancer subgroup could be targeted to an identified group in the community. For example, if more cervical cancer survivors who had chemotherapy had unmet psychological needs than cervical cancer survivors who did not have chemotherapy, where as no difference in psychological needs by chemotherapy was observed within the other gynaecological cancer subgroup, then in particular, cervical cancer survivors who had chemotherapy would be recommended help with unmet psychological needs. The bivariate relationships of the above mentioned variables were stratified by type of cancer.

Furthermore, it was considered that the percentage of reported needs, across age groups, type of cancer, surgery, chemotherapy, radiotherapy, lymphoedema status and menopausal status, may be substantially different depending on survival phase post-cancer diagnosis. For example, proportionally more women who had chemotherapy may have unmet psychological needs in the 3-12 months post-diagnosis subgroup than for the 1-3 or 3-5 years post-diagnosis subgroups. In this case, a need for help with unmet psychological needs would be particularly recommended for women in the earlier survival phases. Therefore, these relationships were stratified by survival phase to determine if there were group level differences which may potentially cause effect modification of the relationship of the outcome with the independent variables. The process of this testing is discussed in detail within sections 3.11.7.2 and 3.11.7.3. As the outcome “service use” was measured as “ever use”, effect modification by survival phase of this outcome with independent variables was not appropriate to consider.

3.9.7 ANALYSIS OF CORRELATES OF SUPPORTIVE CARE NEEDS

3.9.7.1 *BIVARIATE ANALYSIS*

Bivariate analyses were conducted to determine whether any independent variables crudely correlated with each supportive care needs domain. This was done using crosstabulation of counts and percentages and chi square tests for categorical independent variables. Both clinical and statistical significance was quoted. Ordinal variables were also tested statistically for linearity if they showed an increasing or decreasing relationship across categories of the independent variable in relation to the outcome variable. Statistical significance of linearity was tested using a crude logistic regression model and removing the contrast statement to treat the independent variable as continuous. Continuous independent variables were deemed not normal and not transformable and hence their association to the outcome variables were tested by stratifying medians, minimum and maximum values by women who report some need and no need for support within each domain. Mann-Whitney was used to compare statistical significance between the two groups.

3.9.7.2 *IMPACT OF CANCER TYPE AND SURVIVAL PHASE ON CRUDE RELATIONSHIPS*

From the outset of this study, it was recognised that group level difference may exist across types of cancer and survival phase post diagnosis; hence stratified sampling was conducted to enable analyses to consider these subgroups independently. In addition to group level differences, these variables may also contribute to a confounding effect of other relationships. Therefore, cancer type and survival phase were tested for both their confounding and modifying effects on the relationships of interest. However, as confounding is merely a nuisance effect and can be controlled for within multivariable analyses, more attention was focused on the effect modification results.

The bivariate analysis determined which outcome variables “type of cancer” and “survival phase” were associated with. A confounding variable is associated with both the outcome and the independent variable, causing a shift in the results. Hence, to test for confounding of cancer type and survival phase of the relationships of dependent variables and independent variables, cancer type and survival phase were tested for their association with each independent variable. This was done in the same way as crude associations of the outcome and independent variables were tested. When type of cancer was associated with both the dependent and independent variable it was deemed a confounder of this relationship.

The crude relationship of some variables to the outcomes (as discussed in Section 3.8.4 Effect modifying variables) were stratified by the potential effect modifying variables “type of cancer” and “survival phase”, to establish whether the pattern of association was different within different subgroups. Stratified crosstabulation of percentages and chi square tests were used. When subgroups showed a different effect, *i.e.* positive verses negative or positive verses not significant or linear verses not linear, effect modification was documented. Independent variables with less than 20 cases across the dependent variable were ignored due to over sensitivity of the small numbers.

3.9.7.3 *MULTIVARIABLE ANALYSIS*

Logistic regression modelling was used for each of the supportive care needs domains to adjust for the inter-correlations of independent variables and effect modifying variables that were identified in the bivariate analysis. The groups with the highest frequency or the most clinical relevance were selected as the referent groups. Variables that had missing values that accumulated to around ten percent or more of the sample were recoded to include a missing category in the model, so that selected cases included in the analysis was maximised for power. When there was excessively large confidence intervals, or the standard errors were excessively larger than the regression coefficient (B) (such as with geographical location which included 14 categories), the variable categories were collapsed where logically possible for a more stable model. Continuous variable were recoded into quartiles and examined in the final models to determine if the odds ratios increase or decrease in a linear formation. If they did not (such as social support) they were automatically left as quartile categorical variables within the multivariable models. As some of the wellbeing scales were linear in some of the models of supportive care outcome domains and not in others, for consistency it was decided that all wellbeing scales were also left as quartiles in the multivariable models.

Blocks were defined to represent a separate construct within the social-ecological model (see table 3.4). Individually, blocks of variables were removed from the final model, which included all variables as a referent point, to determine the R^2 statistic (Nagelkerke's) and accordingly how much variation in supportive care needs and use was accounted for by the factors in that block. Due to the approximate nature of Nagelkerke's R^2 and the fact that each block contained a number of variables that were likely to correlate with variables in other blocks, this process does not provide a totally unconfounded variation for each block, rather, an indication of relative contribution to variation explained by each block, *i.e.* which block explained the most variation in the model through to the least. The variation of each block plus the unexplained variation was then standardised and presented as a pie chart.

In an exploration of the ability of the model to cope with all blocks encompassed in the social-ecological model, sets of variables were entered hierarchically in steps or blocks of characteristics based on the levels of influence (personal, social support, health care, worksite/ organisational/ community). Within the personal level of influence (the strongest association according to the theoretical model) there are a number of constructs which needed to be entered as separate blocks due to the large number of variables within each construct. Hence, personal levels of influence were divided up into blocks of constructs: demographic characteristics, diagnosis and treatment, physiological condition, perceived wellbeing and health behaviour variables. Within the personal level of influence, the constructs with the most variation explained were entered first. A key relationship of type of cancer with psychological needs was used as the example to test if the odds ratios within the final main effects model were able to be asserted with so many variables included in the model. This was determined by how the odds ratios and confidence intervals changed after each block was added. Any variables that were clinically associated with the needs but not supported statistically and that had few cases across subgroups were also explored hierarchically in steps. If the model seemed unhealthy (that is, odds ratios jumped all over the place as each block was added and confidence intervals in the final model were very wide) then the variable was collapsed if possible or not considered.

TABLE 3.4 MODELLING BLOCKS DEFINED IN RELATION TO THE SOCIAL-ECOLOGICAL MODEL

Blocks	Variables
Block 1 Demographic characteristics	*age, marital status, education levels, employment status, household income, country of origin, children living at home*
Block 2 Diagnosis and treatment	*type of cancer, survival phase, cancer stage, treatment centre, health insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment*
Block 3 Physiological condition	*remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity status*
Block 4 Perceived wellbeing	*physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing*
Block 6 Health behaviours	*alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI*
Block 5 Social support	*social support*
Block 7 Health care utilisation	*services use, complementary therapy use*
Block 8 Worksite/ organisational/ community	*services awareness, provider referral, geographic location, ARIA, RRMA, SEIFA*

The final supportive care needs models, which included all blocks, were used to determine if sub-groups of the independent variables had relatively more support needs than other subgroups of that independent variable. For example, do ovarian cancer survivors report needs more than cervical cancer survivors? Statistical support for the significance of a number of the independent variables was also noted. Variable that included a recoded missing category were also tested for statistical significance without the missing category included in the model. Variables that were originally continuous (*i.e.* quartiles in the final model), were tested for a linear association with needs (as outlined above) and if they were linearly related they were further tested for their statistical significance of linearity by removing the contrast statement to treat the independent variable as continuous.

The effect size of many variables changed from the crude to the adjusted relationship. In a few key examples, the suspected confounding factors were removed from the final model, one at a time and then returned, to determine the shift in odds ratio and hence the amount of confounding of each variable. The main confounding variables with greater than a 10% shift in the odds ratio were identified and were believed to explain the shift in effect size from crude to adjusted modelling of most relationships.

Furthermore, an exploratory analysis with limited power was conducted to test for effect modification. Variables that were tested at the bivariate level of analysis were entered in the multivariable model one at a time to determine if there were statistically significant group level differences at the multivariable level. This was done by including both main effects and interaction terms. Due to lack of power, it was not possible to enter all interaction terms at once. Then for those that were statistically significant, further modelling was conducted to assess the odds ratios and confidence intervals of each effect modifiers subgroup independently. That is, a combination variable was computed to remove the double referent of the interaction terms. For example when the relationship of reporting psychological needs by remission status was modified significantly (statistically) by type of cancer, a variable that had the following categories was created: 1= cervical in remission, 2= cervical not in remission, 3=uterine in remission, 4=uterine not in remission, 5= ovarian in remission, 6= ovarian not in remission, 7=other in remission, 8=other not in remission. To observe the odds ratio of each cancer type subgroup four separate models were fitted with referent categories in this example of 1, 3, 5 and 7 and then in each model the odd of only the corresponding subgroup were noted (*i.e.* for the model with a referent of 1, the “cervical not in remission” category was noted, for the model with a referent of 3, the “uterine not in remission” category was noted, *etc*). Main effects were not included in these models so that the odds ratio and confidence intervals of the interaction terms could be considered. Due to limited power in the analysis of variables with many categories, some variables were dichotomised before the combination variable was computed. In cases where a dichotomy of the independent variable was not meaningfully possible, for example menopausal status, a combination variable was created with all menopause categories and then only the odds ratios of the categories with substantial cases were noted. Hence, in these circumstances the case numbers in each subgroup were reduced, but still possible to consider.

3.9.8 MISSING DATA SENSITIVITY ANALYSIS

A missing values analysis was conducted to determine whether those women who dropped out of the final models due to missing data were any different in their distribution of characteristics (independent variables), from those women included in the final analysis. Women who had a missing value for any of the variables entered in the model were coded as one and everyone else was given a two. Then the independent variables were stratified by this missing variable.

3.9.9 ANALYSIS OF CORRELATES OF SUPPORTIVE CARE USE

This research question included the all same independent variables as the supportive care needs research question, plus it also considered unmet psychological, sexuality, physical/ daily living, health system/ information, and patient care/ support needs as potential correlates of service use. Similarly to the supportive care need analysis, the outcome variable of this research question "service use" was also dichotomous. It therefore followed the same analysis technique. However, due to the nature of the outcome variable asking about whether participants had "ever utilised support services or organisations", this analysis was not stratified by survival phase post-diagnosis.

4 QUALITY OF LIFE, MORBIDITIES, HEALTH BEHAVIOURS AND SUPPORT

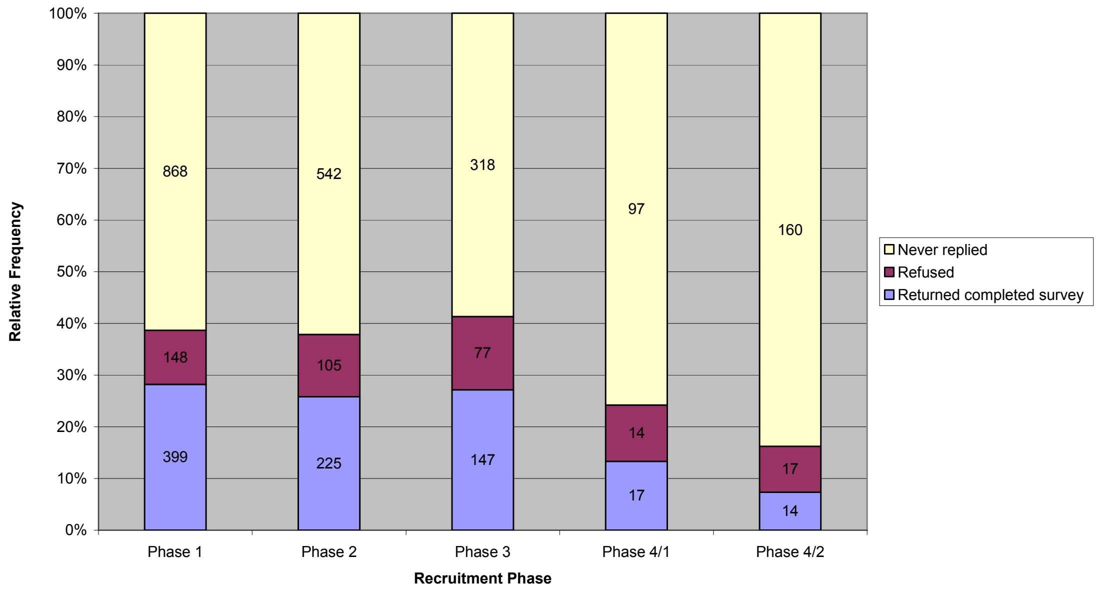
This chapter is broken down into two overarching sections. Section 4.1 will establish the response rate, representativeness, data quality and key characteristics of the sample, to enable a context in which to consider the quality and generalisability of the following research findings. Section 4.2 will describe the quality of life, sequelae, and prevalence of supportive care use within Queensland gynaecological cancer survivors. Supportive care was considered inclusive of community support services, organisations and complementary therapies that women may have utilised for coping with their cancer or reducing the risk of cancer spreading or returning, as well as the adequacy of social support. In addition, this chapter will consider the health behaviours to provide a comprehensive understanding of the health of gynaecological cancer survivors.

4.1 SAMPLE CHARACTERISTICS

4.1.1 RESPONSE RATES

A total of 1774 women diagnosed with gynaecological cancer were mailed a questionnaire package to complete. Of these, 354 were ineligible for the following reasons: 130 (7.3%) were deceased, 121 (6.8%) were "return to sender" *via* Australia Post with incorrect or insufficient address details and hence were uncontactable, 62 (3.5%) were too sick to participate, that is they were in hospital, had another life threatening disease or were physically impaired in some way which excluded them from completing the survey, 23 (1.3%) had moved out of Queensland, 15 (0.8%) reported Non-English Speaking Background (NESB) and an inability to complete the questionnaire, and three (0.2%) were indexed incorrectly on the Gynaecological Cancer Registry and were not diagnosed with gynaecological cancer.

Of the 1420 eligible patients, 56.5% (802) consented to participate and returned completed surveys, 25.4% (361) specified that they did not wish to participate and 18.1% (257) never replied. Response and refusal rates were further broken down into recruitment phases and are illustrated in the figure 4.1.



Phase 1) initial package mail-out
Phase 2) first reminder letter
Phase 3) telephone follow-up
Phase 4 - part 1) final reminder letter for women who indicated intention to return the questionnaire and didn't
Phase 4 - part 2) resend of the questionnaire with a final reminder letter to women for who it could not be established if the questionnaire was ever received

FIGURE 4.1 RESPONSE RATE BY RECRUITMENT PHASE

4.1.2 REPRESENTATIVENESS

As the sampling was stratified by type of cancer and phase post-diagnosis, the representativeness of the sample compared to the population was also considered within strata. As illustrated in figure 4.2, the mean age of participants was similar across types of cancer, except within the "other" category, where it was lower by about five years. Across survival phases of cancer, the mean age was consistently about four years younger in the participants compared with those in the sampling frame. The spread of ages was wider across types of cancer within the sampling frame compared with participants. Typically, older women were slightly under-represented in the sample.

Presence of disease within participants was similar to that of the sampling frame when stratified by type of cancer and phase post-diagnosis (see figure 4.3 and 4.4). The exception was in the 3-12 month post-diagnosis strata where women whose disease was still present were under-represented in the sample by 32% compared to 47%. Stage distribution was also similar between participants and the sampling frame when stratified by type of cancer and phase post-diagnosis (see figure 4.5 and 4.6). The exception was in the "other" category where women who were late stage were slightly over-represented in the sample by 46% compared to 34%. As Socio-Economic Index for Areas and Accessibility/Remoteness Index of Australia, were not likely to be affected by type of cancer and phase post-diagnosis, the comparison of these factors was not stratified by cancer type and phase. The comparison between these characteristics within the participants and the sampling frame showed no difference in distribution (see figure 4.7 and 4.8).

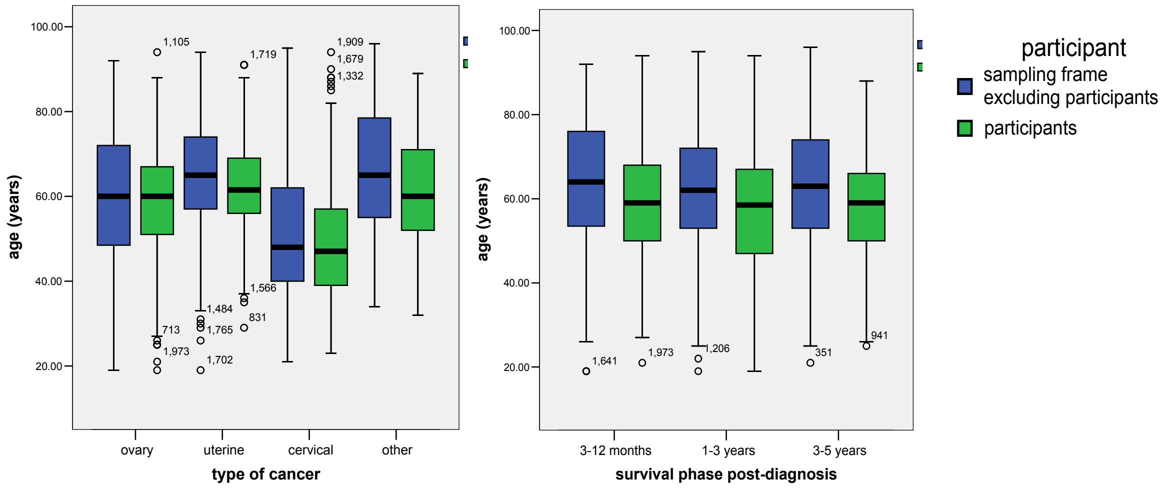


FIGURE 4.2 AGE BY TYPE OF CANCER AND SURVIVAL PHASE STRATIFIED BY PARTICIPANTS

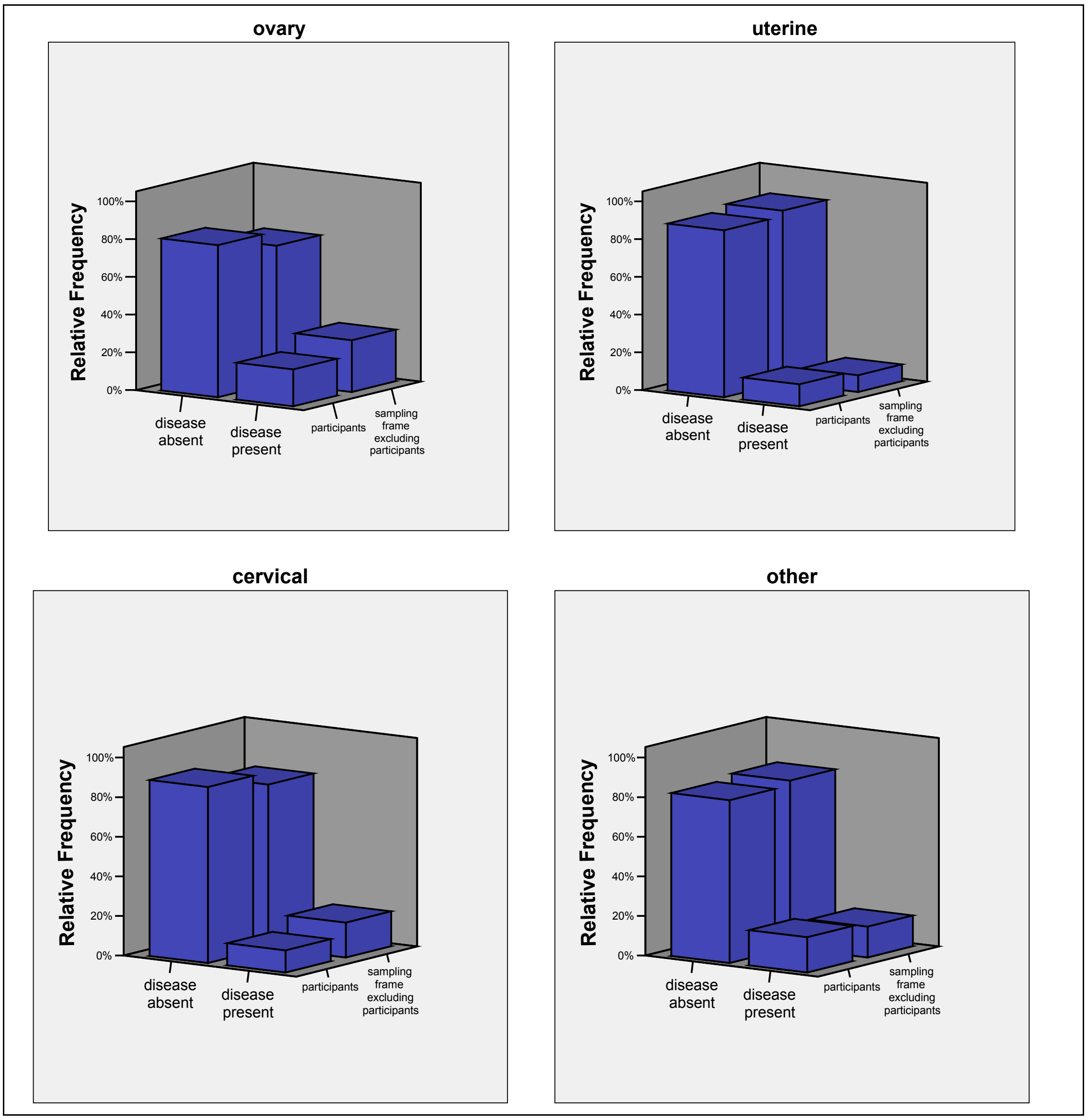


FIGURE 4.3 DISEASE PRESENCE BY TYPE OF CANCER STRATIFIED BY PARTICIPANTS

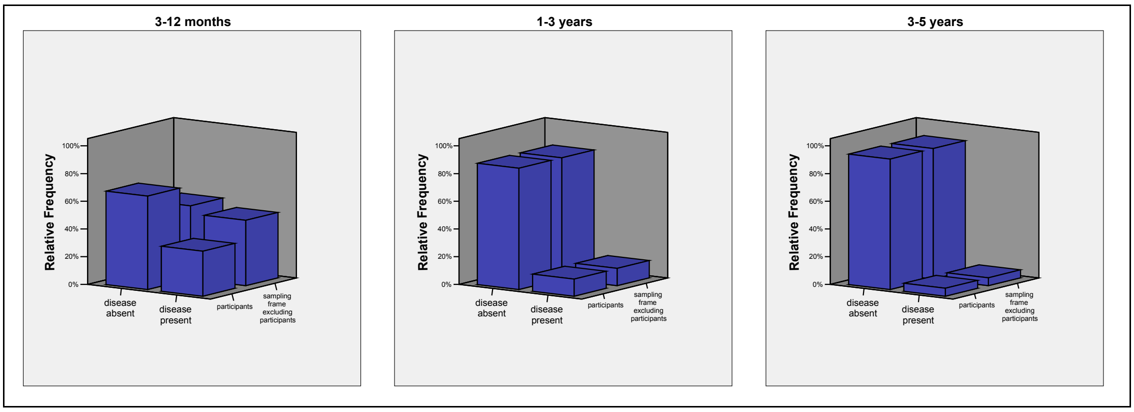


FIGURE 4.4 DISEASE PRESENCE BY SURVIVAL PHASE POST-DIAGNOSIS STRATIFIED BY PARTICIPANTS

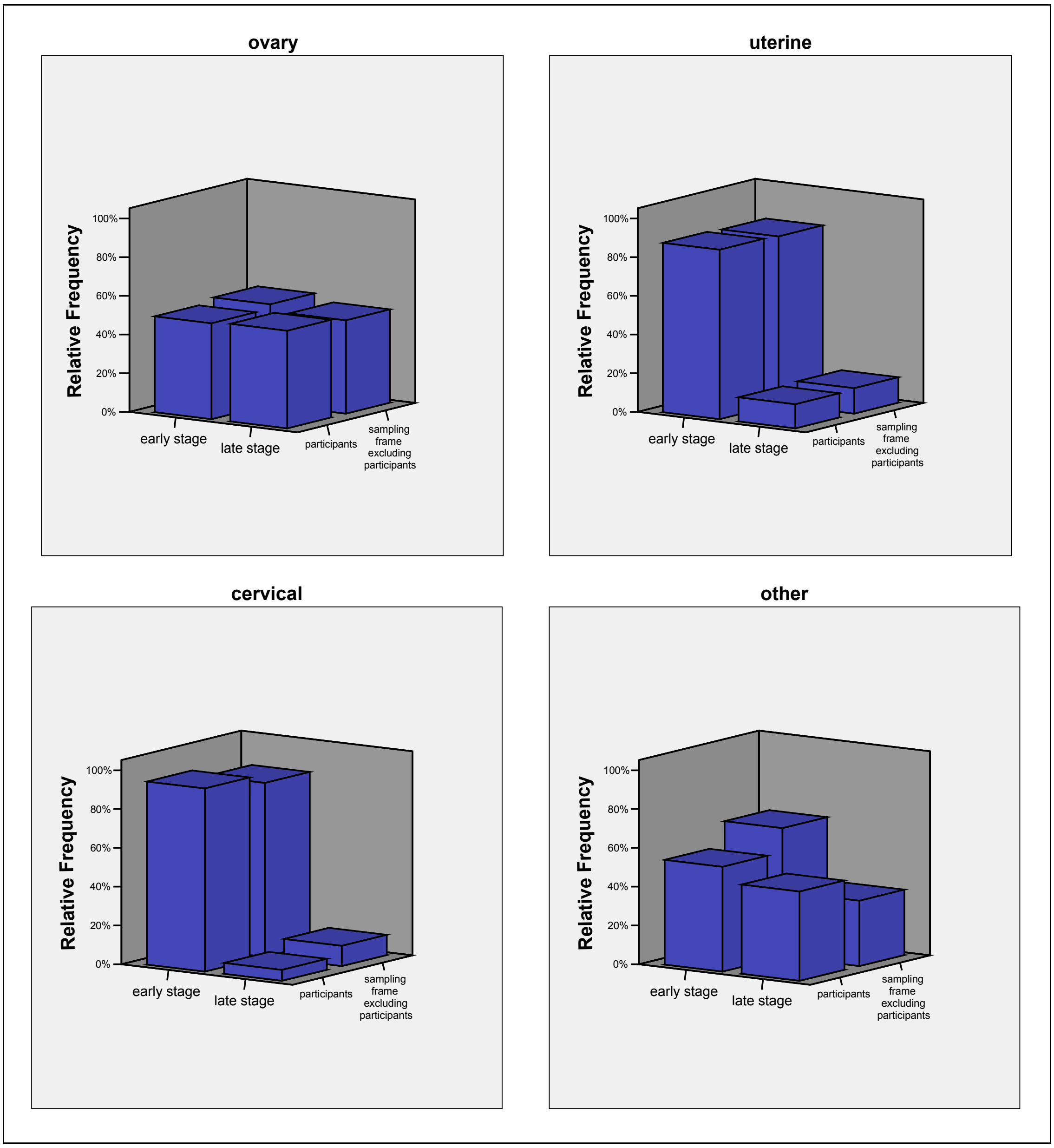


FIGURE 4.5 DISEASE STAGE BY TYPE OF CANCER STRATIFIED BY PARTICIPANTS

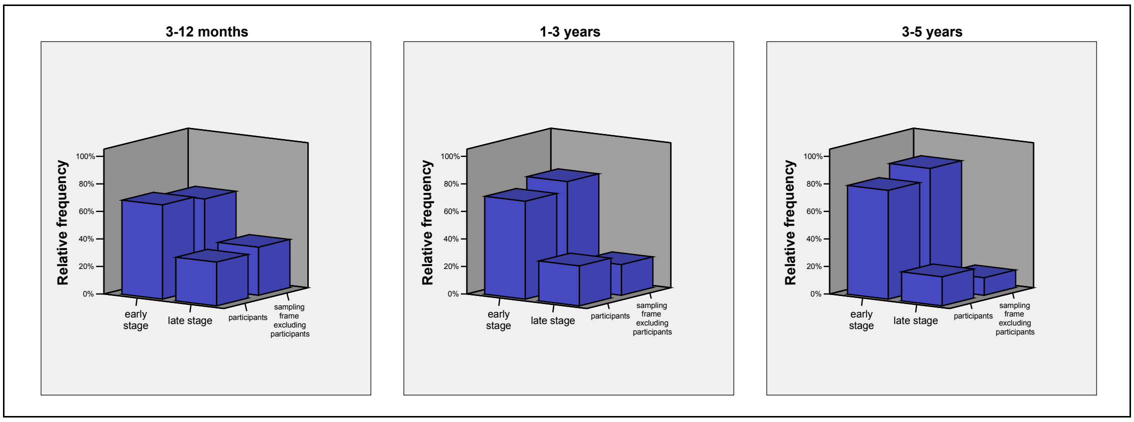


FIGURE 4.6 DISEASE STAGE BY SURVIVAL PHASE POST-DIAGNOSIS STRATIFIED BY PARTICIPANTS

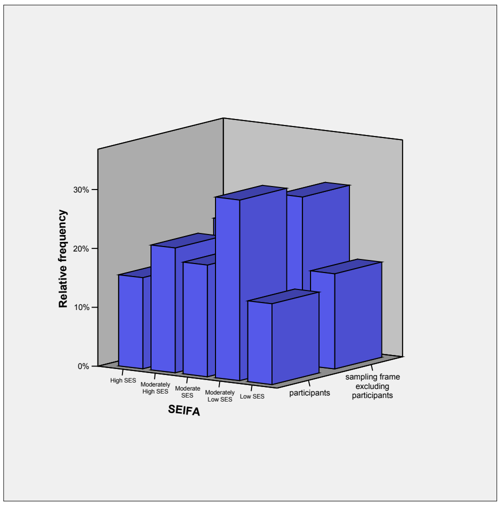


FIGURE 4.7 SOCIO-ECONOMIC INDEX FOR AREAS BY PARTICIPANTS

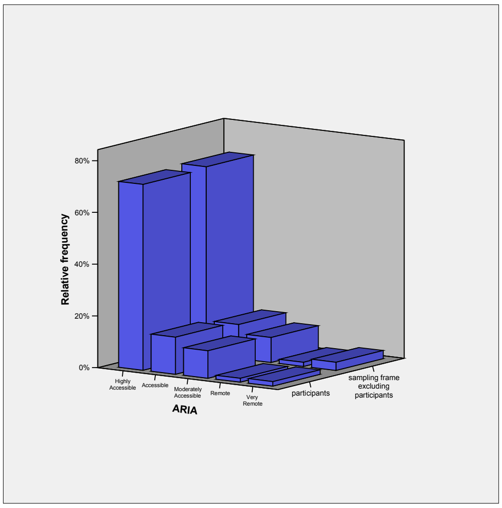


FIGURE 4.8 ACCESSIBILITY/REMOTENESS INDEX OF AUSTRALIA BY PARTICIPANTS

4.1.3 DATA QUALITY

Accuracy checks were performed to quantify non-duplicate records between registry records and survey data. Results showed that there was a high level of agreement between both data sources with regard to age (98%), being diagnosed with cervical cancer (98%), ovarian cancer (96%), vulval cancer (85%), uterine cancer (81%), classification of survival phase (87%), having surgical treatment (82%), having chemotherapy (93%), having radiotherapy (95%) and having lymph nodes removed (76%).

In contrast, the level of agreement was very low for being diagnosed with peritoneal (15%). This may have been due to the low prevalence of this condition and the women not easily recalling the name and not bothering to tick the “don’t know” response option. Level of agreement was also low for disease stage (32%). This was probably because stage is a clinical term that is regularly collapsed into early or late, rather than one to four.

It was decided that during the analysis, registry data would be used for the diagnosis and treatment variables, as this data would not be affected by recall bias. For age, it was more likely that women would remember their date of birth and that the registry made a typographic error. Therefore, self reported data were used where available and registry data were inserted when self reported data were missing.

4.1.4 SAMPLE DEMOGRAPHIC AND TREATMENT CHARACTERISTICS

Study participants were mainly over 50 years old, living with a partner, earning a household income of under $40 000, and without children living at home. The diagnosis and treatment characteristic of the sample included mainly women who had early stage gynaecological cancer, had open abdominal surgery, but no chemotherapy, radiotherapy or hormone therapy, women in remission and not diagnosed or suffering from lymphoedema symptoms. Due to stratified sampling of cancer type and survival phase, results of these two characteristics were as anticipated (see table 4.1).

TABLE 4.1 KEY DEMOGRAPHIC AND TREATMENT CHARACTERISTICS OF PARTICIPATING PATIENTS.

Characteristics	N	%
Age (years)		
18-39	77	9.6
40-49	134	16.7
50-59	216	26.9
60-69	221	27.6
70+	154	19.2
Marital status		
Single	65	8.2
Living with a partner	527	66.3
Seperated/divorced	89	11.2
Widowed	114	14.3
Education level		
University/college degree	132	17.3
Trade or technical certificate	101	13.2
Senior high school	116	15.2
Junior high school	309	40.4
Primary or no schooling	106	13.9
Employment type		
Paid full- time	139	17.7
Paid part time or casual	132	16.8
Home duties	131	16.7
Retired	247	31.5
Unable to work because of illness	74	9.4
Other	62	7.9
Annual household income		
<$20 000	212	26.4
$20 000 - <$40 000	158	19.7
$40 000 - <$60 000	98	12.2
$60 000 - <$80 000	58	7.2
$80 000+	81	10.1
Do not wish to answer	195	24.3
Geographical location		
Gold Coast	86	10.7
Logan-Beaudesert	61	7.6
Bayside	39	4.9
QEII Hospital & District	89	11.1
Prince Charles Hospital & District	122	15.2
Redcliffe-Caboolture	51	6.4
Sunshine Coast	67	8.4
West Moreton	43	5.4
Darling Downs/South West	39	4.9
Wide Bay-Burnett	58	7.2

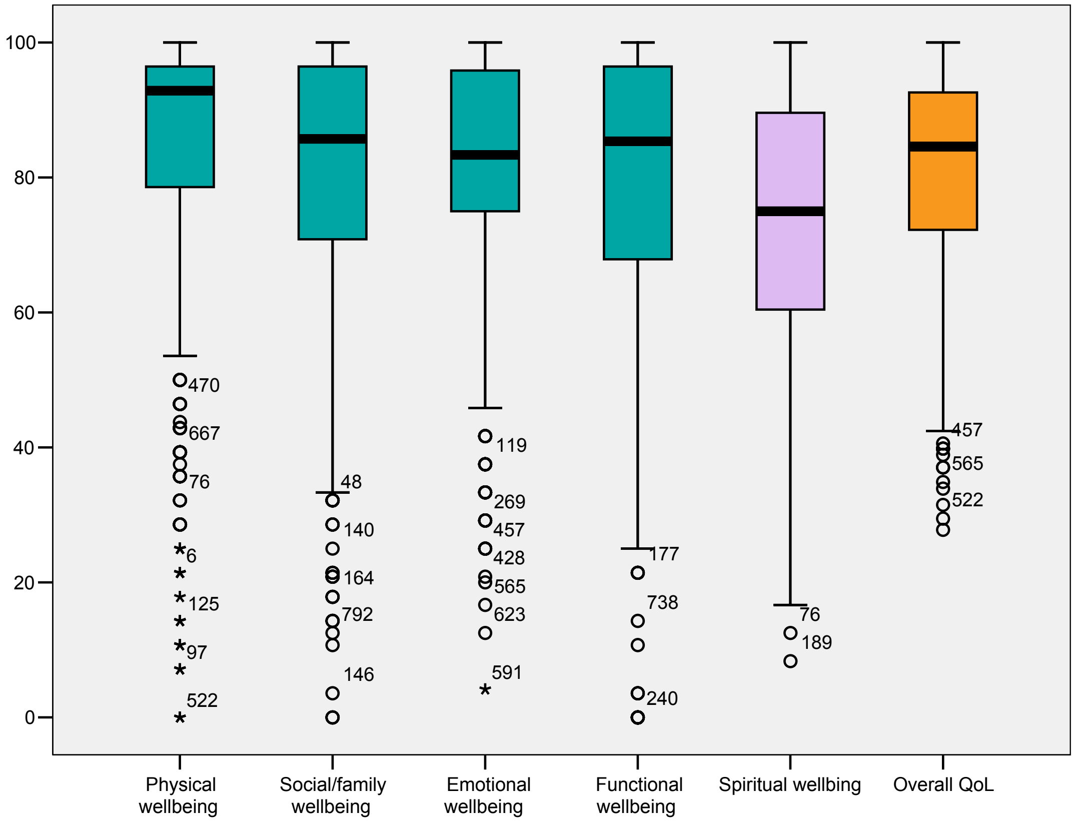
Characteristics	N	%
Fitzroy/Central West	38	4.7
Mackay	21	2.6
Northern/North West	45	5.6
Far North	43	5.4
Children living at home		
No	503	79.0
Yes	134	21.0
Type of gynaecological Cancer		
Cervical	197	24.6
Uterine	243	30.3
Ovarian	234	29.2
Other	128	16.0
Survival phase post-diagnosis		
3-12 months	190	23.7
1-3 years	335	41.8
3-5 years	277	34.5
Stage		
Early stage	558	69.6
Late stage	204	24.4
No stage/ don’t know	40	5.0
Surgery		
None	13	1.6
Laparoscopic only	33	4.1
Vaginal ± laparoscopic	87	10.8
Open abdominal ± laparoscopic	526	65.6
Vaginal and open abdominal	58	7.2
Open bowel resection ± other surgery	67	8.4
Unknown	18	2.2
Chemotherapy		
Yes	297	37.0
No	505	63.0
Radiotherapy		
No radium	598	74.6
Internal brachytherapy	41	5.1
External radium beam therapy ± brachytherapy	163	20.3
Hormone therapy		
Yes	37	4.6
No	765	95.4
Lymph nodes removed		
No	449	56.0
Yes	353	44.0
Last administration of treatment		
Within the last month	27	3.7
1-12 months ago	226	31.3
1-2 years ago	163	22.6
>2 years ago	305	42.3
Remission		
Yes	592	73.8
No/don’t know	210	26.2
Lymphoedema status		
No lower limb swelling	611	76.2
Lower limb swelling but not diagnosed	110	13.7
Diagnosed lymphoedema	81	10.1
Stoma		
No	764	95.3
Yes	38	4.7

4.2 SUPPORTIVE CARE AND OTHER HEALTH OUTCOMES

4.2.1 PERCEIVED LEVEL OF QUALITY OF LIFE

Overall, gynaecological cancer survivors three months to five years post-diagnosis had a median physical wellbeing (PWB) score of 26 (range 0-28), social/family wellbeing (SFWB) score of 24 (range 0-28), emotional wellbeing (EWB) score of 20 (range 1-24), functional wellbeing (FWB) score of 23 (range 0-28), spiritual wellbeing (SPWB) score of 36 (range 4-48) and overall quality of life score of 91 (range 30-108). The site-specific quality of life scales revealed that cervical cancer survivors rated their median quality of life at 137 (range 76-168), ovarian cancer survivors at 132 (range 53-154), endometrial cancer survivors at 151 (range 67-172) and vulval cancer survivors at 149 (range 86-183).

Due to differing scale ranges, to enable direct comparison across wellbeing scales, results were standardised to scores ranging from 0-100, where the minimum value reflected the worst quality of life and the maximum value reflected the best quality of life. Figure 4.9 indicates that median standardised overall quality of life was very good (84, range 28-100). Individual wellbeing subscales were correspondingly also very good (PWB 93, range 0-100, SFWB 86, range 0-100, EWB 83, range 4-100, and FWB 82, range 0-100), with physical wellbeing rating exceptionally well on average. In addition to these, spiritual wellbeing rated a little lower on average by comparison (median 75, range 8-100).



[a] Overall quality of life (QoL) consists of the first four subscales (physical, social/family, emotional and functional wellbeing)

FIGURE 4.9 QUALITY OF LIFE SCALES STANDARDISED TO A SCORE RANGING FROM 0-100 (N=726-775 DEPENDING ON MISSING VALUES FOR EACH SCALE)

The quality of life subscales and the overall scale were further stratified by type of cancer, survival phase post-diagnosis and age to see whether the median scores were different within these variables' subgroups. Across survival phase's post-diagnosis and age, the medians and ranges of self-perceived quality of life were similar for all subscales and overall scale.

On average, cervical cancer survivors had lower social/family wellbeing than other gynaecological cancer survivors and lower spiritual wellbeing than uterine and ovarian cancer survivors (see table 4.2). Vulval cancer survivors had lower functional wellbeing on average than uterine cancer survivors. Physical, emotional, and overall wellbeing did not differ substantially across gynaecological subtypes.

Data from this gynaecological cancer population were compared with Queensland female general population norms from the Queensland Cancer Risk Study (DiSipio *et al*, 2006), to determine if perceived wellbeing was different. T-scores indicated that social wellbeing was higher in pooled gynaecological cancer survivors. When considered by type of cancer, social wellbeing remained higher for uterine, ovarian and vulval cancer survivors, but cervical cancer survivors were not significantly different from the general female population (see table 4.2). Moreover, uterine cancer survivors had significantly higher functional wellbeing and overall quality of life than the general female population (see table 4.2). All other physical, emotional, functional and overall quality of life comparisons by cancer type, to the Queensland female general population norms were similar.

TABLE 4.2 QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS QUALITY OF LIFE AND WELLBEING SCALES STRATIFIED BY TYPE OF GYNAECOLOGICAL CANCER AND COMPARED WITH QUEENSLAND FEMALE POPULATION NORMS

	Cervical		Uterine		Ovarian		Vulva	
	N	Median (min-max)	N	Median (min-max)	N	Median (min-max)	N	Median (min-max)
Physical wellbeing	193	26 (2-28)	223	26 (3-28)	227	25 (0-28)	51	26 (7-28)
Social/family wellbeing	194	23 (0-28)	229	25 (3-28) *	231	25 (0-28) *	50	25 (4-28) *
Emotional wellbeing	190	20 (7-24)	220	21 (5-24)	224	20 (1-24)	45	20 (8-24)
Functional Wellbeing	191	23 (0-28)	228	24 (0-28) *	230	23 (0-28)	49	22 (1-28)
Overall quality of life	186	89 (34-108)	209	94 (40-108) *	219	91 (30-108)	45	88 (48-108)
Spiritual wellbeing	186	33 (4-48) ^{NC}	220	39 (8-48) ^{NC}	223	37 (8-48) ^{NC}	47	36 (18-48) ^{NC}

Clinically significant difference is defined as a difference of at least eight between groups' overall quality of life (2004). Corresponding to narrower range, proportional differences of at least two between all wellbeing subscales were clinically significant, except spiritual for which a difference of four between groups was clinically significant.

* Significantly higher than Queensland female general population norms when compared with T-scores from the Queensland Cancer Risk Study (DiSipio *et al*, 2006)

^{NC} Not compared to the Queensland female population norms as data not available

4.2.2 PREVALENCE OF DIAGNOSED AND SYMPTOMATIC LYMPHOEDEMA

The second aim of this study was to determine the prevalence of diagnosed and symptomatic lymphoedema within the gynaecological cancer survivors' population. Results showed 10% (95% CI: 3% to 17%, n=81) of gynaecological cancer survivors reported being diagnosed with lower limb lymphoedema and an additional 14% (95% CI: 8% to 20%, n=110) reported lower limb swelling that had not been medically diagnosed. To infer generalisability of prevalence to the gynaecological cancer survivor population at large, prevalence scores were weighted by the chance of selection within this study's sample (*i.e.* chance of selection across type of cancer and phase post diagnosis stratum). Similarly, weighted results found that ten percent were diagnosed with lymphoedema and 15% had non-diagnosed lower limb swelling.

The prevalence of women diagnosed with and symptomatic (*i.e.* lower limb swelling) of lymphoedema was significantly different across cancer type and survival phase. Table 4.3 indicates that vulval cancer survivors had a significantly higher prevalence of diagnosed lymphoedema (36%), than all other gynaecological cancer subgroups (5-12%). Undiagnosed lower limb swelling was similar across cancer types. Gynaecological cancer survivors with no symptoms of lymphoedema decreased proportionately after the first year post-diagnosis.

TABLE 4.3 LYMPHOEDEMA STATUS STRATIFIED BY TYPE OF CANCER AND SURVIVAL PHASE (N=802)

	% (n) of sample and their lymphoedema status		
	No lower limb swelling	Undiagnosed lower limb swelling	Diagnosed lymphoedema
Types of Gynaecological Cancer			
Cervical	73.6 (145)	14.2 (28)	12.2 (24)
Uterine	77.8 (189)	14.0 (34)	8.2 (20)
Ovarian	79.5 (186)	15.8 (37)	4.7 (11)
Vulva	49.1 (26)	15.1 (8)	35.8 (19)
Other	86.7 (65)	4.0 (3)	9.3 (7)
	[a]		[a]
Survival Phases Post-Diagnosis			
3-12 months	83.2 (158)	11.1 (21)	5.8 (11)
1-3 years	74.3 (249)	16.1 (54)	9.6 (32)
3-5 years	73.6 (204)	12.6 (35)	13.7 (38)
	[a]		

[a] clinically significant difference between groups

Of the 81 women with diagnosed lymphoedema in this study, 75% were diagnosed with the condition within the first year post cancer diagnosis, 19% were diagnosed the following year and 6% were diagnosed with lymphoedema between two years and five years post cancer diagnosis. While 31% reported being informed about lymphoedema before their cancer treatment, 30% were informed after their treatment but before symptoms, 34% were informed during lymphoedema diagnosis, and 5% can not remember when they were informed about lymphoedema.

In addition to swelling of the lower limbs, 46% of women with diagnosed lymphoedema report legs feeling heavy, 43% noticed skin feeling tight in the legs, 41% reported pain in the legs, 31% noticed pins and needles in the lower limbs, 28% noticed heat in the legs, 26% reported tenderness in the legs, 26% reported puffiness and reddened areas in the legs, 25% noticed flesh feeling thick and hard in the legs, 24% reported stiffness of the legs, 20% noticed decreased range of movement in the legs, 9% noticed visible lumps and 7% reported some other symptom in their lower limbs. On average in the last month from when this survey was conducted, 40% perceived their symptoms as mild, 30% as moderate, 10% as severe and 20% had had no symptoms in the last month. By far, the three most common factors which women reported triggering or preceding the appearance or worsening the lymphoedema symptoms were: being on their feet all day (64%), hot weather (47%) and long distance travel (44%). On average, 40% of women with diagnosed lymphoedema reported having no difficult performing their daily tasks, while 30% had mild difficulty, 26% had moderate difficulty and 5% had severe difficulty. However, none reported being unable to perform their daily tasks.

Women with diagnosed lymphoedema utilised a variety of treatments, as illustrated in the table below. The most common, and those perceived to be the most effective treatments included, compression garments (64%), lymphatic massage (62%), and lymphatic exercises (42%).

TABLE 4.4 LYMPHOEDEMA TREATMENTS USED AND THEIR PERCEIVED EFFECTIVENESS BY QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS WITH LYMPHOEDEMA (N≈81)

	Lymphoedema treatments used	Effectiveness (Range: 0=not effective to 4 = very effective)
	% (n)	Median
Compression garment eg. stockings	64 (52)	3
Lymphatic massage	62 (50)	3
Lymphatic exercise	42 (34)	3
Bandaging	24 (19)	2
Care of limb instructions	20 (16)	2
Diuretics	19 (15)	2
Paddling in water	17 (14)	3
Bike shorts	16 (13)	1
Anti-inflammatory drugs, analgesics	14 (11)	1
Other (please specify)	16 (13)	4

[a] % are based on available data for each item, items ranged between 79 and 82 responses from 82 participants with lymphoedema. Participants could nominate each source independently.

4.2.3 PREVALENCE OF SEXUAL DYSFUNCTION

The third aim of this study was to determine the prevalence of sexual dysfunction within the gynaecological cancer survivors' population. Overall, eight percent (n=54) of gynaecological cancer survivors reported that their gynaecological cancer had made sexual relations too difficult or too uncomfortable. Forty-three percent (weighted for chance of selection in the sample) of gynaecological cancer survivors and 59% (weighted) of gynaecological cancer survivors living with a partner, reported still engaging in sexual activity. When comparing the frequency of sexual activity between Australian females and gynaecological cancer survivors, limiting both groups age to less than 60, it was observed that the proportion of sexually active gynaecological cancer survivors (60% weighted) was much less than Australian females (72%) (Richters *et al*, 2003). However, it is likely that a large amount of this difference maybe explained by differing age distributions between these two groups, with the cancer population's age being negatively skewed.

This proportion of sexually active gynaecological cancer survivors did not significantly differ across survival phases post-diagnosis. Sexual activity did decline linearly with increasing age. Interestingly, there was also an age adjusted difference in sexual activity across types of cancer. As shown in table 4.5, women diagnosed with cervical cancer, aged less than 50 and between 60 and 69, were significantly more likely to engage in sexual activity after their diagnosis than women diagnosed with uterine or ovarian cancer.

TABLE 4.5 PREVALENCE OF SEXUALLY ACTIVE GYNAECOLOGICAL CANCER SURVIVORS, THREE MONTHS TO FIVE YEARS POST-DIAGNOSIS, BY CANCER TYPE AND AGE GROUP (N=802).

Age group (years)	Cervical % (n)	Uterine % (n)	Ovarian % (n)	Other % (n)
20-39	83.0 (44)	*66.7 (4)*	*64.3 (9)*	*100.0 (2)*
40-49	77.8 (42)	52.4 (11)	48.6 (18)	*73.7 (14)*
50-59	44.7 (21)	57.4 (39)	50.0 (28)	41.2 (14)
60-69	48.0 (12)	25.6 (20)	27.3 (18)	35.3 (12)
70+	*6.7% (1)*	19.6 (10)	14.7 (5)	0.0 (0)

< 20 cases across the sexual activity categories, therefore over sensitive and not considered

Of the gynaecological cancer survivors who were sexually active, 35% noticed quite a bit or very much dryness of the vagina, 17% reported quite a bit or very much pain or discomfort during penetration and eight percent of women who reported having sex in the last month said they did not at all desire to have sex with their partner that month and 14% said they only desired to have sex with their partner a little bit that month.

4.2.4 SUPPORTIVE CARE USE

The fourth aim of this study was to determine the prevalence of supportive care use. This section describes community support service use, as well as awareness, referral and satisfaction, providing an overall picture of the service use and potential barriers to use. As part of the supportive framework, this section also explores other issues important to the wellbeing of survivors, including complementary therapy use, the adequacy of social support and participation in healthy behaviours. In addition to overall prevalence, results are considered by type of cancer, survival phase post-diagnosis, and by age groups. Within the health behaviour section, change in behaviour post-diagnosis, and a comparison of health behaviours to the general female Queensland population are also considered.

4.2.4.1 *USE OF COMMUNITY SUPPORT SERVICES*

Over one half of gynaecological cancer survivors', 54% (95% CI: 50% to 58%, n=589, weighted by each woman's chance of selection) have utilised at least one community support service since being diagnosed. Higher proportions of cervical, ovarian and "other" gynaecological cancer survivors reported use of at least one service, relative to uterine cancer survivors (61%, 62%, 60% relative to 43% respectively, $p<0.001$)

As shown in table 4.6, the most commonly used services were: cancer information booklets (37%), internet information on cancer (23%), and telephone information and support lines (20%). The most commonly used support organisation was the Queensland Cancer Fund (21%). On average, women were completely satisfied with the support services or organisations that they used, except for the internet base support groups and information, which had a median rating of three (0-4 scale of satisfaction, where 0 represented "not at all satisfied" and 4 represented "completely satisfied").

TABLE 4.6 COMMUNITY SUPPORT SERVICE AND ORGANISATION USE, AND SATISFACTION RATING BY QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS, IN 2004 (N≈622)[A]

	Use	**Satisfaction** [b]
Community support services	**% (n)**	**Median (min-max)**
Cancer information and support telephone lines	19.9 (136)	4 (0-4)
Community-based cancer support groups	11.0 (71)	4 (0-4)
Workshops/programs for coping with cancer	11.7 (74)	4 (0-4)
Internet based cancer support groups	7.0 (44)	3 (0-4)
Information booklets on cancer from support organisations	37.2 (240)	4 (0-4)
Information on cancer available on the internet	23.1 (146)	3 (0-4)
Face-to-face counselling services for cancer patients	10.6 (65)	4 (0-4)
Physiotherapy service for cancer patients	15.2 (96)	4 (0-4)
Financial assistance for cancer patients	12.5 (79)	4 (0-4)
Respite care for cancer patients	3.0 (19)	4 (0-4)
Community health nurse for cancer patients	7.3 (46)	4 (0-4)
Community support organisations	**% (n)**	**Median (min-max)**
Centre for Gynaecological Cancer at Royal Brisbane & Women's Hospital	12.3 (76)	4 (0-4)
Gynaecological Cancer Society	6.7 (40)	4 (0-4)
Lymphoedema Association of Queensland	5.1 (30)	4 (0-4)
Ostomy/Stoma Association	5.9 (34)	4 (0-4)
Queensland Cancer Fund	21.0 (130)	4 (0-4)
Cancer Support Centre at Griffith University	1.7 (10)	4 (0-4)
Bloomhill Cancer Help Centres in Buderim	2.4 (14)	4 (0-4)

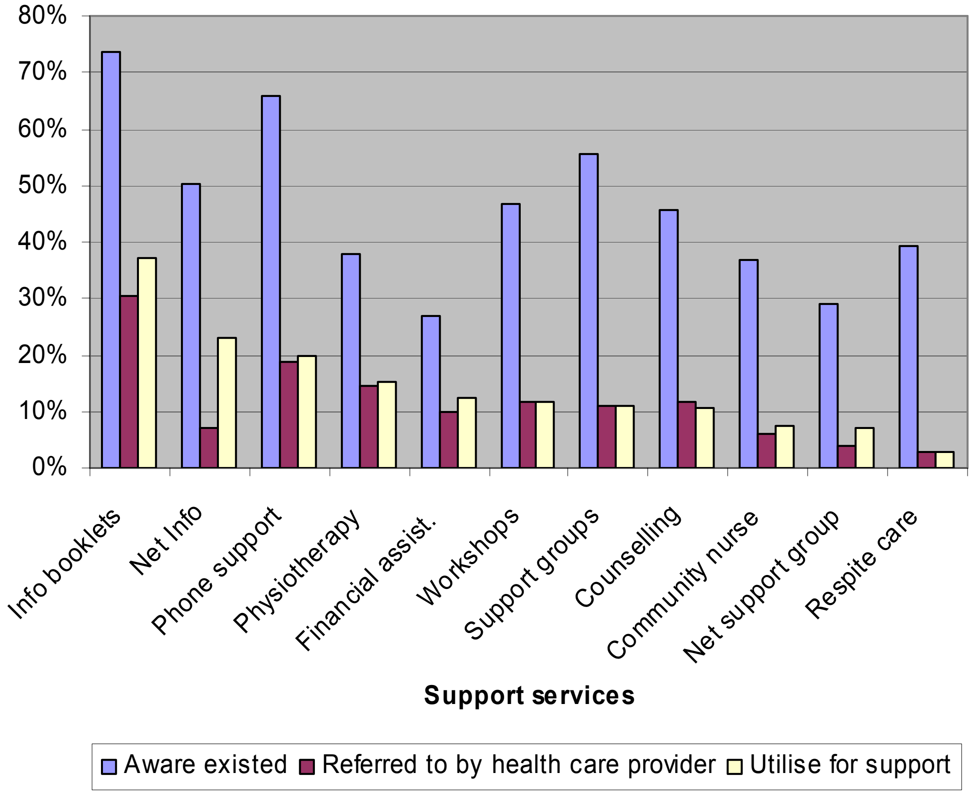
[a] % are based on available data for each item, items ranged between 579 and 682 responses from 802 participants. Participants could nominate each source independently.

[b] Satisfaction was ranked on a scale of 0-4, where 0 represented not at all satisfied and 4 represented completely satisfied.

As illustrated in figure 4.10, about three quarters of women (74%) were aware of information booklets from support organisations, two thirds (66%) were aware of telephone support lines and about half were aware of community support groups (56%), information on the internet (50%), workshops for coping with cancer (47%), and face-to-face counselling (46%). Less than 40% of gynaecological cancer survivors were aware of respite care, physiotherapy services for cancer patients, access to community health nurses, and less than 30% were aware of internet-based support groups or financial assistance for cancer patients.

Health providers referred more women to information booklets than any other service with 31% of women reporting having been referred to these booklets. Telephone support lines were the next most frequently referred support service, with 19% of women reporting being referred. Less than 15% of survivors were referred to other services.

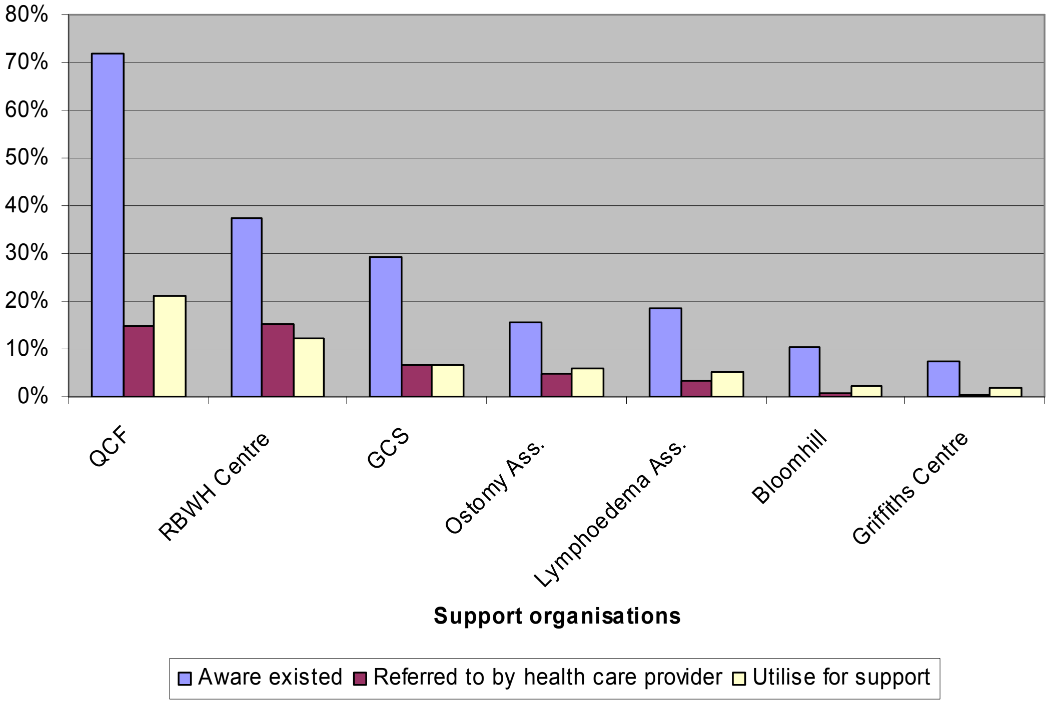
Awareness of support services was between two and thirteen fold higher than use. The proportion of women who were referred by a heath provider to a support service was generally fairly similar to the proportion of women who used a support service, except with cancer information on the internet, where use was approximately three fold higher than referral.



[a] % are based on available data for each item, items ranged between 579 and 682 responses from 802 participants. Participants could nominate each source independently.

FIGURE 4.10 COMMUNITY SUPPORT SERVICES AWARENESS, REFERRAL TO, AND USE BY, GYNAECOLOGICAL CANCER SURVIVORS, IN 2004 (N≈622)[A]

As illustrated in figure 4.11, about three quarters of women (72%) were aware of the Queensland Cancer Fund. Less than 40% were aware of the gynaecological cancer specific organisations such as the Centre for Gynaecological Cancer at Royal Brisbane and Women's Hospital (37%) and the Gynaecological Cancer Society (29%). Awareness was low for symptom-specific or localised support centres. As reported by participants, referrals by health providers to the organisations were low. The Queensland Cancer Fund and Centre for Gynaecological Cancer at Royal Brisbane and Women's Hospital were the most commonly referred support services, with 15% of women reporting being referred. Awareness of support organisations was three to four times higher than use. Similarly to support services, the proportion of women who were referred by a heath provider to a support organisation was generally fairly similar to the proportion of women who used a support organisation.



[a] % are based on available data for each item, items ranged between 579 and 682 responses from 802 participants. Participants could nominate each source independently.

FIGURE 4.11 COMMUNITY SUPPORT ORGANISATION AWARENESS, REFERRAL TO, AND USE BY, GYNAECOLOGICAL CANCER SURVIVORS, IN 2004 (N≈622)[A]

4.2.4.2 *COMPLEMENTARY THERAPY SUPPORT*

Twenty-nine percent (95% CI: 23% to 35%, n=232) of gynaecological cancer survivors reported using a complementary therapy or alternative therapist for coping with cancer or reducing the risk of cancer spreading or returning. The weighted average, for chance of selection within the sample, resulted in the same prevalence. Ovarian cancer survivors were significantly higher users of complementary therapy support compared to uterine cancer survivors, with 36% and 24% use, respectively (p=0.003). Seventeen percent of participants reported using alternative medicine providers such as an acupuncturist, massage therapist, naturopath or spiritual healer, 21% reported consuming an anticancer diet, herbs, vitamins or other supplements, and 18% reported using mind-body techniques such as meditation, yoga, tai chi, music therapy or visualisation.

Overall, naturopaths and massage therapists were the most prevalently utilised alternative medicine providers, with about 10% of the sample utilising them to cope with the cancer. Women used a wide variety of dietary and nutritional complementary therapies to cope with cancer or reduce the risk of cancer spreading or returning. However, the prevalence rate for each of the individual therapies was quite low. The most common use (approximately 5%) included multi-vitamins and minerals, unspecified healthy diets, and vitamin C. In the mind-body class of therapies, meditation was the most common utilised with 11% of the sample practising this therapy.

Table 4.7 shows the top ten most used therapies/ therapists, and self-reported median improvement scores. On average, women reported great improvement in health and wellbeing from meditation, imagery/ visualisation, eating a healthy diet, and consumption of vitamin C.

TABLE 4.7 TOP TEN PREVALENTLY USED COMPLEMENTARY THERAPIES/THERAPISTS FOR COPING WITH CANCER OR REDUCING THE RISK OF CANCER SPREADING OR RETURNING, AND THEIR PERCEIVED IMPROVEMENT TO HEALTH AND WELLBEING.

	Therapy Used		Improvement [a]	
	N	%	Median	Range
Meditation	90	11.2	4	0-4
Naturopath	80	10.0	3	0-4
Massage therapist	74	9.2	3	0-4
Imagery/visualisation	60	7.5	4	0-4
Music therapy	53	6.6	3	0-4
Yoga	43	5.4	3	0-4
Multi vitamins and minerals	42	5.2	3	1-4
Unspecified healthy diet	40	5.0	4	1-4
Vitamin C	38	4.7	4	1-4
Tai chi	29	3.6	3	0-4

[a] Improvement was ranked on a scale of 0-4, where 0 represented no improvement and 4 represented great Improvement

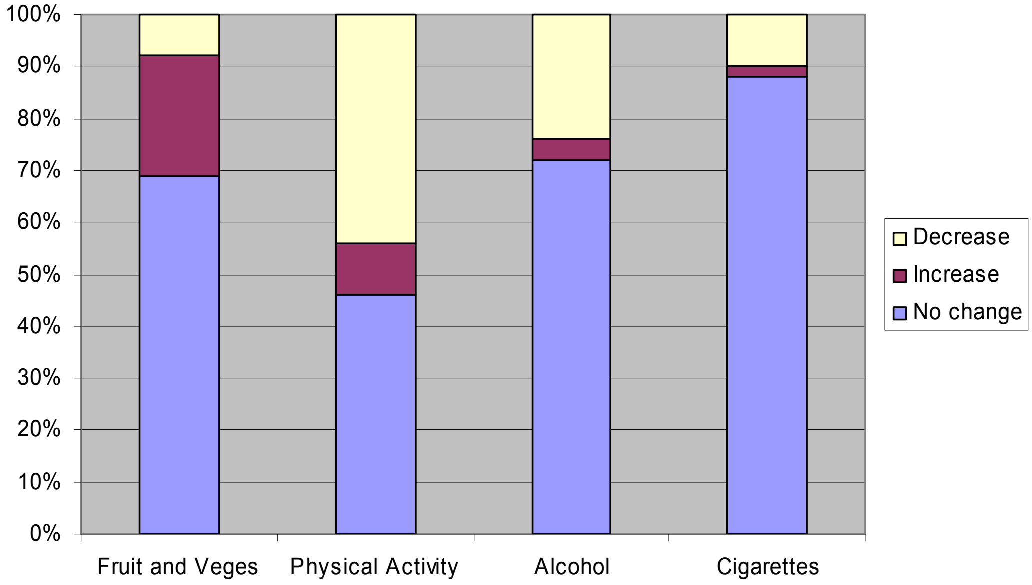
4.2.4.3 SOCIAL SUPPORT

The social support questionnaire measured two types of support, confidant support, which reflects primarily a confidant relationship where important matters in life are discussed and shared, and affective support, which reflects a more emotional form of support and caring. Of those gynaecological cancer survivors who completed the social support questionnaire (87% of 802), the median confidant support score reported was 23 with a range of 5-25, where the higher number reflects greater support. The median affective support score reported was 14 with a range of 3-15.

These domains were combined for an overall social support score. The median overall social support score reported was 37, ranging from 8-40. These levels of social support were similar across types of cancer and survival phases.

4.2.4.4 HEALTH BEHAVIOURS

Women were asked to compare their current health behaviours, including fruit and vegetable intake, physical activity levels, alcohol intake and cigarette smoking, to "just prior" to their cancer diagnosis. Participants were asked to indicate whether these behaviours were the same, had increased or decreased. While most women (69%, weighted by chance of selection in the sample) reported eating the same amounts of fruits and vegetables before and after cancer diagnosis, 23% reported increasing their fruit and vegetable intake and 8% reported decreasing their intake (see figure 4.12). Forty six percent (weighted) reported continuing the same level of physical activity as before their cancer diagnosis, while 44% decreased their physical activity level after their diagnosis. The majority of women's alcohol and cigarette consumption remained the same before and after cancer diagnosis. It is noted that this is partly due to 58% of the sample being lifelong non-smokers and 25% being lifelong non-drinkers. A 24% decrease in alcohol consumption and a 10% decrease in cigarette smoking were detected. Also a 4% increase in alcohol consumption and a 2% increase in cigarette smoking were observed.



* Prevalence's are weighted by chance of selection in the sample. Weighted fruit and vegetable n=1224. Weighted physical activity n=1187. Weighted alcohol n=872. Weighted cigarette n=1148.

FIGURE 4.12 HEALTH BEHAVIOUR CHANGE AFTER BEING DIAGNOSED WITH GYNAECOLOGICAL CANCER

The following sections consider each health behaviour separately. Differences in prevalence by cancer type and survival phase are explored, along with comparisons to the general female population in Queensland, adjusted for age

4.2.4.4.1 DIETARY BEHAVIOUR

On average, gynaecological cancer survivors ate two serves of vegetables and two serves of fruits per day (medians quoted with a capped range of 0-15). Four percent of the gynaecological cancer patients in this sample, reported on average, eating no vegetables, and seven percent reported not eating any fruit.

The recommended daily intake for healthy Australians of fruit is two serves per day, where a ‘serve’ is one medium piece or two small pieces of fruit or a cup of diced pieces (Cashel & Jeffreson, 1995). In this study 66% (weighted) of gynaecological cancer survivors (aged 20-75 years) meet this recommended daily intake, whereas the Queensland Cancer Risk Study found that 51% of Queensland women (aged 20-75 years) meet this guideline (DiSipio *et al*, 2006). When this relationship was stratified by age (see figure 4.13), it showed fruit intake increased with age but there was still a greater proportion within each age group of women meeting the recommended intakes within the gynaecological cancer survivors’ population compared with Queensland females. The difference in population proportions meeting this guideline, within the 20-39 and 40-59 age groups, were clinically significant.

The Australian recommended daily intake of vegetables is five serves per day, where a ‘serve’ is half a cup cooked vegetables or one cup of salad vegetables (Cashel & Jeffreson, 1995). Eighteen percent (weighted) of gynaecological cancer survivors (aged 20-75 years) meet this recommended daily intake, whereas the Queensland Cancer Risk Study reported 14% of the Queensland women meet this guideline (DiSipio *et al*, 2006). Vegetable intake was relatively similar in both populations (see figure 4.13),

The proportion of women diagnosed with gynaecological cancer, who meet these recommended daily intakes for fruit and vegetables was no different across survival phase or type of cancer.

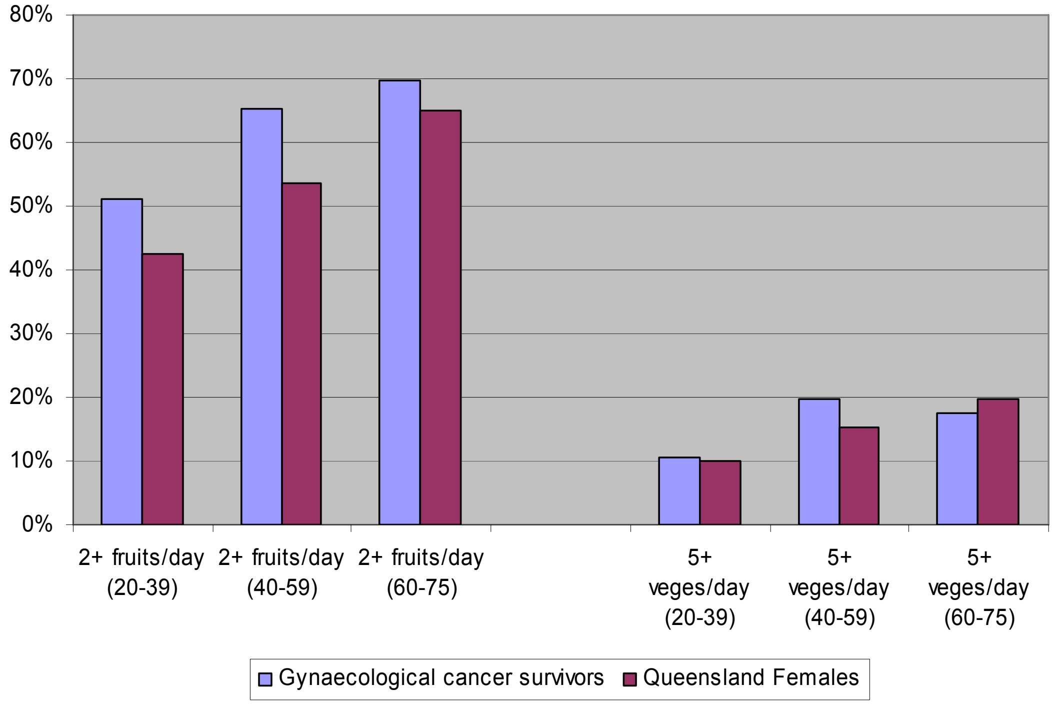


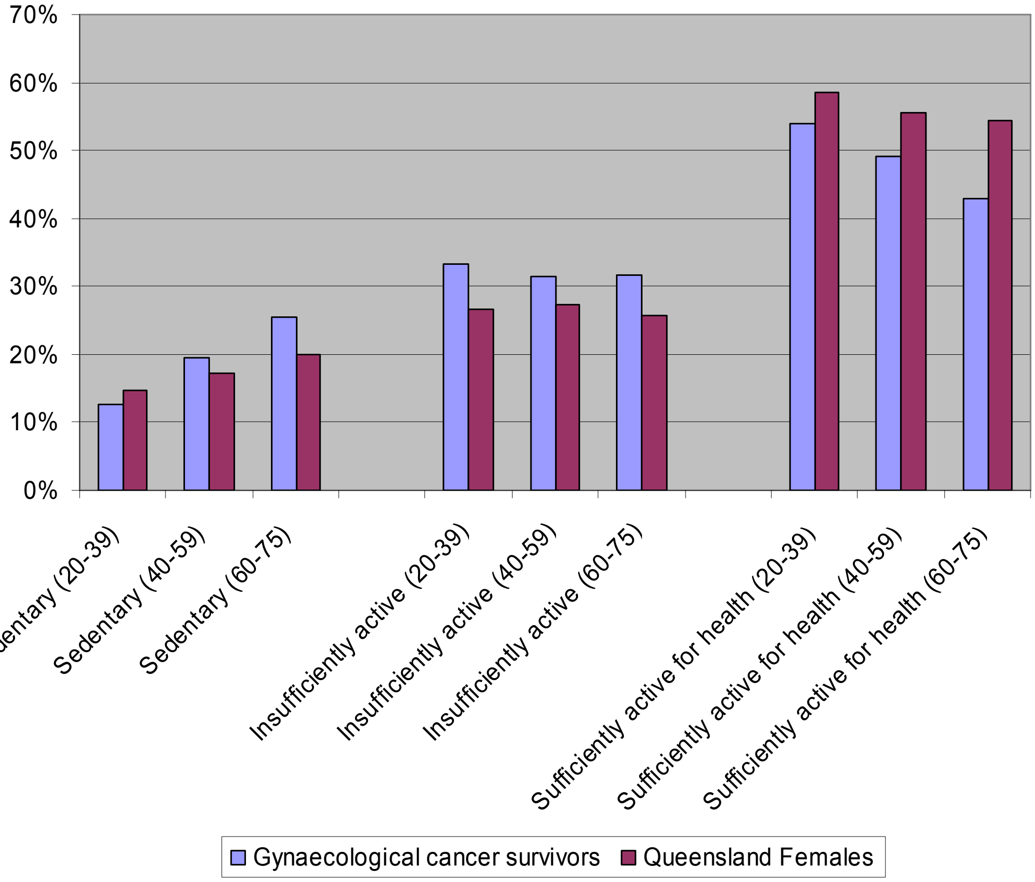
FIGURE 4.13 MEETING THE RECOMMENDED DAILY INTAKE FOR FRUITS AND VEGETABLES BY AGE, COMPARED TO QUEENSLAND POPULATION IN 2004

4.2.4.4.2 PHYSICAL ACTIVITY AND BODY MASS INDEX

The National Physical Activity Guidelines for Australians (DHAC, 1999), recommends that, to achieve health benefits, a person should participate in 30 minutes of at least moderate-intensity physical activity on most days of the week. ‘Sufficient physical activity’ is defined in two ways: (a) the accumulation of at least 150 minutes of activity over one week and; (b) the accumulation of at least 150 minutes of activity over one week and at least five sessions of activity over one week. Both these classifications define minutes using the sum of walking, moderate activity and vigorous activity (weighted by two). (Australian Institute of Health and Welfare, 2003a)

In this study, 22% (weighted) of women diagnosed with gynaecological cancer (aged 20-75 years) were sedentary (reported no physical activity); 47% (weighted) engaged in ‘sufficient physical activity’ (150 minutes/week) and 32% (weighted) engaged in insufficient activity. Thirty-six percent (weighted) engaged in sufficient activity (150 minutes/week over 5 sessions) and 42% (weighted) engaged in insufficient activity. In comparison, the Queensland Cancer Risk Study indicated that 57% of female Queenslanders (aged 20-75 years) were classed as having sufficient levels of physical activity, when considering the accumulation of minutes only (DiSipio *et al*, 2006).

Within the gynaecological cancer population, physical activity did not differ significantly by type of cancer or survival phase. However, there was a meaningful difference in the 60-75 age group, with study participants engaging in less physical activity than their Queensland peers



* 'Sufficient' time and sessions are defined as 150 minutes (using the sum of walking, moderate activity and vigorous activity (weighted by two)).

FIGURE 4.14 PHYSICAL ACTIVITY BY AGE, COMPARED TO THE QUEENSLAND POPULATION IN 2004

This research also explored body mass index (BMI) as a lifestyle factor affecting health outcomes. BMI differed significantly across types of gynaecological cancer. Fifty three percent of cervical cancer patients were classified as having a normal BMI, compared with 39% of ovarian, 25% of uterine, and 32% of "other" gynaecological cancer types (p<001). There was no significant difference in BMI by phase post-diagnosis.

When comparing gynaecological cancer survivors (aged 20-75) with Queensland females within the Queensland Cancer Risk Study (DiSipio *et al*, 2006), the proportion of women who were in each age group was similar in the underweight and overweight BMI classes. However, there were significant differences in the 40-59 and 60-75 age groups, in the normal and obese classes. Gynaecological cancer survivors in these age groups were 1.7 times more likely to be obese than Queensland females, and less likely to report a BMI within the normal range.

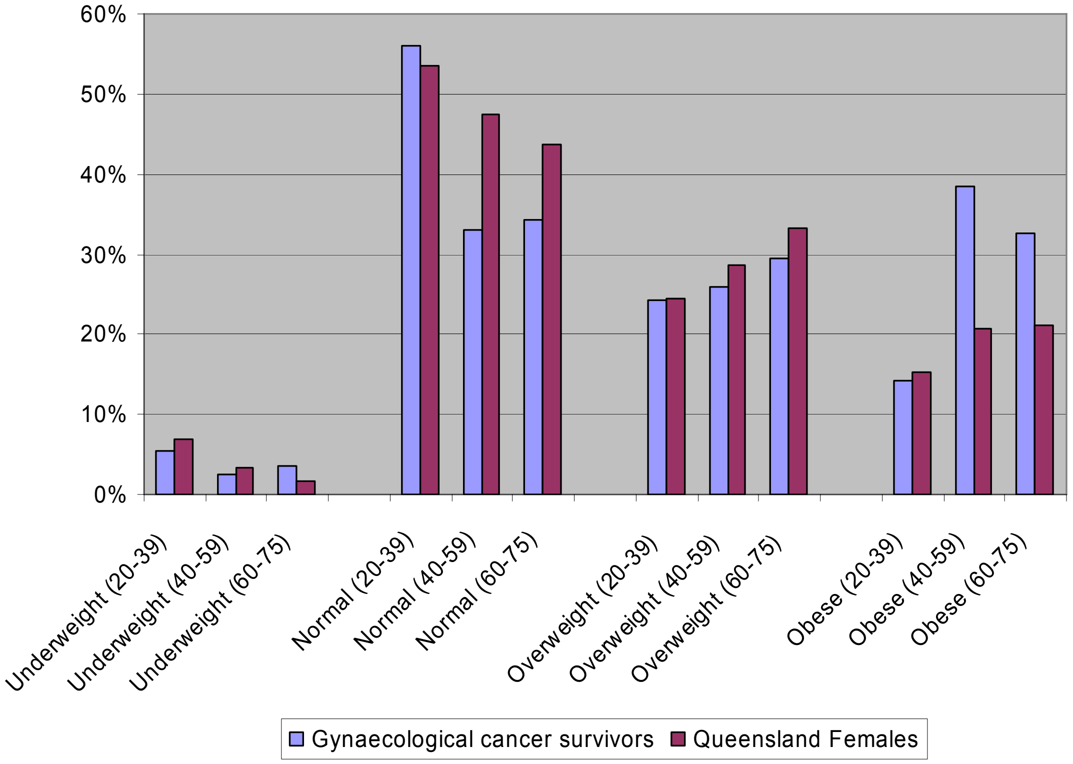


FIGURE 4.15 BODY MASS INDEX BY AGE, COMPARED TO THE QUEENSLAND POPULATION IN 2004

4.2.4.4.3 CIGARETTE SMOKING

Smoking status differed significantly across types of gynaecological cancer with 21% (weighted) of cervical cancer patients currently smoking compared with 9% of ovarian, 6% of uterine and 11% of "other" gynaecological cancer types (p<001). This difference across types of cancer is most likely attributed to cervical cancer survivors having a younger mean age, although there were small numbers of smokers when stratified by age groups making this difficult to test conclusively. There was no significant difference in smoking status in phase post-diagnosis.

Overall, 11% (weighted) of the gynaecological cancer survivors (aged 20-75) currently smoke. This proportion is significantly less than the 21% of female smokers in the general Queensland population as indicated in the Queensland Cancer Risk Study (DiSipio *et al*, 2006). The proportion of smokers decreases with age (see figure 4.16). The largest difference in smoking status between populations was observed within the 40-59 age group of ex-smokers, where significantly more gynaecological cancer survivors had given up smoking cigarettes.

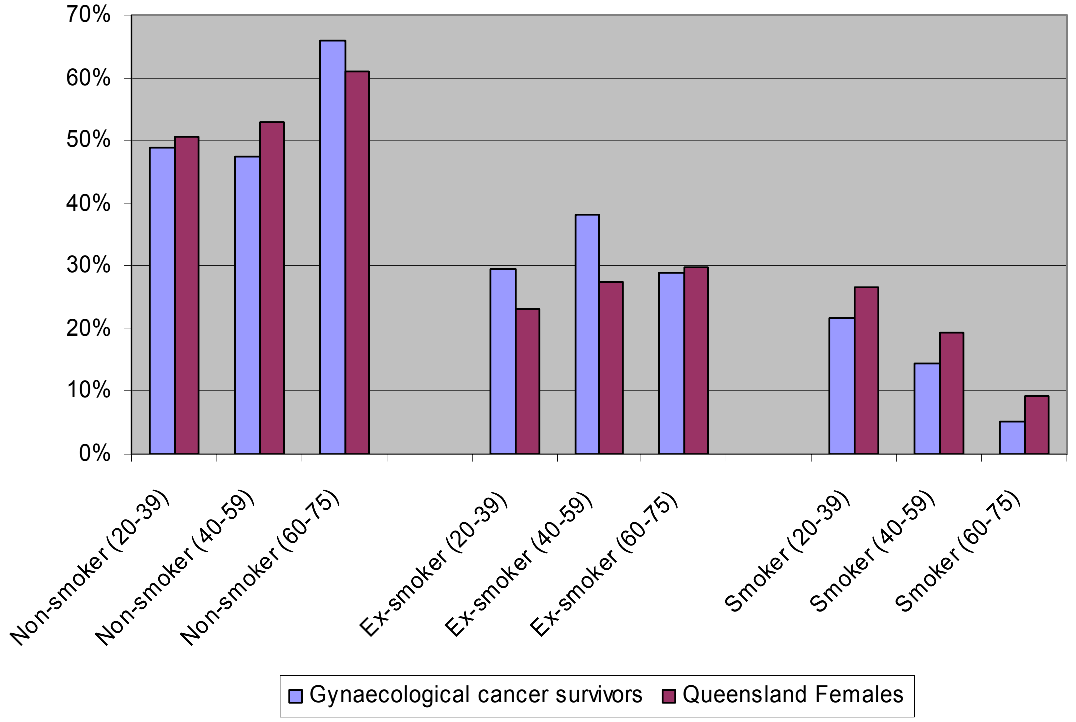


FIGURE 4.16 CIGARETTE SMOKING BY AGE, COMPARED TO THE QUEENSLAND POPULATION IN 2004

4.2.4.4.4 ALCOHOL CONSUMPTION

Drinking status was similar across types of gynaecological cancer. The only notable differences were proportionately less cervical cancer survivors classifying themselves as life long non-drinkers (17%) compared with the other sites (25-27%) and more cervical cancer patients being regular drinkers (56%) compared with uterine (46%) and “other” (48%). This difference in the cervical cancer groups is most likely attributed to a younger mean age than the other cancer types. When the relationship of drinking status and type of cancer was stratified by age groups, proportions within drinking categories across cancer types were similar within the 40-59 and 60-75 subgroups. However, within the 20-39 age group, cervical cancer survivors was the only cancer type with substantial cases per drinking categories. There was no significant difference in drinking status in phase post-diagnosis.

Approximately half (51%) of gynaecological cancer survivors (aged 20-75) drank alcohol more than once a month (13% drinking 5 or more days a week), 20% drank less than once a month, 6% used to drink but have stopped and 23% were life-long non-drinkers. Overall, significantly more gynaecological cancer survivors were life-long non-drinkers when compared with Queensland females in the Cancer Risk Study (DiSipio *et al*, 2006). In particular, the difference in population proportions of non-drinkers were clinically significant within the 20-39 and 60-75 age groups (see figure 4.17).

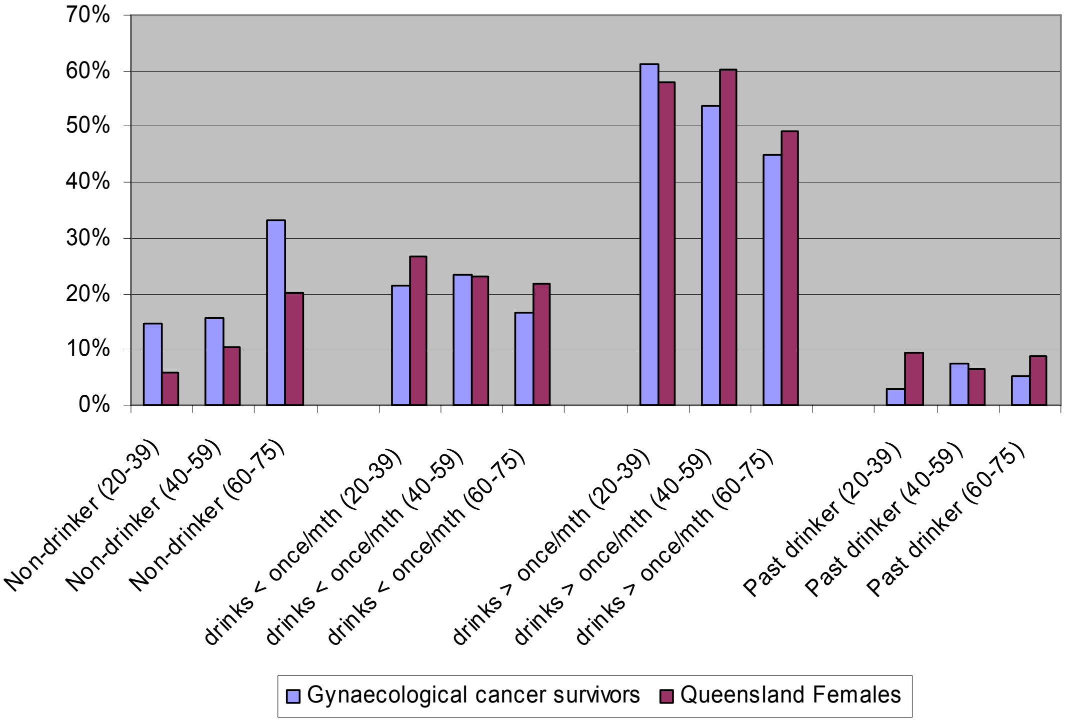


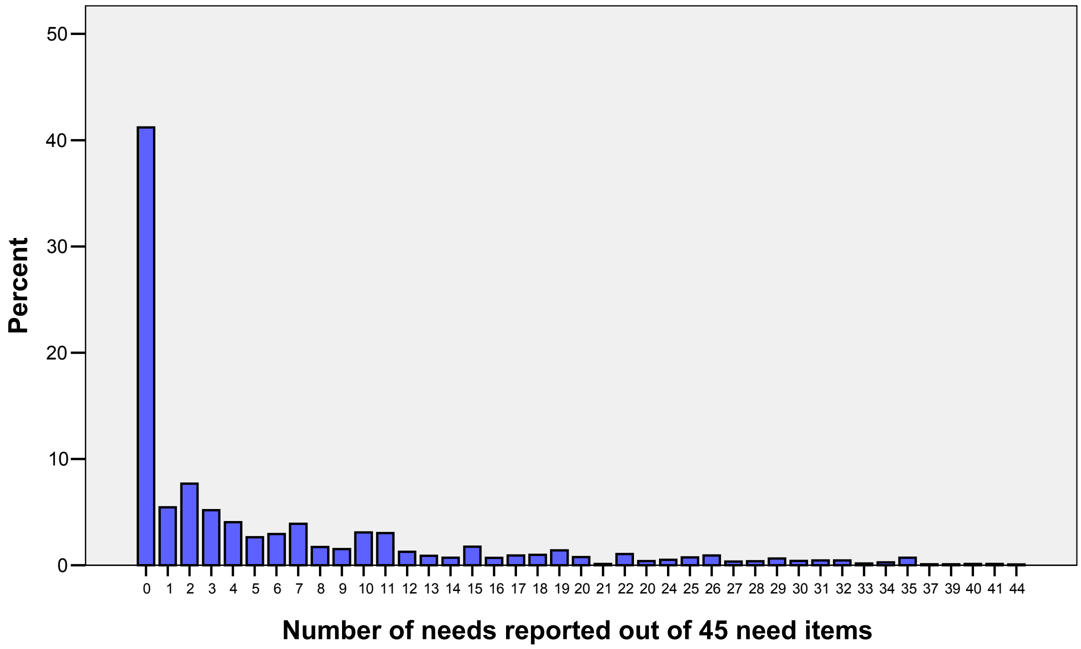
FIGURE 4.17 ALCOHOL CONSUMPTION BY AGE, COMPARED TO THE QUEENSLAND POPULATION IN 2004

5 PREVALENCE OF UNMET NEEDS, AND CORRELATES OF SUPPORT NEEDS AND SERVICE USE

In the previous chapter, the prevalence of use of supportive care was described. In this chapter, the prevalence of unmet supportive care needs will firstly be determined in addressing research question five. Following this, an analysis of correlates of four supportive care need domains, and use of community support services or organisations, will be conducted in addressing research question six. A similar type of analysis will be used for each outcome. These relationships between correlates and needs or use will be further considered by gynaecological cancer sub-types. Through out this chapter and the latter discussion, community support service or organisation use will be defined as service use.

5.1 PREVALENCE OF UNMET SUPPORTIVE CARE NEEDS

Out of a possible 45 need items across six domains: psychological needs, sexuality needs, physical/ daily living needs, patient care/ support needs, health system/ information needs and community service/ resource needs, 59% of gynaecological cancer survivors reported having at least one unmet supportive care need (see figure 5.1). The number of unmet needs ranged from one to 44, with 41% of women reporting between one and eleven unmet needs and 18% having twelve and over. Furthermore, when just considering moderate or high level unmet needs, 43% of participants reported at least one. Similarly to other research, in the exploration of individual needs items, moderate or high level needs were considered. In the analysis of correlates of needs domains, the outcome variable was inclusive of any unmet needs (low, moderate or high).



Cases weighted by cancer type and survival phase for actual population prevalence rather than prevalence within the stratified sample (n=1231)

FIGURE 5.1 FREQUENCY OF UNMET NEEDS REPORTED IN WOMEN WHO WERE 3 MONTHS TO 5 YEARS POST GYNAECOLOGICAL CANCER DIAGNOSIS, IN QUEENSLAND, AUSTRALIA, 2004

The ten highest ranked moderate or high unmet need items reported by Queensland gynaecological cancer survivors are indicated in the table 5.1. The top three unmet needs were related to the psychological needs domain. When these unmet needs were stratified by cancer type it was observed that a significantly higher proportion of “other” gynaecological cancer survivors expressed a moderate or high need for help with 1) fear about the cancer spreading, 2) uncertainty about the future 3) worry that the results of treatment are beyond their control and 4) work around the home, compared to uterine cancer survivors. Survivors diagnosed with an “other” type of cancer also had a significantly higher proportion of moderate or high need for help with work around the home than cervical cancer survivors. Moreover, cervical cancer survivors had a significantly higher proportion of moderate or high need for help with changes in sexual feelings than uterine and ovarian cancer survivors.

The ten highest ranked need items were also stratified by the following three survival phases post-diagnosis: 3-12 months post-diagnosis, 1-3 years post-diagnosis and 3-5 years post-diagnosis. No statistical or clinical differences were observed between survival phases and reporting of unmet needs items.

TABLE 5.1 PERCENTAGE OF WOMEN REPORTING NEED WITHIN THE TEN MOST COMMON RANKED[A] MODERATE OR HIGH UNMET NEEDS REPORTED IN APPROXIMATELY 728[B] WOMEN WHO WERE 3 MONTHS TO 5 YEARS POST GYNAECOLOGICAL CANCER DIAGNOSIS, IN QUEENSLAND, AUSTRALIA, 2004, ALSO STRATIFIED BY TYPE OF GYNAECOLOGICAL CANCER.

Item	Cervical sample % (n)	Uterine sample % (n)	Ovarian sample % (n)	Other sample % (n)	Total sample % (n)	Domain
Fear about the cancer spreading	17 (32)	13 (27)	18 (39)	23 (25)	17 (123)	Psychological
Concerns about the worries of those close to you	14 (27)	13 (28)	15 (33)	19 (21)	15 (109)	Psychological
Uncertainty about the future	13 (25)	10 (21)	17 (36)	19 (22)	14 (104)	Psychological
Lack of energy/tiredness	13 (25)	11 (25)	17 (37)	13 (15)	14 (102)	Physical/ daily living
Not being able to do things you used to do	13 (25)	12 (26)	13 (28)	19 (22)	14 (101)	Physical/ daily living
Changes in sexual feelings	18 (33)*	9 (19)*	8 (18)*	13 (14)	12 (84)	Sexuality
Changes in your sexual relationship	16 (30)	9 (20)	9 (20)	12 (13)	11 (83)	Sexuality
Worry that the results of treatment are beyond your control	11 (20)	9 (20)	11 (24)	17 (18)	11 (82)	Psychological
Being informed about things you can do to help yourself get well	9 (17)	10 (21)	14 (30)	11 (12)	11 (80)	Health system/ information
Work around the home	9 (17)	9 (19)	10 (23)	17 (20)	11 (79)	Physical/ daily living
Having one member of hospital staff with who you can talk to about all aspects of your condition, treatment and follow-up	10 (18)	8 (17)	13 (29)	14 (15)	11 (79)	Health system/ information

Clinically significant difference in groups

*statistically significant difference in groups

[a] 11 items included in this table due to the last two obtaining equal 10th rank

[b] each items has a different number of participants who completed that question and on average across the 11 items, 728 women completed the items

All participants were asked an additional set of questions relating to their perceived need for access to services or resources. Since participants' in this study were predominantly post-treatment, and community rather than hospital support was of interest, only community based services or resources items were included in this sub-scale. As seen in Table 5.2, the three most prevalently reported moderate or high unmet needs were monetary allowance for travel, treatment and equipment expenses (8%); counselling services (7%); and relaxation classes (7%). As the proportion of women reporting moderate or high unmet community service and resource needs was low, stratification by type of cancer and survival phase was not meaningful.

TABLE 5.2 MODERATE OR HIGH UNMET COMMUNITY SERVICE AND RESOURCE NEEDS REPORTED BY WOMEN WHO WERE 3 MONTHS TO 5 YEARS POST-GYNAECOLOGICAL CANCER DIAGNOSIS, IN QUEENSLAND, AUSTRALIA, 2004 (N=743 [A]).

Item	Survivors with moderate – high unmet needs % (n)
Monetary allowance for travel, treatment and equipment expenses	7.6 (56)
Counselling services	7.4 (55)
Relaxation classes	7.1 (52)
Drop-in counselling and support service	6.4 (47)
Brochures about services and benefits for patients with cancer	5.6 (42)
Home cleaning service	5.0 (37)
24-hour telephone support and cancer advisory service	4.7 (35)
Library of books and videos about cancer and related issues	4.7 (35)
Home gardening service	3.6 (27)
Home nursing service	1.2 (9)
Respite care	0.8 (6)

[a] each items has a different number of participants who completed that question and on average across the 11 items, 743 women completed the items

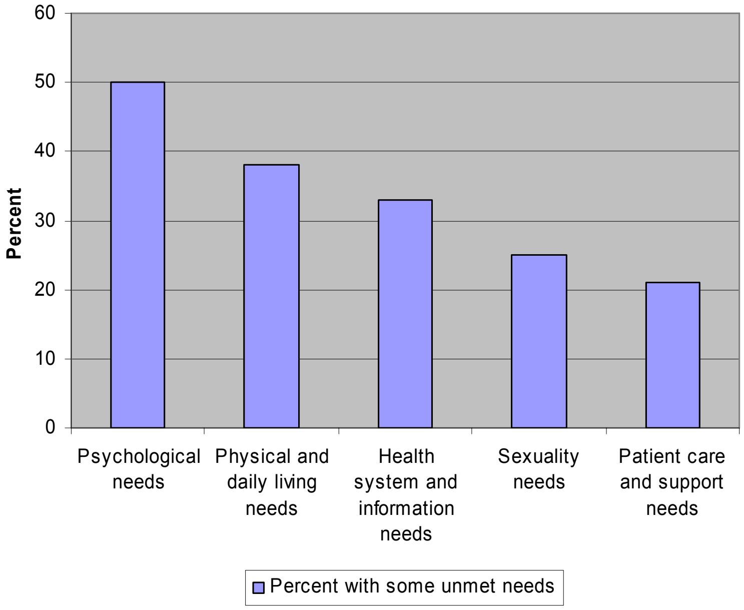
Women who experienced swelling in their lower limbs or who had been diagnosed with lower limb lymphoedema were asked to complete a further needs assessment in relation to these symptoms. Table 5.3 indicates the need for lymphoedema-specific help within this sub-group of women. A quarter of women with symptomatic or diagnosed lower limb lymphoedema reported a moderate or high need for help to be more informed about the causes, prevention and treatment of lymphoedema, and to be given written information about ways to manage symptoms of lymphoedema. Also, about a fifth of women reported a moderate or high need for help with pain or discomfort in the legs or groin and with managing the symptoms of lymphoedema.

TABLE 5.3 MODERATE OR HIGH UNMET NEEDS REPORTED BY SYMPTOMATIC AND DIAGNOSED LYMPHOEDEMA SUFFERERS WHO WERE 3 MONTHS TO 5 YEARS POST GYNAECOLOGICAL CANCER DIAGNOSIS, IN QUEENSLAND, AUSTRALIA, 2004 (N=231 [A]).

Item	Survivors with moderate – high unmet needs % (n)
To be more informed about the causes, preventions & treatment of lymphoedema	25.4 (59)
To be given written information about ways to manage symptoms of lymphoedema	25.0 (59)
Pain or discomfort in the legs or groin	20.2 (48)
To be given more help in managing the symptoms of lymphoedema.	18.8 (45)
The cost of having lymphoedema	14.5 (33)
Coping with changes in your self-image as a result of having lymphoedema	14.4 (33)
To have help in initially coping with the emotional shock of having lymphoedema	13.2 (30)
Managing the symptoms of lymphoedema in the workplace	11.8 (27)
Doing your daily activities around the home	11.2 (26)
Finding a support group which addresses your particular lymphoedema needs	7.5 (17)
Dealing with your partner's reaction to your legs	4.4 (10)

[a] each items has a different number of participants who completed that question and on average across the 11 items, 231 women completed the items

Following the exploration of individual need items, a total domain score was calculated for those participants who answered all need items within each supportive care domain. As illustrated in figure 5.2, it was found that 50% of the sample reported at least one unmet psychological need, 38% reported at least one unmet physical and daily living need, 33% reported at least one unmet health system and information need, 25% had a need for support with sexuality and 21% reported at least one unmet patient care and support need.



[a] each needs domain has a different number of participants who completed all the questions in that domain and on average across the 5 domains, 738 women completed all questions within each domain

FIGURE 5.2 SOME UNMET NEEDS WITHIN EACH SUPPORTIVE CARE DOMAIN, REPORTED BY WOMEN WHO WERE 3 MONTHS TO 5 YEARS POST-GYNAECOLOGICAL CANCER DIAGNOSIS, IN QUEENSLAND, AUSTRALIA, 2004 (N=738 [A]).

There were no individual patient care and support need items listed within the ten highest ranked moderate or high unmet need items. Also few women reported at least one unmet patient care and support need. This is probably because need items within this domain pertained to hospital-based questions (*i.e.* more choice about which cancer specialist you see, more choice about which hospital you attend, reassurance by medical staff that the way you feel is normal, hospital staff attending promptly to your physical needs, and hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs). Women in this study were selected if they were at least three months post-diagnosis, as the objective was to study women post-treatment. For this reason, it was not appropriate to consider the patient care and support needs domain any further within this analysis.

5.2 CORRELATES OF SUPPORTIVE CARE NEEDS

Initially, bivariate relationships of unmet needs with factors within the social-ecological model were explored to determine, without complex multivariable models, which independent variables crudely related to each of the four needs domains, and to describe in absolute terms, the percentages of subgroups within the independent variables who had unmet needs. Next confounding and effect modification of the crude relationship by type of cancer and survival phase was explored *via* stratification. Finally, multivariable modelling was conducted to adjust for correlations of independent variables and to include effect modifying variables that were identified in the bivariate analysis.

5.2.1 BIVARIATE RELATIONSHIPS

At the bivariate level of analysis, 47 variables were tested for their strength of association to each of the four supportive care needs domains. These variables were chosen based on their inclusion within the social-ecological model. There were many contextually and statistically significant social-ecological correlates of needs. Some showed the same relationship with two or more of the support domains, others showed different associations across domains or were only associated with a single domain. While all results are presented in tables, only the consistent associations across multiple domains are discussed in the text, as these recurring themes are likely to have the most public health importance. In preparation for later multivariable modelling, on the basis of the rationale in section 3.8.2, bivariate associations are summarised in sections reflecting the various influences identified in the social-ecological model. Variables' associations with each of the needs domains were firstly examined in groups of similar characteristics (see rationale in section 3.9.7). The first block included demographic variables.

5.2.1.1 *DEMOGRAPHIC CHARACTERISTICS ASSOCIATED WITH UNMET NEEDS*

As summarised in table 5.4, women who were younger, had children living at home or who were unable to work because of illness, had, on average, higher levels of need for help across all four supportive care domains compared to older women, women who had no children living at home or working women, respectively. There was a negative linear relationship of increasing age with decreasing unmet needs, except within the physical/ daily living needs domain.

Relative to widows, more single and separated/ divorced women had unmet psychological, sexuality, and health system/ information needs. Education level had a positive linear relationship with sexuality needs and was also clinically associated with health system/ information needs. A linear relationship was observed with household income and unmet sexuality needs and physical/ daily living needs, however was in the opposite direction in each domain. Women who had a higher household income reported a significantly greater need for help with sexuality needs. Women who had a lower household income reported a significantly greater need for help with physical/ daily living needs.

Table 5.4 Associations between demographic characteristics and reporting "some need" within each of the supportive care domains for Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Age (years)				
18-39	61.0 (47)	42.9 (33)	46.7 (35)	48.1 (37)
40-49	60.8 (79)	42.7 (56)	37.7 (49)	47.0 (62)
50-59	47.8 (97)	26.7 (55)	33.8 (69)	31.3 (63)
60-69	43.5 (87)	16.5 (32)	34.2 (69)	24.6 (50)
70+	43.9 (58)	6.0 (7)	46.4 (64)	26.4 (33)
	a + c	a + c	a	a + c
Children living at home				
No	48.4 (225)	23.4 (107)	36.4 (172)	33.0 (154)
Yes	59.1 (78)	43.4 (56)	46.1 (59)	43.9 (58)
	a	a	b	a
Employment type				
Paid full- time	53.8 (71)	33.1 (45)	34.8 (46)	36.5 (50)
Paid part time/ casual	51.2 (66)	36.2 (47)	33.9 (43)	37.2 (48)
Home duties	48.7 (58)	19.8 (23)	34.7 (42)	28.8 (34)
Retired	40.9 (90)	12.1 (25)	37.3 (84)	22.1 (47)
Unable to work due to illness	76.8 (53)	40.3 (25)	70.4 (50)	59.7 (40)
Other	38.3 (23)	25.0 (15)	27.1 (16)	36.1 (22)
	a	a	a	a
Country of origin				
Australia	49.5 (284)	23.9 (133)	39.0 (226)	31.7 (182)
Other	49.3 (74)	30.5 (46)	36.4 (55)	38.8 (57)
	NS	NS	NS	NS
Marital status				
Single	59.0 (36)	20.3 (12)	45.8 (27)	44.3 (27)
Living with a partner	48.8 (240)	29.0 (141)	35.1 (176)	31.4 (155)
Seperated/divorced	54.8 (46)	27.2 (22)	43.2 (35)	44.4 (36)
Widowed	43.4 (43)	6.5 (6)	44.6 (45)	26.0 (25)
	b	a	b	a

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Education level				
University/college degree	51.6 (63)	30.2 (38)	38.9 (49)	36.5 (46)
Trade or technical certificate	52.6 (51)	28.9 (28)	37.5 (36)	42.9 (42)
Senior high school	50.0 (56)	26.6 (29)	36.6 (41)	35.1 (39)
Junior high school	48.4 (139)	24.5 (68)	36.7 (106)	28.9 (82)
Primary/ no schooling	48.4 (45)	16.3 (14)	44.1 (41)	30.3 (27)
	NS	b + c	NS	b
Household income				
<$20 000	48.8 (98)	19.3 (37)	45.0 (91)	32.8 (64)
$20 000 - <$40 000	55.3 (83)	26.7 (39)	41.2 (61)	41.3 (62)
$40 000 - <$60 000	41.5 (39)	25.0 (24)	29.0 (27)	28.4 (27)
$60 000 - <$80 000	51.7 (30)	31.6 (18)	29.3 (17)	31.6 (18)
$80 000+	46.8 (36)	33.8 (27)	27.5 (22)	34.2 (27)
Do not wish to answer	50.6 (82)	24.8 (38)	40.5 (68)	29.0 (47)
	b	b + c	a + c	b

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.2 DIAGNOSIS AND TREATMENT VARIABLES ASSOCIATED WITH UNMET NEEDS

The second block of variables examined for their effect on unmet supportive care needs included diagnosis and treatment variables (see table 5.5). Relative to uterine cancer survivors, more survivors with “other” gynaecological cancer had unmet needs across three domains. Also, more cervical cancer survivors had unmet sexuality needs compared to uterine cancer survivors. Survival phase was significantly associated with psychological and physical/ daily living needs with substantially less women who were three to five years post-diagnosis reporting needs in these domains than those who were three months to three years post-diagnosis.

More women diagnosed with late stage cancer reported having psychological, physical/ daily living and health system/ information needs compared to women with early stage cancer. Substantially less women reported physical/ daily living needs and health system/ information needs after being treated at hospital B or C, compared to women treated at hospital A.

Across all supportive care domains (except sexuality), women who were more recently treated, who had more extensive surgery (excluding no surgery as data in this category were limited and because women who have no surgery generally have co-morbidities or are too old for surgery) and women who had hormone therapy, had higher unmet needs than their corresponding counterparts. The relationship of increasing time since last administration of treatment with decreasing reported needs appeared negatively linear across all needs domains.

Significantly more women who had chemotherapy had psychological and health system/ information needs compared to those who had not had chemotherapy. The need for help across all supportive care domains was observed in significantly more women who received external radium beam therapy compared to both women who had no radium or women who had internal brachytherapy.

TABLE 5.5 ASSOCIATIONS BETWEEN DIAGNOSIS AND TREATMENT VARIABLES AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Type of gynaecological Cancer				
Cervical	48.7 (93)	33.0 (62)	41.7 (78)	34.0 (65)
Uterine	44.7 (96)	20.1 (43)	35.0 (78)	28.0 (61)
Ovarian	52.0 (115)	22.2 (48)	36.0 (80)	35.7 (79)
Other	55.7 (64)	28.3 (30)	42.7 (50)	37.0 (40)
	b	a	NS	b
Survival phase post-diagnosis				
3-12 months	49.2 (87)	25.7 (44)	44.4 (80)	33.1 (59)
1-3 years	54.8 (167)	28.1 (83)	41.5 (130)	36.6 (111)
3-5 years	43.8 (114)	21.7 (56)	29.7 (76)	29.2 (75)
	a	NS	a + c	NS
Stage				
Early stage	46.1 (236)	26.2 (132)	35.9 (185)	30.4 (157)
Late stage	59.1 (114)	23.2 (43)	44.4 (87)	40.5 (75)
	a	NS	b	a
Treatment centre				
Treatment hospital A	50.9 (113)	26.2 (56)	45.5 (101)	38.1 (85)
Treatment hospital B	48.3 (69)	22.0 (31)	35.1 (52)	25.9 (37)
Treatment hospital C	47.9 (57)	25.6 (31)	33.1 (40)	25.0 (30)
Other hospitals	51.4 (57)	25.5 (27)	34.5 (39)	38.0 (41)
Multi-treatment centres	48.1 (64)	25.6 (33)	39.4 (52)	34.9 (45)
	NS	NS	b	a
Insurance				
Medicare only	49.9 (174)	25.6 (86)	43.8 (153)	34.9 (120)
Private insurance	49.6 (186)	25.0 (93)	32.5 (124)	30.9 (116)
	NS	NS	a	NS
Last administration of treatment				
Within the last month	73.1 (19)	32.0 (8)	55.6 (15)	50.0 (13)
1-12 months ago	53.5 (115)	28.4 (58)	48.1 (104)	42.0 (89)
1-2 years ago	54.3 (82)	25.3 (38)	41.4 (63)	34.0 (52)
>2 years ago	45.4 (129)	24.6 (69)	30.5 (86)	26.5 (74)
	a + c	NS	a + c	a

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Surgery				
None	46.2 (6)	33.3 (4)	46.2 (6)	23.1 (3)
Vaginal/ laparoscopic	40.4 (44)	21.7 (23)	30.6 (33)	27.5 (30)
Open abdominal	49.2 (265)	25.8 (138)	38.0 (208)	32.5 (176)
Open bowel resection	65.6 (42)	25.9 (15)	49.2 (31)	52.5 (32)
	a	NS	b	a
Hormone therapy				
Yes	69.4 (25)	25.7 (9)	67.6 (25)	51.4 (18)
No	48.6 (343)	25.3 (174)	36.7 (261)	32.3 (227)
	a	NS	a	a
Chemotherapy				
Yes	55.7 (157)	27.1 (74)	42.7 (120)	40.9 (113)
No	45.9 (211)	24.2 (109)	35.5 (166)	28.6 (132)
	a	NS	NS	a
Radiotherapy				
No radium	47.8 (265)	23.1 (125)	33.5 (187)	31.2 (172)
Internal brachytherapy	34.3 (12)	22.2 (8)	43.2 (16)	27.0 (10)
External radium beam	59.5 (91)	34.2 (50)	53.9 (83)	42.3 (63)
	a	a	a	a
Lymph nodes removed				
No	50.0 (207)	23.1 (92)	38.3 (59)	32.1 (133)
Yes	49.1 (161)	27.9 (91)	38.0 (127)	34.6 (112)
	NS	NS	NS	NS

[a] Statistically and clinically significant
[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)
[c] Clinically and statistically linear
[NS] Non-significant statistically and clinically
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.3 PHYSIOLOGICAL VARIABLES ASSOCIATED WITH UNMET NEEDS

A third set of variables, relating to physiological conditions, were examined for their effect on unmet supportive care needs. Table 5.6 shows that a higher proportion of women who were not in remission compared with those who were, and a higher proportion of women whose disease was still present compared to those who were disease free, reported needs across all of the supportive care domains, except sexuality.

Compared to participants with no lower limb swelling, more participants with diagnosed lymphoedema reported needs across all domains. In addition, a higher proportion of women who experience lower limb swelling but who had not had this diagnosed, reported psychological and physical/ daily living unmet needs compared to those with no lower limb swelling.

There was some evidence that a higher proportion of women who were fitted with a stoma had unmet psychological, physical/ daily living and health system/ information needs compared to those not fitted with a stoma. This association was not statistically significant, most likely because there were so few (5%) women fitted with a stoma.

More women who had been hospitalised since completing treatment for gynaecological cancer reported psychological and physical/ daily living needs, compared to women who had not been hospitalised. Relative to women who went through menopause prior to cancer diagnosis, significantly more women who experienced treatment-related menopause reported a need for help across all supportive care domains, except physical/daily living needs.

TABLE 5.6 ASSOCIATIONS BETWEEN PHYSIOLOGICAL CONDITION VARIABLES AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Remission				
Yes	46.1 (253)	24.6 (133)	35.3 (198)	29.7 (163)
No/don't know	59.6 (115)	27.2 (50)	46.8 (88)	43.2 (82)
	a	NS	a	a
Disease presence				
Disease absent	47.0 (296)	24.8 (153)	34.6 (220)	30.7 (192)
Disease present	65.1 (71)	28.2 (29)	57.3 (63)	46.4 (51)
	a	NS	a	a
Lymphoedema status				
No lower limb swelling	45.5 (259)	23.0 (127)	34.0 (193)	31.6 (178)
Lower limb swelling but not diagnosed	59.6 (59)	25.5 (25)	50.0 (52)	37.4 (37)
Diagnosed lymphoedema	67.6 (50)	41.9 (31)	53.2 (41)	40.0 (30)
	a	a	a	a
Stoma				
No	49.2 (347)	25.0 (173)	37.8 (269)	32.8 (231)
Yes	58.3 (21)	31.3 (10)	45.9 (17)	41.2 (14)
	b	NS	b	b
Hospitalisation since completing treatment for gynaecological cancer				
No	47.1 (261)	23.4 (127)	34.3 (191)	33.0 (183)
Yes	56.7 (101)	29.5 (51)	48.6 (89)	32.4 (56)
	a	NS	a	NS
Ever diagnosed with a physical or emotional illness				
No	47.0 (118)	28.0 (70)	31.7 (80)	32.8 (84)
Yes	50.9 (244)	23.8 (110)	41.6 (202)	33.1 (156)
	NS	NS	a	NS
Menopausal status				
Pre/ peri menopausal	26.7 (8)	12.5 (4)	25.0 (8)	28.1 (9)
Post menopause	45.2 (188)	17.2 (70)	35.1 (147)	26.9 (111)
Iatrogenic menopause	58.1 (132)	40.8 (93)	40. 9(92)	43.4 (98)
	a	a	a	a

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
HRT in the past 3 months				
Yes	51.9 (69)	30.8 (41)	40.2 (53)	35.3 (47)
No	49.1 (288) NS	24.3 (138) NS	37.7 (223) NS	32.8 (191) NS
Sexually active				
Yes	45.6 (140)	29.9 (93)	29.6 (91)	31.9 (99)
No	51.9 (200) NS	21.7 (80) a	44.8 (175) a	33.9 (129) NS

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.4 QUALITY OF LIFE VARIABLES ASSOCIATED WITH UNMET NEEDS

The fourth block of variables examined the associations between quality of life and unmet supportive care needs. Table 5.7 shows that average physical, social, emotional, functional and spiritual wellbeing were significantly lower in those women who reported having at least one need for help compared with those who had no unmet needs. This association was evident across all of the supportive care needs domains.

TABLE 5.7 ASSOCIATIONS BETWEEN QUALITY OF LIFE VARIABLES AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	N, Median (min - max) wellbeing scores stratified by women who report some need and no need for support within each domain				
	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	Spiritual wellbeing
Psychological domain					
No need	361 27.0 (8-28)	364 26.0 (3-28)	357 22.0 (7-24)	359 26.0 (0-28)	349 40.0 (8-48)
Some need	356 24.0 (0-28)	359 22.0 (0-28)	349 18.0 (1-24)	357 20.0 (1-28)	349 33.0 (4-48)
Sexuality domain					
No need	526 26.0 (0-28)	526 25.0 (0-28)	520 21.0 (6-24)	523 24.5 (0-28)	509 38.0 (4-48)
Some need	177 23.0 (0-28)	182 20.5 (0-28)	180 19.0 (3-24)	182 21.0 (7-28)	181 33.0 (6-48)
Physical / daily living domain					
No need	448 27.0 (6-28)	448 25.0 (0-28)	439 21.0 (6-24)	441 25.0 (0-28)	428 38.6 (8-48)
Some need	272 22.0 (0-28)	281 22.0 (0-28)	269 18.0 (1-24)	278 19.0 (3-28)	271 33.0 (4-48)

	N, Median (min - max) wellbeing scores stratified by women who report some need and no need for support within each domain				
	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	Spiritual wellbeing
Health system / information domain					
No need	476 26.0 (0 -28)	479 25.0 (0-28)	473 21.0 (7-24)	476 25.0 (0-28)	463 38.0 (8-48)
Some need	240 23.0 (0-28)	241 21.0 (0-28)	235 18.0 (1-24)	238 20.5 (0-28)	233 33.0 (4-48)

[a] All associations were statistically and clinically significant

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.5 HEALTH BEHAVIOURS ASSOCIATED WITH UNMET NEEDS

The fifth block of variables examined for their effect on unmet supportive care needs included health behaviour variables. Table 5.8 shows that generally, more women reported unmet needs across all domains who drank alcohol less than weekly, compared to women who drank alcohol five-to-seven days per week. Relative to women who were non-smokers, more women who smoked had unmet psychological and sexuality needs. The proportion of women reporting unmet psychological and physical/ daily living needs increased with decreasing physical activity. Significantly more women who did not eat the recommended intake of fruits had unmet psychological and physical/ daily living needs, compared to those who did meet the recommended intake.

There was some evidence that a higher proportion of women who were underweight reported unmet psychological, physical/ daily living and health system/ information needs compared to women in the normal or overweight BMI range and also reported more unmet psychological and health system/ information needs compared to obese women. However, cases within the underweight subgroup were limited, making up only 4% of the sample, thus this conclusion is not asserted with confidence.

TABLE 5.8 ASSOCIATIONS BETWEEN HEALTH BEHAVIOURS VARIABLES AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Alcohol consumption				
None	47.9 (103)	16.7 (35)	39.6 (86)	30.4 (65)
< weekly	55.6 (135)	30.3 (71)	39.9 (97)	38.3 (93)
1-4 days / week	50.3 (87)	33.5 (58)	35.8 (62)	33.3 (57)
5-7 days / week	38.2 (34)	20.9 (19)	31.5 (29)	27.8 (25)
	a	a	b	b
Smoker				
Yes	57.8 (48)	32.5 (26)	44.2 (34)	39.8 (33)
No	48.3 (310)	24.4 (155)	37.1 (242)	32.2 (206)
	b	b	NS	NS
Physical activity				
Sedentary	56.2 (100)	25.0 (43)	49.7 (89)	36.0 (64)
Insufficient activity	50 (150)	26.4 (76)	38.5 (117)	31.7 (93)
Sufficient activity for Health	44.7 (118)	24.2 (64)	30.1 (80)	33.0 (88)
	b + c	NS	a + c	NS
Vegetable intake				
Inadequate serves	49.8 (282)	25.7 (142)	37.3 (214)	32.0 (180)
Adequate serves (5 per day)	47.3 (53)	22.2 (24)	41.3 (45)	41.1 (46)
	NS	NS	NS	b
Fruit intake				
Inadequate serves	55.8 (139)	27.1 (65)	44.6 (111)	37.6 (92)
Adequate serves (2 per day)	46.8 (210)	24.5 (108)	34.6 (157)	31.0 (139)
	a	NS	a	NS
Body Mass Index				
Underweight	65.2 (15)	27.3 (6)	50.0 (12)	47.8 (11)
Normal weight	50.0 (127)	26.3 (65)	36.9 (92)	33.9 (86)
Overweight	46.5 (86)	22.5 (41)	32.6 (61)	33.0 (60)
Obese	50.8 (98)	24.1 (46)	43.3 (87)	31.1 (61)
	b	NS	b	b

[a] Statistically and clinically significant
[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)
[c] Clinically and statistically linear
[NS] Non-significant statistically and clinically
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.6 *SOCIAL SUPPORT AND UNMET NEEDS*

Next the associations between social support and unmet supportive care needs were examined. As illustrated in table 5.9, average social support was lower for women who reported having unmet supportive care needs compared to those who did not have a need for help. This association was consistent across all four of the supportive care needs domains.

TABLE 5.9 ASSOCIATIONS BETWEEN SOCIAL SUPPORT AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	Social support scores stratified by women who report some need and no need for support within each domain		
	N	Median	Min - Max
Psychological domain			
No need	330	39	8-40
Some need	328	34	8-40
Sexuality domain			
No need	482	38	8-40
Some need	169	34	10-40
Physical / daily living domain			
No need	414	38	8-40
Some need	251	34	8-40
Health system / information domain			
No need	436	38	8-40
Some need	221	35	8-40

[a] All associations were statistically and clinically significant

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.7 *ASSOCIATION OF HEALTH CARE WITH UNMET NEEDS*

The seventh block of variables examined the association between healthcare utilisation and unmet supportive care needs. A significantly higher proportion of women who used a support service reported unmet psychological and health system/ information needs, compared to non-users. A significantly higher proportion of women who used complementary therapy support for coping with the cancer or reducing the risk of its spread or return, reported unmet needs across all four supportive care domains, compared to non-users of complementary therapy.

TABLE 5.10 ASSOCIATIONS BETWEEN HEALTH CARE UTILISATION AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Use of at least 1 support service or organisation				
Yes	54.4 (209)	28.7 (110)	39.1 (152)	37.6 (146)
No	44.8 (130)	21.2 (59)	35.9 (103)	27.4 (78)
missing	42.6 (29)	22.2 (14)	42.5 (31)	32.3 (21)
	a	NS	NS	a
Complementary therapy support				
Yes	60.6 (134)	34.1 (75)	44.7 (97)	46.0 (99)
No	44.9 (234)	21.4 (108)	35.5 (189)	27.9 (146)
	a	a	a	a

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.8 COMMUNITY FACTORS ASSOCIATED WITH UNMET NEEDS

The final block of variables that was examined included organisational and community factors (see table 5.11). Relative to women who were not aware of support services, a higher proportion of women who were, had unmet needs across all domains. Clinically significant associations with the geographical locations women lived in were observed across all of the supportive care needs domains. However, when geographical location was collapsed into three areas, in preparation for later multivariable modelling, there was no significant difference in any of the supportive care needs domains reported across the three areas.

TABLE 5.11 ASSOCIATIONS BETWEEN WORKSITE/ ORGANISATIONAL/ COMMUNITY VARIABLES AND REPORTING "SOME NEED" WITHIN EACH OF THE SUPPORTIVE CARE DOMAINS FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004. BIVARIATE ANALYSIS.

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Total participants	49.6 (368)	25.3 (183)	38.2 (286)	33.2 (245)
Awareness of at least 1 support service or organisation(excluding QCF, the project sponsor)				
Yes	52.1 (303)	27.7 (159)	39.0 (227)	35.5 (206)
No	39.1 (36)	11.6 (10)	29.8 (28)	19.6 (18)
Missing	42.6 (29)	22.2 (14)	42.5 (31)	32.3 (21)
	a	a	b	a
Referral to at least 1 support service or org.				
Yes	51.8 (176)	29.0 (98)	40.4 (138)	37.1 (126)
No	48.8 (163)	22.0 (71)	35.0 (117)	29.4 (98)
Missing	42.6 (29)	22.2 (14)	42.5 (31)	32.3 (21)
	NS	NS	NS	NS
Geographical location				
Gold Coast	53.8 (43)	25.0 (19)	39.5 (32)	30.0 (24)
Logan-Beaudesert	37.9 (22)	24.1 (14)	33.9 (20)	28.1 (16)
Bayside	40.5 (15)	33.3 (12)	32.4 (12)	31.4 (11)
QEII Hospital & District	50.6 (42)	23.5 (20)	39. 5(32)	32.9 (28)
Prince Charles Hospital & District	48.7 (56)	28.3 (32)	35.9 (42)	36.5 (42)
Redcliffe-Caboolture	48.9 (23)	18.8 (9)	32.6 (15)	23.9 (11)
Sunshine Coast	51.7 (31)	27.1 (16)	48.4 (30)	39.7 (23)
West Moreton	57.5 (23)	23.1 (9)	31.7 (13)	35.0 (14)
Darling Downs/South West	51.4 (18)	25.0 (8)	31.4 (11)	40.0 (14)
Wide Bay-Burnett	43.4 (23)	18.0 (9)	37.5 (21)	29.1 (16)
Fitzroy/Central West	51.6 (16)	36.7 (11)	41.2 (14)	33.3 (11)
Mackay	28.6 (6)	14.3 (3)	25.0 (5)	23.8 (5)
Northern/North West	62.8 (27)	24.4 (10)	40.5 (17)	50.0 (21)
Far North	59.0 (23)	30.6 (11)	57.9 (22)	25.0 (9)
	b	b	b	b

	% (n) who reported some need for support within each domain			
	Psychological	Sexuality	Physical / daily living	Health system / information
Geographical locations collapsed				
South East QLD	49.0 (255)	25.5 (131)	37.4 (196)	32.8 (169)
Central/ South West	47.9 (57)	25.0 (28)	36.8 (46)	33.3 (41)
Northern Zone	54.4 (56) [NS]	24.5 (24) [NS]	44.0 (44) [NS]	35.4 (35) [NS]
Accessibility / remoteness index of Australia				
Highly Accessible	50.3 (268)	25.8 (135)	37.2 (200)	33.0 (174)
Accessible	52.0 (53)	23.2 (22)	39.8 (41)	38.2 (39)
Moderately Accessible	41.0 (34)	26.2 (22)	41.0 (34)	30.6 (26)
Remote/ very remote	54.2 (13) [b]	18.2 (4) [NS]	44.0 (11) [NS]	26.1 (6) [b]
Rural Remote and Metropolitan Area Classification				
Capital City	46.5 (159)	24.1 (82)	34.5 (118)	31.2 (106)
Other Metropolitan Centre	58.6 (58)	25.3 (24)	42.0 (42)	36.4 (36)
Rural/ Remote Zone	47.7 (113) [b]	24.0 (57) [NS]	39.8 (96) [NS]	34.5 (81) [NS]
Socio-economic status for areas				
High SES	55.3 (63)	25.9 (29)	36.8 (42)	36.5 (42)
Moderately high SES	46.5 (74)	27.8 (44)	43.4 (69)	27.5 (44)
Moderate SES	45.6 (62)	25.9 (35)	34.8 (48)	33.8 (46)
Moderately low SES	50.2 (115)	20.5 (45)	35.5 (83)	35.8 (81)
Low SES	51.9 (54) [b]	30.0 (30) [b]	42.3 (44) [b]	31.7 (32) [b]

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.1.9 SUMMATION OF BIVARIATE CORRELATES WITHIN THE SOCIAL-ECOLOGICAL MODEL

At the bivariate stage of analysis, demographic and wellbeing disposition were the constructs within the personal level of the social-ecological model that predominantly influenced the reporting of unmet supportive care needs across all needs domains. Independently from other treatment modalities, radiation therapy was also strongly associated with all needs domains. Radiation therapy also sits within the personal level of the social-ecological model, confirming that this level is highly influential on supportive care needs. The next level of influence within the model is social support and this construct was also shown to be significantly correlated with all supportive care domains. Complementary therapy use and awareness of support services were the only variables that were strongly associated with all the needs domains that fell outside the models' two inner levels of influence. Complementary therapy use is situated in the health care layer of the social-ecological model and awareness is situated in the community level of influence.

5.2.2 IMPACT OF CANCER TYPE AND SURVIVAL PHASE ON CRUDE RELATIONSHIPS

A number of variables (see section 3.8.4 for rationale as to which variables) were tested to determine if type of cancer or phase post-diagnosis were confounders and/ or effect modifiers of the relationship of reported unmet needs with these selected variables. The identified confounding effects are presented and discussed in this section. The amount of confounding justifies the importance of conducting multivariable analysis that adjusts for these nuisance confounding effects. During this stage of the analysis bivariate stratification of crude relationships by type of cancer and survival phase were also conducted to determine whether there was effect modification of the crude relationship. Tables of stratified results are presented in appendix 16. Because of the amount of confounding, effect modification by type of cancer and survival phase of the relationships of interest changed from what was observed in the bivariate stratification to what was observed in the multivariable analysis. Therefore, only the presentation of multivariable stratification is emphasised in the body of this thesis.

As established in section 5.2.1.2, type of cancer was associated with the outcome variables: psychological, sexuality, and health system/information needs. Survival phase was associated with the outcome variables: psychological and physical/ daily living needs. Type of cancer and survival phase were also tested for their association with each of the independent variables to determine if they were confounders of the crude relationships. Moreover, when type of cancer and survival phase were associated with both the dependent and independent variables they were considered a confounder of that relationship.

Results from this analysis indicated that the crude relationships of psychological, sexuality, and health system/information needs with demographic variables, age, marital status, education levels, employment status, household income, children living at home and country of origin were confounded by type of cancer. Type of cancer was also a confounder of the relationship of several diagnosis, treatment and physical condition variables with the above need domains including, survival phase, cancer stage, treatment centre, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, ever diagnosed with a physical or emotional illness, menopausal status, HRT and sexual activity status.

Moreover, the following perceived wellbeing, lifestyle, health care and community factors and their relationship with psychological, sexuality, and health system/information needs was confounded by type of cancer: physical wellbeing, social/ family wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, BMI, physical activity, vegetable intake, social support, service use, use of complementary therapy support, service awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA) and Socio-Economic Indexes of Areas (SEIFA).

Survival phase was also considered for potential confounding of the crude relationships of psychological and physical/ daily living needs with independent variables. Results showed that the relationship of the above needs domains with a number of demographic variables (age, employment status and children living at home), diagnosis, treatment and physiological variables (type of cancer, cancer stage, treatment centre, radiotherapy, surgery, last admission for treatment, disease presence, lymphedema status, hospitalised since completing treatment for gynaecological cancer, menopausal status, HRT), and lifestyle, healthcare and community variables (alcohol consumption, BMI, service use, use of complementary therapy support and, Rural Remote and Metropolitan Area Classification) were confounded by survival phase.

5.2.3 MULTIVARIABLE RESULTS

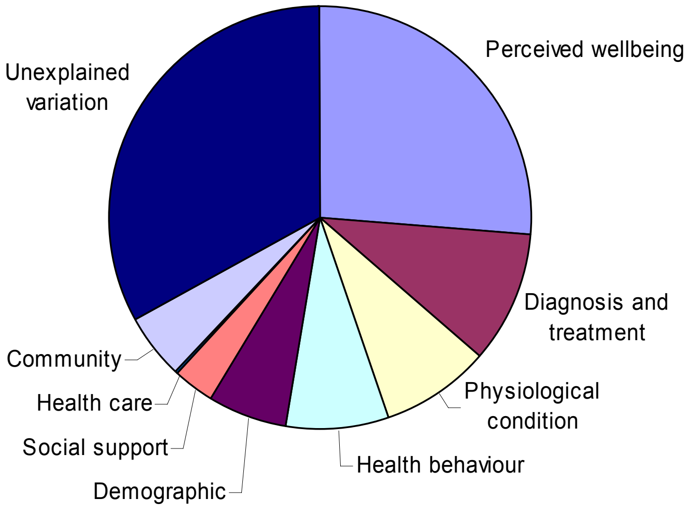
As many of the independent variables in the bivariate model were likely to be confounders of each other in their relationships with unmet needs, multivariable logistic regression modelling was used to adjust for confounding to provide estimates of independent association of these variables with unmet needs, and was extended to formally explore effect modifying variables. Each level of influence within the social-ecological model was assessed using a pseudo-R^2 statistic (Nagelkerke's), a proportion-of-variation-explained statistic, to determine the relative contribution of each block of factors within the model.

However, before this occurred, the known or suspected correlated independent variables in the model were tested for multicollinearity to determine the degree of redundancy, as outlined in section 3.9.4. All tested variables were significantly correlated as expected; however, none of them were correlated to an extreme degree (± 0.9). Hence, all independent variables were retained in the multivariable analysis.

5.2.3.1 PSYCHOLOGICAL NEEDS

5.2.3.1.1 VARIATION EXPLAINED

Factors included in the final model of psychological needs explained 67% (Nagelkerke R Square = 0.671) of the variation of psychological supportive care needs. The figure below presents the relative contribution to variation explained by each block of factors within the social-ecological model, standardised to 100%. The perceived wellbeing construct had by far the most predictive value. Within the social-ecological model, the five blocks which made up the personal level of influence on supportive care needs, accounted for 62% of the variation. Social support, health care and community levels of influence accounted for very little of the variation.



The personal level of influence within the social-ecological model is made up of: personal wellbeing, diagnosis and treatment, physiological condition, health behaviour, and demographic characteristics.

Other levels of influence are presented as individual blocks

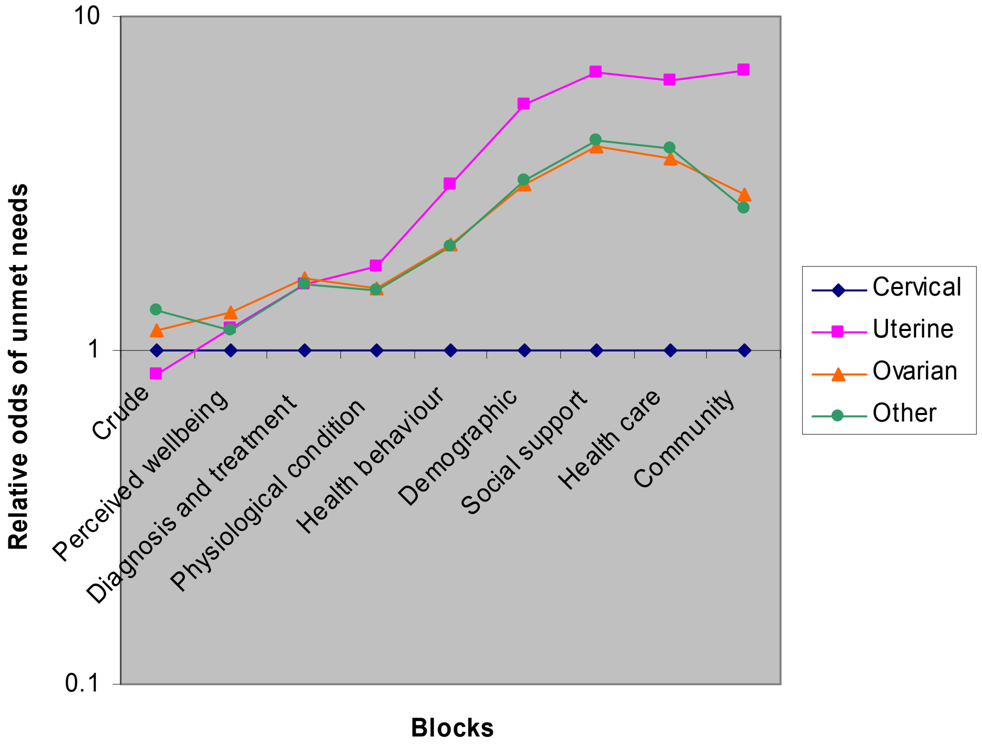
FIGURE 5.3 VARIATION IN PSYCHOLOGICAL NEEDS EXPLAINED BY INDEPENDENT VARIABLES WITHIN THE FINAL MODEL (SCALED TO 100%), REFLECTING A SOCIAL-ECOLOGICAL THEORETICAL FRAMEWORK.

5.2.3.1.2 TESTING MODEL ROBUSTNESS

The final main effects model estimates were imprecise with wide confidence intervals. Therefore, an exercise in building the model block by block was conducted with the correlate “type of cancer” to determine if the final odds ratios were credible or just random statistical findings. This example was selected as “type of cancer” is a key variable in this study. However, other variables with extremely imprecise point estimates and wide confidence intervals are explored throughout this results chapter, when necessary.

Figure 5.4 outlines the change in odds ratios and confidence intervals around psychological needs by cancer type as each block of variables is added to the model, in order of levels of influence within the social-ecological model, for adjustment. It was concluded from this figure that the odds steadily increase across all subgroups as more factors were adjusted for. When the health behaviour block was added a clinically meaningful difference in psychological need for uterine, ovarian and other, compared with cervical cancer survivors, was observed with precise confidence intervals. With each additional block after health behaviours, the odds continue to increase, although with substantial widening of confidence intervals. Irrespective of the substantial imprecision at this point, the conclusion remains consistent, that there was a meaningful difference in psychological needs across cancer subgroups. While the specific odds ratios in these complex final models may not be completely precise due to wide confidence intervals, the relative associations can be asserted as credible due to the observed steady increase.

It may further be deduced that health behaviours and demographic characteristics, while explaining less of the variation than other personal constructs, may strongly influence psychological needs in uterine as well as ovarian and “other” gynaecological cancer survivors compared with cervical cancer survivors.



	Cervical	Uterine	Ovarian	Other
	Referent	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)
Crude	1	0.85 (0.58-1.26)	1.14 (0.78-1.68)	1.32 (0.83-2.10)
Perceived wellbeing	1	1.17 (0.70-1.97)	1.3 (0.78-2.16)	1.15 (0.62-2.14)
Diagnosis and treatment	1	1.57 (0.86-2.88)	1.65 (0.82-3.31)	1.57 (0.73-3.39)
Physiological condition	1	1.79 (0.88-3.64)	1.53 (0.70-3.38)	1.52 (0.63-3.64)
Health behaviour	1	3.12 (1.33-7.27)	2.08 (0.84-5.16)	2.04 (0.74-5.59)
Demographic	1	5.43 (1.99-14.85)	3.12 (1.10-8.81)	3.21 (0.98-10.55)
Social support	1	6.83 (2.26-20.66)	4.07 (1.34-12.40)	4.23 (1.18-15.19)
Health care	1	6.47 (2.12-19.78)	3.74 (1.22-11.48)	4.01 (1.09-14.82)
Community	1	6.89 (1.96-24.25)	2.93 (0.86-10.05)	2.66 (0.66-10.83)

FIGURE 5.4 PSYCHOLOGICAL NEEDS BY TYPE OF CANCER AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

5.2.3.1.3 CORRELATES OF UNMET PSYCHOLOGICAL NEEDS

As defined in the methods chapter, significant correlates were identified as those with odds ratios above 2 or below 0.5, reasonably precise 95% confidence intervals and adequate case numbers per subgroups. Statistical support for a number of clinically significant independent variables was noted (see table 5.12). Type of gynaecological cancer was both clinically and statistically (p=0.028) associated with unmet psychological needs. The odds of having unmet psychological needs amongst uterine, ovarian and “other” gynaecological cancer survivors were higher than the odds for cervical cancer survivors (OR 6.89, CI 1.96-24.25, OR 2.93, CI 0.86-10.05 and OR 2.66, CI 0.66-10.83 respectively). This association appeared particularly stronger for uterine cancer subgroup.

Type of surgery was also clinically and statistically (p=0.038) associated with unmet psychological needs. The odds of unmet psychological needs amongst women who had open abdominal surgery were higher than for women with who had vaginal or laparoscopic surgery (OR 4.41, CI 1.32-14.78). No surgery, and open bowel surgery, were also compared with vaginal or laparoscopic surgery; however, the small number of cases within these subgroups were associated with confidence intervals that were too wide to interpret convincingly.

Lymphoedema status was clinically and statistically (p<0.001) associated with unmet psychological needs. The odds of unmet psychological needs amongst women with undiagnosed lower limb swelling were higher than for women with no lower limb swelling (OR 2.41, CI 0.77-7.53). For women with diagnosed lymphoedema, the odds of unmet psychological needs were also higher compared with women with no lower limb swelling (OR 17.82, CI 4.92-64.57). While there were only 47 women in this subgroup, and the 95% confidence interval was wide, this conclusion is likely to be real, although not necessarily of this high magnitude, due to the lower bound of the confidence interval being positive. Also, compared with the bivariate model, a similar but larger effect was observed in the adjusted model.

Relative to women who were treated more than two years ago, the odds of unmet psychological needs in women who were treated 1-12 months ago and 1-2 years ago were higher (OR 5.18, CI 1.26-21.25 and OR 2.72, CI 0.99-7.45 respectively). Case numbers within the last month of treatment administration were too small (18) to consider with confidence. There was a negative linear relationship of higher emotional and functional wellbeing with decreasing unmet psychological needs. The odds of unmet psychological needs in smokers were higher compared to non-smokers (OR 4.28, CI 1.33-13.73).

TABLE 5.12 STATISTICALLY AND CLINICALLY SIGNIFICANT CORRELATES OF REPORTING "SOME NEED" IN THE PSYCHOLOGICAL DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [c] OR (95% CI)	p value
Type of gynaecological cancer				
Cervical	126	Referent	Referent	0.028
Uterine	143	0.76 (0.47-1.23)	6.89 (1.96-24.25)	
Ovarian	148	1.05 (0.65-1.68)	2.93 (0.86-10.05)	
Other	62	1.07 (0.58-1.96)	2.66 (0.66-10.83)	
Surgery				
None	7	1.66 (0.34-8.15)	1.16 (0.06-23.71)	0.038
Vagina or laparoscopic	61	Referent	Referent	
Open abdominal	365	2.32 (1.30-4.15)	4.41 (1.32-14.78)	
Open bowel resection	46	4.57 (2.01-10.38)	11.52 (1.68-78.93)	
Last administration of treatment				
Within the last month	18	3.13 (1.08-9.13)	0.72 (0.09-5.59)	0.033 [a]
1-12 months ago	140	1.56 (1.01-2.42)	5.18 (1.26-21.25)	
1-2 years ago	91	1.61 (0.97-2.65)	2.72 (0.99-7.45)	
>2 years ago	194	Referent	Referent	
Lymphoedema status				
No lower limb swelling	369	Referent	Referent	0.001
Lower limb swelling but not diagnosed	63	1.65 (0.96-2.83)	2.41 (0.77-7.53)	
Diagnosed lymphoedema	47	2.47 (1.29-4.72)	17.82 (4.92-64.57)	
Emotional wellbeing				
Lowest quartile	113	27.53 (13.71-55.26)	31.78 (9.05-111.62)	0.001[b]
2nd quartile	146	4.99 (2.94-8.46)	4.20 (1.72-10.27)	
3rd quartile	83	2.32 (1.26-4.27)	1.12 (0.41-3.07)	
Highest quartile	137	Referent	Referent	
Functional wellbeing				
Lowest quartile	115	11.88 (6.50-21.72)	6.88 (1.42-33.44)	0.011[b]
2nd quartile	118	4.18 (2.44-7.16)	3.82 (1.21-12.05)	
3rd quartile	115	1.98 (1.15-3.41)	2.26 (0.85-6.01)	
Highest quartile	131	Referent	Referent	
Smoker				
Yes	55	1.71 (0.96-3.05)	4.28 (1.33-13.73)	0.015
No	424	Referent	Referent	

[a] significance value when missing category of this variable was removed from the model

[b] significance value when the variable is treated as continuous and fitted as a linear trend

[c] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

A number of other variables were considered clinically important (see table 5.13). The odds of unmet psychological needs in women who were unable to work because of illness were significantly higher than all other employment categories (relative to retired women OR 7.03, CI 1.32-37.48). While cases were low in this category, this effect was present both in the bivariate and multivariable analysis and the lower bound of the confidence interval was above one, indicating plausibility.

The odds of unmet psychological needs in women who were not born in Australia were higher than for those who were born in Australia (OR 2.04, CI 0.87-4.79). Relative to women who were treated at hospital A, the odds of unmet psychological needs in women treated at the hospital B or multiple centres were lower (OR 0.52, CI 0.16-1.17 and OR 0.22, 0.07-0.72 respectively). There was no meaningful difference in the reporting of unmet psychological needs between hospital A and C. The odds of unmet psychological needs in women with private insurance were substantially higher than for those who were covered by Medicare only (OR 2.25, CI 0.94-5.37).

The odds of unmet psychological needs in women who had chemotherapy were higher than for those who had not had chemotherapy (OR 2.56, CI 0.92-7.08). Relative to women who were disease free, the odds of unmet psychological needs in women whose disease was still present, were substantially higher (OR 2.56, CI 0.81-8.08).

Relative to women who experienced menopause prior to cancer diagnosis, the odds of unmet psychological needs in women who had iatrogenic menopause were higher (OR 2.72, CI 0.94-7.87). Cases in pre or peri menopause subgroup were too small to consider. The odds of unmet psychological needs in women who were sexually active, were higher than for women who were not sexually active (OR 2.25, CI 0.90-5.65). The odds of unmet psychological needs in women who used a support service were higher than for non-users (OR 2.06, CI 0.86-4.91). Relative to women who consumed alcohol on five to seven days per week, the odds of unmet psychological needs in those who drank “not at all”, “on a less than weekly basis” or “one to four days per week” were higher (OR 4.49, CI 1.21-16.69, OR 4.81, CI 1.46-15.85 and OR 2.82, CI 0.83-9.51 respectively).

The odds of unmet psychological needs in women who were aware of at least one support service were substantially higher than for women who were not aware (OR 2.94, CI 0.74-11.62). The odds of unmet psychological needs in women who lived outside of Brisbane, in other metropolitan centres or in rural and remote areas, were also higher than for those who lived in the capital city (OR 2.64, CI 0.81-8.62 and OR 2.47, CI 0.74-8.29 respectively). Also, relative to women who lived in a high socio-economic area, the odds of unmet psychological needs in women who lived in a moderately high socio-economic area, moderate socio-economic area and moderately low socio-economic area were lower (OR 0.36, CI 0.11-1.19, OR 0.19, CI 0.05-0.69 and, OR 0.37, CI 0.12-1.21 respectively).

TABLE 5.13 REMAINING NON-STATISTICALLY SIGNIFICANT BUT CLINICALLY IMPORTANT CORRELATES OF REPORTING "SOME NEED" IN THE PSYCHOLOGICAL DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [b] OR (95% CI)	p value
Employment type				0.165
Paid full- time	93	1.68 (1.09-2.60)	1.07 (0.30-3.86)	
Paid part time or casual	97	1.51 (0.98-2.34)	1.60 (0.50-5.16)	
Home duties	79	1.37 (0.88-2.15)	1.12 (0.37-3.42)	
Retired	127	Referent	Referent	
Unable to work because of illness	45	4.79 (2.57-8.90)	7.03 (1.32-37.48)	
Other	38	0.90 (0.50-1.61)	0.65 (0.15-2.88)	
Country of origin				
Australia	387	Referent	Referent	0.101
Other	92	1.05 (0.67-1.65)	2.04 (0.87-4.79)	
Treatment centre				
Treatment hospital A	139	Referent	Referent	0.064 [a]
Treatment hospital B	98	1.03 (0.62-1.73)	0.52 (0.16-1.70)	
Treatment hospital C	86	0.80 (0.45-1.42)	0.83 (0.26-2.67)	
Other treatment hospitals	64	1.02 (0.54-1.92)	0.88 (0.25-3.08)	
Multi-treatment centres	85	0.90 (0.50-1.60)	0.22 (0.07-0.72)	
Insurance				
Medicare only	225	Referent	Referent	0.068
Private insurance	254	1.13 (0.79-1.62)	2.25 (0.94-5.37)	
Chemotherapy				
Yes	182	1.89 (1.30-2.75)	2.56 (0.92-7.08)	0.071
No	297	Referent	Referent	
Disease presence				
Disease absent	410	Referent	Referent	0.110
Disease present	69	2.40 (1.40-4.13)	2.56 (0.81-8.08)	
Menopausal status				
Pre/ peri menopausal	15	0.32 (0.09-1.14)	1.51 (0.10-23.24)	0.068 [a]
Post menopause	269	Referent	Referent	
Iatrogenic menopause	173	1.90 (1.29-2.80)	2.72 (0.94-7.87)	
Sexually active				
Yes	218	0.77 (0.53-1.10)	2.25 (0.90-5.65)	0.083 [a]
No	245	Referent	Referent	
Alcohol consumption				
None	129	1.57 (0.83-2.97)	4.49 (1.21-16.69)	0.067
< weekly	181	1.79 (0.97-3.29)	4.81 (1.46-15.85)	
1-4 days / week	113	1.52 (0.79-2.91)	2.82 (0.83-9.51)	
5-7 days / week	56	Referent	Referent	
Use of at least 1 support service or organisation				
Yes	287	2.05 (1.39-3.02)	2.06 (0.86-4.91)	0.104 [a]
No	169	Referent	Referent	
Awareness of at least 1 support service or organisation (excluding QCF, the project sponsor)				
Yes	409	2.61 (1.36-5.03)	2.94 (0.74-11.62)	0.124
No	47	Referent	Referent	
Rural Remote and Metropolitan Area Classification				
Capital City	229	Referent	Referent	0.054 [a]
Other Metropolitan Centre	62	1.41 (0.80-2.48)	2.64 (0.81-8.62)	
Rural and Remote Zone	145	1.18 (0.78-1.78)	2.47 (0.74-8.29)	

	N	Crude OR (95% CI)	Adjusted [b] OR (95% CI)	p value
Socio-economic status for areas				
High SES	77	Referent	Referent	0.064
Moderately high SES	103	0.48 (0.26-8.7)	0.36 (0.11-1.19)	
Moderate SES	88	0.49 (0.26-0.90)	0.19 (0.05-0.69)	
Moderately low SES	150	0.66 (0.38-1.15)	0.37 (0.12-1.21)	
Low SES	61	0.86 (0.43-1.70)	0.93 (0.23-3.66)	

[a] significance value when missing category of this variable was removed from the model

[b] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

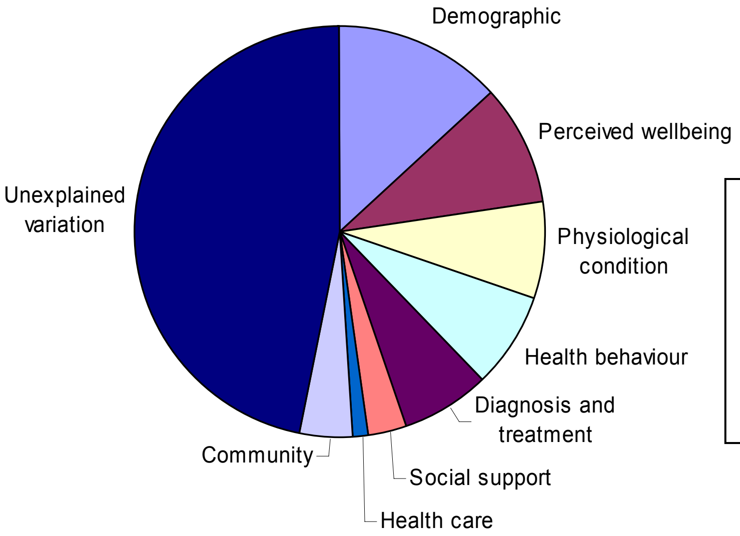
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Factors that were adjusted for, that were not included in table 5.12 or 5.13, were identified as not being significantly correlated with unmet psychological needs, or in the cases of marital status, education level, BMI, geographical locations and accessibility/ remoteness index of Australia, were identified as having low case numbers and excessively wide confidence intervals in the possibly significant subgroups.

5.2.3.2 SEXUALITY NEEDS

5.2.3.2.1 VARIATION EXPLAINED

The final model of sexuality needs accounted for 53% (Nagelkerke R Square = 0.530) of the variation. Again the personal level of influence on supportive care needs accounted for most of the explained variation (48%), with the demographic construct having the greatest predictive value.



The personal level of influence within the social-ecological model is made up of: personal wellbeing, diagnosis and treatment, physiological condition, health behaviour, and demographic characteristics.

Other levels of influence are presented as individual blocks

FIGURE 5.5 VARIATION IN SEXUALITY NEEDS EXPLAINED BY INDEPENDENT VARIABLES WITHIN THE FINAL MODEL (SCALED TO 100%), REFLECTING A SOCIAL-ECOLOGICAL THEORETICAL FRAMEWORK.

5.2.3.2.2 CORRELATES OF UNMET SEXUALITY NEEDS

Age, marital status, employment type, remission status, menopausal status and social/ family wellbeing were identified as being both clinically and statistically correlated with reporting unmet sexuality needs in the adjusted model (see table 5.14). There was a negative linear relationship of increasing age with decreasing unmet sexuality needs. Relative to women living with a partner, the odds of unmet sexuality needs in single, separated/ divorced, or widowed women were lower (OR 0.20, CI 0.04-0.89, OR 0.27, CI 0.08-0.94 and OR 0.17, CI 0.03-0.90 respectively).

Relative to women who performed home duties, the odds of unmet sexuality needs in women in full-time or part-time paid work or who were unable to work due to illness were considerably higher (OR 2.26, CI 0.64-8.00, OR 3.84, CI 1.23-11.96 and OR 6.48, CI 1.43-29.36 respectively). Cases are lower in some subgroups; however, since the final model indicates a similar conclusion to the bivariate model and lower bounds of confidence intervals are generally above one, the conclusions of this relationship can be declared with confidence.

The odds of unmet sexuality needs in women not in remission were higher than for those in remission (OR 2.92, CI 1.15-7.40). The odds of unmet sexuality needs in women who had treatment-induced menopause were substantially higher than for women who experience menopause prior to cancer diagnosis (OR 2.55, CI 0.95-

6.82). There was a negative linear relationship of higher social/ family wellbeing with decreasing unmet sexuality needs.

The multivariable results of age, employment type and social/ family wellbeing reflected the bivariate results. Marital status was significant at the bivariate level of analysis, and after adjustment, there was an increase in effect size in both the single and separated/ divorced subgroups. Negative confounding was witnessed in the relationship of sexuality needs with remission status after adjustment, as no difference in remission categories was observed in the crude model (crude OR = 1.44). Surgery, radiotherapy, social/ functional wellbeing and menopausal status were in order the main suppressors of the crude relationship.

TABLE 5.14 STATISTICALLY AND CLINICALLY SIGNIFICANT CORRELATES OF REPORTING "SOME NEED" IN THE SEXUALITY DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [b] OR (95% CI)	p value
Age (years)				
18-39	62	Referent	Referent	0.043 [a]
40-49	84	1.05 (0.55-2.03)	0.59 (0.19-1.80)	
50-59	152	0.45 (0.24-0.83)	0.41 (0.12-1.42)	
60-69	122	0.17 (0.08-0.36)	0.18 (0.03-0.98)	
70+	55	0.07 (0.02-0.25)	0.13 (0.01-1.26)	
Marital status				
Single	33	0.74 (0.32-1.70)	0.20 (0.04-0.89)	0.023
Living with a partner	335	Referent	Referent	
Seperated/divorced	54	0.81 (0.42-1.56)	0.27 (0.08-0.94)	
Widowed	53	0.14 (0.04-0.46)	0.17 (0.03-0.90)	
Employment type				
Paid full- time	97	2.00 (1.12-3.57)	2.26 (0.64-8.00)	0.039
Paid part time or casual	97	2.29 (1.28-4.09)	3.84 (1.23-11.96)	
Home duties	76	Referent	Referent	
Retired	125	0.56 (0.30-1.03)	1.59 (0.43-5.97)	
Unable to work because of illness	42	2.73 (1.38-5.41)	6.48 (1.43-29.36)	
Other	38	1.35 (0.64-2.83)	0.79 (0.17-3.60)	
Remission				
Yes	363	Referent	Referent	0.024
No/don't know	112	1.44 (0.91-2.28)	2.92 (1.15-7.40)	
Menopausal status				
Pre/ peri menopausal	16	0.69 (0.15-3.15)	0.35 (0.03-4.58)	0.027 [a]
Post menopause	263	Referent	Referent	
Iatrogenic menopause	176	3.43 (2.21-5.33)	2.55 (0.95-6.82)	
Social/ family wellbeing				
Lowest quartile	120	7.28 (3.45-15.34)	8.16 (19.2-34.66)	0.001 [a]
2nd quartile	124	4.55 (2.14-9.64)	4.62 (1.30-16.45)	
3rd quartile	129	1.89 (0.85-4.20)	1.17 (0.37-3.75)	
Highest quartile	102	Referent	Referent	

[a] significance value when the variable is treated as continuous and fitted as a linear trend

[b] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location,

Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

A number of other variables which were not statistically significant, were considered clinically (see table 5.15). Many of these variables had four or more categories, which limited cases in each subgroup and affected the robustness of the results. Model stability was further weakened by the fact that the sexuality needs outcome was only prevalent in 25% of the sample, whereas 50% of the sample experienced psychological needs. Hence, the results of the variables with limited cases in categories of interest (type of cancer and socio-economic status for areas) were first considered with further analyses for integrity.

Relative to cervical cancer survivors, the odds of unmet sexuality needs in women diagnosed with an "other" type of gynaecological cancer were possibly higher (OR 2.66, CI 0.69-10.21). Although this effect did not become apparent until the addition of block five (see figure 5.6) and at this point the confidence intervals were very wide (OR 2.83, CI 0.86-9.27). Therefore, this conclusion is asserted with little certainty.

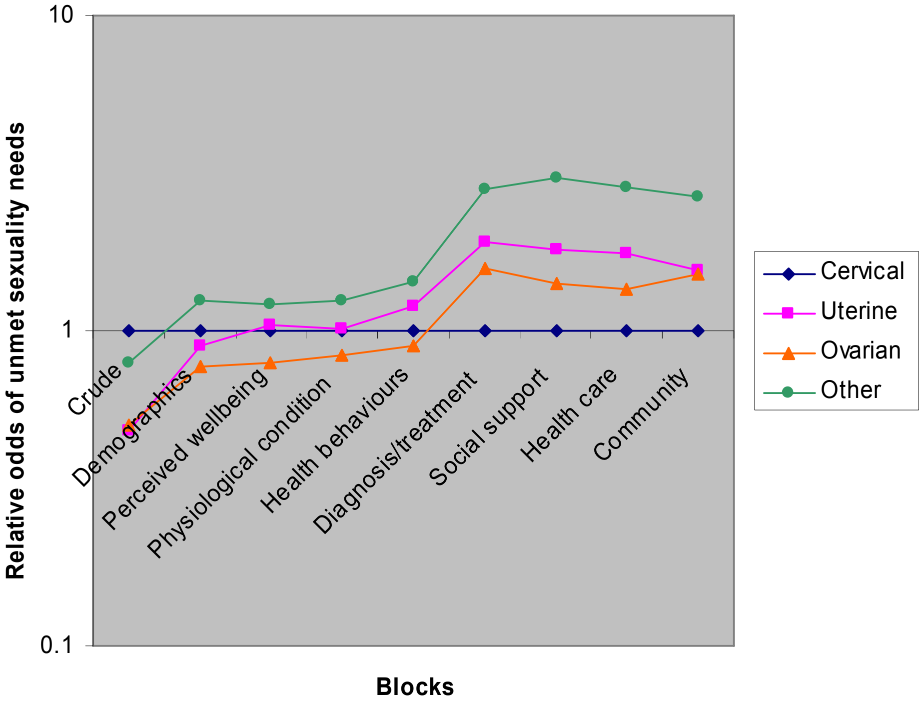


FIGURE 5.6 UNMET SEXUALITY NEEDS BY TYPE OF CANCER AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

Relative to women who lived in high or moderately high socio-economic areas of Queensland, the odds of unmet sexuality needs in women who lived in moderate or moderately low socio-economic areas were considerably lower (OR 0.38, CI 0.11-

1.33 and OR 0.38, CI 0.12-1.23 respectively). This relationship consistently existed after the addition of the third blocks of variables (see figure 5.7) and at this point the confidence intervals were creditable (OR 0.52, CI 0.21-1.27 and OR 0.54, CI 0.24-1.22). Cases within the women who lived in the low socio-economic areas were too small to consider with confidence.

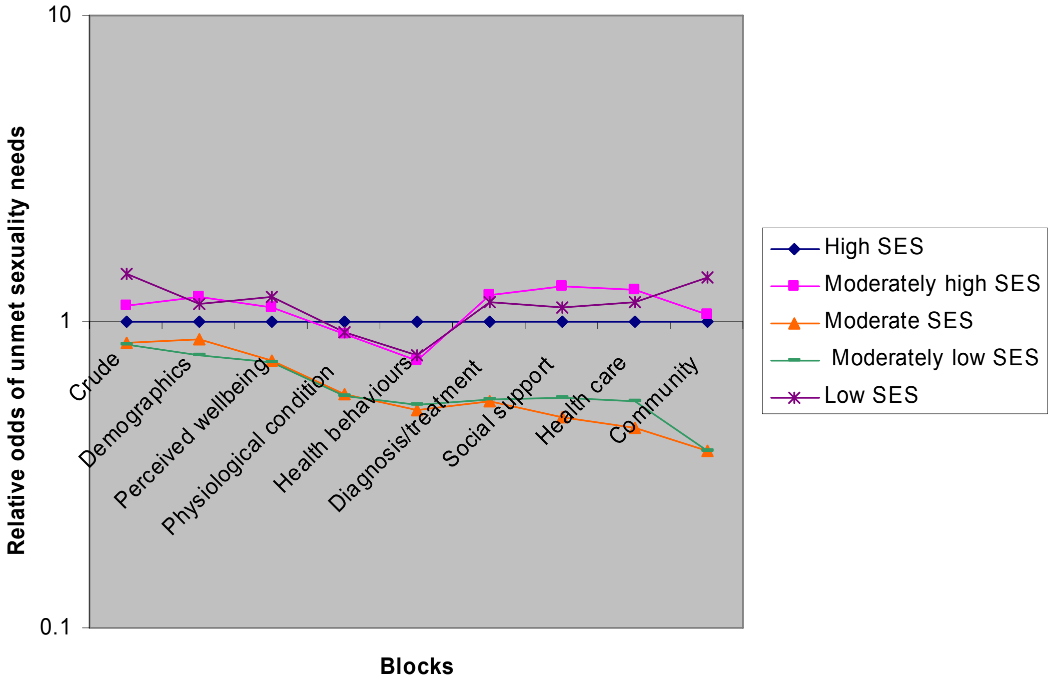


FIGURE 5.7 UNMET SEXUALITY NEEDS BY SOCIO-ECONOMIC STATUS FOR AREAS AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

The odds of unmet sexuality needs in women not born in Australia were substantially higher than for Australian born residence (OR 2.23, CI 0.95-5.24). The odds of unmet sexuality needs in women with diagnosed lymphoedema were considerably higher than for women with no lower limb swelling (OR 2.90, CI 0.90-9.36). Relative to women who had HRT in the past 3 months, the odds of unmet sexuality needs in those who didn't were higher (OR 2.13, CI 0.87-5.23).

In addition to social/ family wellbeing which was found to be statistically and clinically associated with sexuality needs, there was also a near significant, negative linear relationship of higher emotional wellbeing with decreasing sexuality needs.

The odds of unmet sexuality needs in women who used a support service were higher than for non-users (OR 1.96, CI 0.82-4.69). The odds of unmet sexuality needs in women who lived in rural or remote regions of Queensland were substantially higher than for those who lived in the capital city (OR 2.76, CI 0.88-8.72).

TABLE 5.15 REMAINING NON-STATISTICALLY SIGNIFICANT BUT CLINICALLY IMPORTANT CORRELATES OF REPORTING "SOME NEED" IN THE SEXUALITY DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted[c] OR (95% CI)	p value
Country of origin				
Australia	380	Referent	Referent	0.067
Other	95	1.28 (0.78-2.10)	2.23 (0.95-5.24)	
Lymphoedema status				
No lower limb swelling	366	Referent	Referent	0.179
Lower limb swelling but not Diagnosed	63	1.03 (0.56-1.90)	0.89 (0.31-2.54)	
Diagnosed lymphoedema	46	2.13 (1.13-4.01)	2.90 (0.90-9.36)	
HRT in the 3 past months				
Yes	106	Referent	Referent	0.100
No	369	0.70 (0.44-1.13)	2.13 (0.87-5.23)	
Emotional wellbeing				
Lowest quartile	106	6.66 (3.53-12.55)	2.68 (0.84-8.59)	0.081[b]
2nd quartile	145	2.93 (1.57-5.45)	1.63 (0.60-4.39)	
3rd quartile	85	1.66 (0.79-3.50)	1.18 (0.39-3.55)	
Highest quartile	139	Referent	Referent	
Use of at least 1 support service or organisation				
Yes	287	1.81 (1.14-2.87)	1.96 (0.82-4.69)	0.093[a]
No	165	Referent	Referent	
Rural Remote and Metropolitan Area Classification				
Capital City	229	Referent	Referent	0.169
Other Metropolitan Centre	62	0.73 (0.37-1.44)	0.73 (0.21-2.51)	
Rural and Remote Zone	141	0.98 (0.61-1.58)	2.76 (0.88-8.72)	
Socio-economic status for areas				
High SES	75	Referent	Referent	0.093
Moderately high SES	104	1.12 (0.57-2.17)	1.06 (0.33-3.41)	
Moderate SES	89	0.85 (0.42-1.72)	0.38 (0.11-1.33)	
Moderately low SES	146	0.84 (0.44-1.58)	0.38 (0.12-1.23)	
Low SES	61	1.44 (0.69-3.01)	1.39 (0.33-5.79)	

[a] significance value when missing or do not wish to answer categories of this variable was removed from the model

[b] significance value when the variable is treated as continuous and fitted as a linear trend

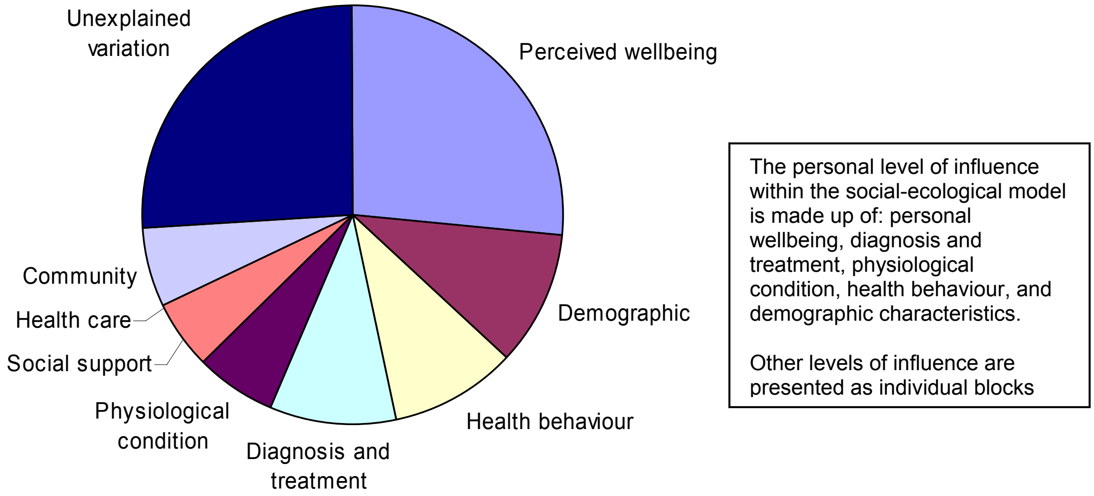
[c] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.3.3 PHYSICAL AND DAILY LIVING NEEDS

5.2.3.3.1 VARIATION EXPLAINED

The final model of physical and daily living needs captured 74% (Nagelkerke R Square = 0.740) of the variation. The perceived wellbeing construct had the most predictive value, whereas health care factors had a negligible predictive value. The personal level of influence on supportive care needs accounted for 68% of the variation when fitting a model with just these blocks.



The personal level of influence within the social-ecological model is made up of: personal wellbeing, diagnosis and treatment, physiological condition, health behaviour, and demographic characteristics.

Other levels of influence are presented as individual blocks

FIGURE 5.8 VARIATION IN PHYSICAL AND DAILY LIVING NEEDS EXPLAINED BY INDEPENDENT VARIABLES WITHIN THE FINAL MODEL (SCALED TO 100%), REFLECTING A SOCIAL-ECOLOGICAL THEORETICAL FRAMEWORK.

5.2.3.3.2 CORRELATES OF UNMET PHYSICAL AND DAILY LIVING NEEDS

Age, employment status, children living at home, stage, surgery, chemotherapy, physical wellbeing and Rural Remote and Metropolitan Area Classification were identified as being both clinically and statistically correlated with reporting unmet physical and daily living needs in the adjusted model (see table 5.16). All these variables were also identified as clinically and/or statistically significant within the bivariate analysis, except Rural Remote and Metropolitan Area Classification.

Relative to women aged 18-39, the odds of unmet physical and daily living needs in women aged 40-49 and 50-59 were possibly lower (OR 0.07, CI 0.01-0.39 and OR 0.53, CI 0.08-3.38 respectively) whereas, the odds of unmet physical and daily living needs in women aged 60-69 and 70+ were possibly higher than for women aged 18-

39 (OR 5.02, CI 0.53-47.37 and OR 7.08, CI 0.62-81.33 respectively). As the confidence intervals were wide around the age group estimates, a building block model was created (see figure 5.9). This model showed that after the addition of the third block, the odds ratio was less than 0.5 for the 40-49 age group with a reasonable confidence interval at that point (OR 0.47, CI 0.18-1.22). Therefore, this subgroup difference is plausible. However, the 70+ age group had an odds ratio above 2 with wide confidence intervals (OR 2.22, CI 0.62-7.95). It was not until block five that the 60-69 age group had an odds ratio above 2 and confidence intervals were extremely wide (OR 3.84, CI 0.65-22.83). Therefore, these latter subgroup differences may only be statistical findings.

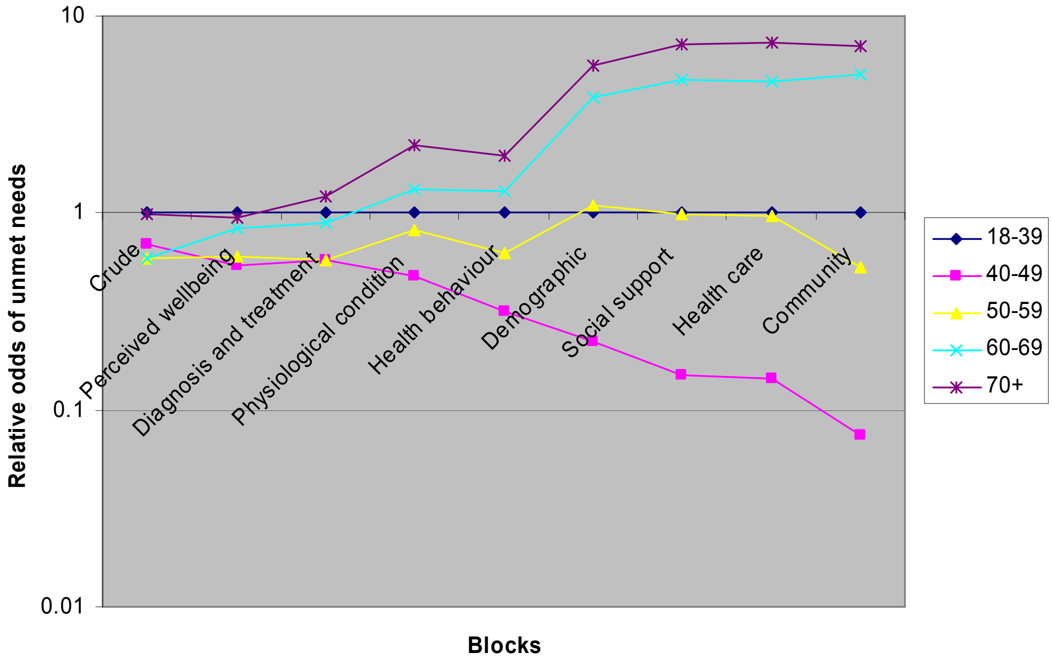


FIGURE 5.9 PHYSICAL AND DAILY LIVING NEEDS BY AGE AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

Relative to women who performed home duties, the odds of unmet physical and daily living needs in women who were unable to work due to illness were higher (OR 66.91, CI 6.57-681.20). The final model had extremely wide confidence intervals, yet the conclusion for this particular relationship remained stable when addition blocks were added to the model (see figure 5.10). This relationship of higher odds is likely although the point estimate imprecise. Other employment categories were also consider for their relative association with physical and daily living needs, but little confidence in their conclusions existed.

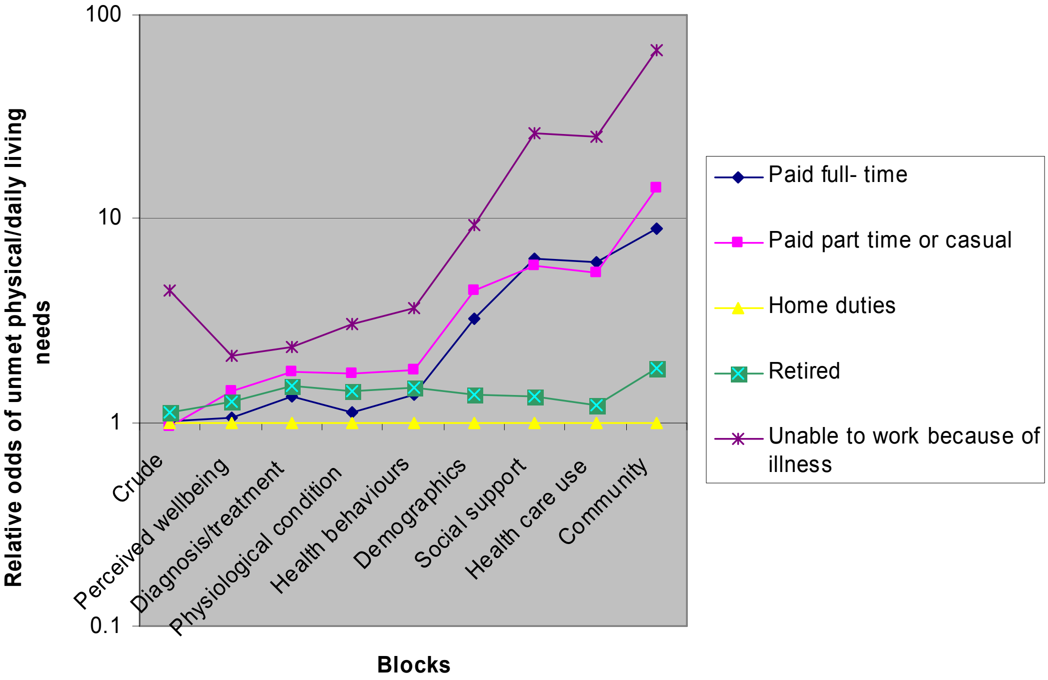


FIGURE 5.10 **PHYSICAL AND DAILY LIVING NEEDS BY EMPLOYMENT TYPE AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK**

Relative to women who had vagina or laparoscopic surgery, the odds of unmet physical and daily living needs in women who had open abdominal surgery were much higher (OR 9.28, CI 1.93-44.63). While cases were small and confidence intervals wide in the subgroup of women who had an open bowel resection, this subgroup also appeared to have higher odds of unmet physical and daily living needs than women who had vagina or laparoscopic surgery in both the crude and adjusted results with the lower bound of the confidence interval indicating a positive result (OR 28.30, CI 2.90-276.56). The odds of unmet physical and daily living needs in women who had chemotherapy were higher than for women who had not had chemotherapy (OR 3.66, CI 1.02-13.18).

There was a negative linear relationship of higher physical wellbeing with decreasing unmet physical and daily living needs (p=0.001). Relative to women who lived in the capital city of Queensland, the odds of unmet physical and daily living needs in women who lived in Other Metropolitan Centres were probably higher (OR 2.66, CI 0.58-12.19) and the odds of unmet physical and daily living needs in women who lived in Rural and Remote Zones were severely higher (OR 9.01, CI 2.05-39.50).

TABLE 5.16 STATISTICALLY AND CLINICALLY SIGNIFICANT CORRELATES OF REPORTING "SOME NEED" IN THE PHYSICAL AND DAILY LIVING DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [c] OR (95% CI)	p value
Age (years)				
18-39	59	Referent	Referent	0.001
40-49	83	0.65 (0.33-1.28)	0.07 (0.01-0.39)	
50-59	145	0.56 (0.30-1.04)	0.53 (0.08-3.38)	
60-69	124	0.51 (0.27-0.96)	5.02 (0.53-47.37)	
70+	61	0.94 (0.46-1.92)	7.08 (0.62-81.33)	
Employment type				
Paid full- time	89	1.01 (0.60-1.69)	9.00 (1.48-54.56)	0.007
Paid part time or casual	94	0.96 (0.57-1.63)	14.08 (2.79-71.21)	
Home duties	80	Referent	Referent	
Retired	127	1.12 (0.71-1.78)	1.83 (0.43-7.74)	
Unable to work because of illness	45	4.48 (2.38-8.43)	66.91 (6.57-681.20)	
Other	37	0.70 (0.35-1.39)	6.07 (0.73-50.74)	
Children living at home				
No	305	Referent	Referent	0.044
Yes	91	1.68 (1.05-2.70)	4.57 (1.04-20.12)	
Stage				
Early stage	334	0.58 (0.38-0.88)	4.67 (1.30-16.82)	0.017 [a]
Late stage	117	Referent	Referent	
Surgery				
None	7	2.94 (0.58-14.93)	1.86 (0.06-54.86)	0.018
Vagina or laparoscopic	59	Referent	Referent	
Open abdominal	360	2.64 (1.35-5.15)	9.28 (1.93-44.63)	
Open bowel resection	46	3.59 (1.52-8.47)	28.30 (2.90-276.56)	
Chemotherapy				
Yes	183	1.78 (1.22-2.61)	3.66 (1.02-13.18)	0.047
No	289	Referent	Referent	
Physical wellbeing				
Lowest quartile	131	57.45 (22.86-144.40)	62.61 (9.14-428.73)	0.001 [b]
2nd quartile	95	17.40 (6.95-43.54)	30.68 (5.20-180.91)	
3rd quartile	142	3.49 (1.38-8.85)	1.90 (0.37-9.92)	
Highest quartile	104	Referent	Referent	
Rural Remote and Metropolitan Area Classification				
Capital City	222	Referent	Referent	0.003 [a]
Other Metropolitan Centre	62	1.10 (0.61-1.99)	2.66 (0.58-12.19)	
Rural and Remote Zone	145	1.49 (0.97-2.30)	9.01 (2.05-39.50)	

[a] significance value when missing category of this variable was removed from the model

[b] significance value when the variable is treated as continuous and fitted as a linear trend

[c] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

A number of other subgroup comparisons within variables (see table 5.17) were considered clinically important. Relative to women treated at hospital B, the odds of unmet physical and daily living needs in women treated at hospital A were probably higher (OR 3.29, CI 0.77-14.14). Relative to women admitted to treatment more than two years ago, the odds of unmet physical and daily living needs in women admitted to treatment 1-12 months ago and 1-2 years ago were substantially higher (OR 4.00, CI 0.74-21.61 and OR 3.05, CI 0.81-11.50 respectively). The odds of unmet physical and daily living needs in women whose disease was still present were higher than for women whose disease was absent (OR 3.38, CI 0.94-12.82).

Relative to women who experienced no lower limb swelling, the odds of unmet physical and daily living needs in women diagnosed with lymphoedema appeared much higher (OR 6.39, CI 1.39-29.48). The odds of unmet physical and daily living needs in women who have been diagnosed with a physical or emotional illness apart from gynaecological cancer were higher than for women who have not been diagnosed with another illness (OR 2.56, CI 0.98-6.74). The odds of unmet physical and daily living needs in women who had treatment-induced menopause were substantially higher than for women who experience menopause prior to cancer diagnosis (OR 4.36, CI 1.11-17.14).

While emotional wellbeing was not linearly related to unmet physical and daily living needs, there was a difference between the lower and the upper three quartiles that may be meaningful. Relatively to women in the lowest emotional wellbeing quartile (*i.e.* the least emotionally well), the odds of unmet physical and daily living needs in women in the higher three emotional wellbeing quartiles were lower (OR 0.31, CI 0.09-1.01, OR 0.45, CI 0.12-1.70 and OR 0.27, CI 0.07-1.07).

Relative to women who consumed alcohol on five to seven days per week, the odds of unmet physical and daily living needs in women who consumed alcohol on one to four days per week or who do not consume alcohol were moderately higher (OR 2.13, CI 0.48-9.50 and OR 2.84, CI 0.62-13.03 respectively) and reflective of the crude odds. There was no meaningful difference in physical and daily living needs between women who consumed alcohol on five to seven days per week and women who consumed alcohol less than weekly. The odds of unmet physical and daily living needs in women who were aware of one or more support services were much times higher than for women who were unaware (OR 5.65, CI 0.91-35.21).

Similarly to the sexuality analysis of needs, the odds of unmet physical and daily living needs in women who lived in a moderate or moderately low socio-economic area appeared much lower relative to women who lived in a high or moderately high socio-economic areas (OR 0.34, CI 0.07-1.61 and OR 0.32, CI 0.07-1.43

respectively). The relationship of socio-economic status for areas with sexuality needs was tested for robustness in a building block model and proved plausible. Therefore, it is convincing that this similar relationship with physical and daily living needs exists.

TABLE 5.17 REMAINING NON-STATISTICALLY SIGNIFICANT BUT CLINICALLY IMPORTANT CORRELATES OF REPORTING "SOME NEED" IN THE PHYSICAL AND DAILY LIVING DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	**Crude OR (95% CI)**	**Adjusted [b] OR (95% CI)**	**p value**
Treatment centre				
Treatment hospital A	136	1.92 (1.12-3.29)	3.29 (0.77-14.14)	0.111
Treatment hospital B	99	Referent	Referent	
Treatment hospital C	86	0.96 (0.52-1.78)	1.36 (0.34-5.47)	
Other treatment hospitals	66	0.98 (0.50-1.91)	0.60 (0.11-3.21)	
Multi-treatment centres	85	1.61 (0.89-2.94)	0.54 (0.13-2.22)	
Last administration of treatment				
Within the last month	19	4.03 (1.51-10.76)	2.07 (0.21-20.17)	0.072
1-12 months ago	137	2.32 (1.47-3.66)	4.00 (0.74-21.61)	
1-2 years ago	91	1.84 (1.10-3.09)	3.05 (0.81-11.50)	
>2 years ago	191	Referent	Referent	
Disease presence				
Disease absent	403	Referent	Referent	0.061
Disease present	69	3.14 (1.85-5.33)	3.48 (0.94-12.82)	
Lymphoedema status				
No lower limb swelling	363	Referent	Referent	0.059
Lower limb swelling but not diagnosed	62	2.01 (1.17-3.45)	1.10 (0.31-3.95)	
Diagnosed lymphoedema	47	1.96 (1.07-3.62)	6.39 (1.39-29.48)	
Ever diagnosed with a physical or emotional illness				
No	157	Referent	Referent	0.056
Yes	315	1.48 (0.99-2.21)	2.56 (0.98-6.74)	
Menopausal status				
Pre/ peri menopausal	16	0.27 (0.06-1.20)	0.64 (0.02-19.89)	0.086 [a]
Post menopause	264	Referent	Referent	
Iatrogenic menopause	171	1.50 (1.01-2.22)	4.36 (1.11-17.14)	
Emotional wellbeing				
Lowest quartile	110	Referent	Referent	0.210
2nd quartile	145	0.28 (0.17-0.48)	0.31 (0.09-1.01)	
3rd quartile	81	0.22 (0.12-0.41)	0.45 (0.12-1.70)	
Highest quartile	136	0.09 (0.05-0.17)	0.27 (0.07-1.07)	
Alcohol consumption				
None	126	2.12 (1.08-4.16)	2.84 (0.62-13.03)	0.490
< weekly	179	1.65 (0.86-3.16)	1.54 (0.37-6.48)	
1-4 days / week	110	1.41 (0.70-2.83)	2.13 (0.48-9.50)	
5-7 days / week	57	Referent	Referent	
Awareness of at least 1 support service or organisation(excluding QCF, the project sponsor)				
Yes	402	2.99 (1.41-6.33)	5.65 (0.91-35.21)	0.064
No	48	Referent	Referent	
Socio-economic status for areas				
High SES	74	Referent	Referent	0.062
Moderately high SES	103	1.28 (0.69-2.35)	1.94 (0.48-7.92)	
Moderate SES	86	0.71 (0.37-1.37)	0.34 (0.07-1.61)	
Moderately low SES	148	0.94 (0.53-1.68)	0.32 (0.07-1.43)	
Low SES	61	1.49 (0.75-2.96)	1.29 (0.24-7.06)	

[a] significance value when missing category of this variable was removed from the model

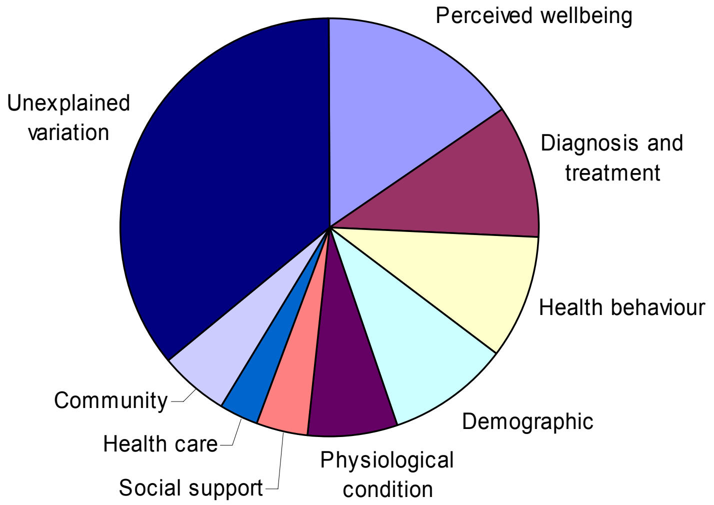
[b] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery,

chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.3.4 HEALTH SYSTEM AND INFORMATION NEEDS

5.2.3.4.1 VARIATION EXPLAINED

Factors included in the final model of health system and information needs explained 64% (Nagelkerke R Square = 0.638) of the variation. The perceived wellbeing construct had the most predictive value. These first five blocks, located within the personal level of influence, accounted for 57% of the variation when fitting a model with just these blocks, thus accounting for most of the explained variation.



The personal level of influence within the social-ecological model is made up of: personal wellbeing, diagnosis and treatment, physiological condition, health behaviour, and demographic characteristics.

Other levels of influence are presented as individual blocks

FIGURE 5.11 VARIATION IN HEALTH SYSTEM AND INFORMATION NEEDS EXPLAINED BY INDEPENDENT VARIABLES WITHIN THE FINAL MODEL (SCALED TO 100%), REFLECTING A SOCIAL-ECOLOGICAL THEORETICAL FRAMEWORK.

5.2.3.4.2 CORRELATES OF UNMET HEALTH SYSTEM AND INFORMATION NEEDS

Variables included in table 5.18 were both statistically and clinically associated with health system/ information needs. With the exception of “lymph nodes removed” and “hospitalisation since completing treatment for gynaecological cancer”, all these variables were also identified as clinically, and some statistically, significant at the bivariate level of analysis.

Relative to cervical cancer survivors, the odds of unmet health system and information needs in uterine, ovarian and "other" gynaecological cancer survivors were significantly higher (OR 6.14, CI 1.65-22.81, OR 5.62, CI 1.50-21.09, and OR 6.56, CI 1.27-33.80 respectively). The odds of unmet health system and information needs in women diagnosed with an early disease stage were higher than for women diagnosed with a late stage (OR 3.60, CI 1.15-11.31). The odds of unmet health system and information needs in women who had chemotherapy were higher than for women who had not had chemotherapy (OR 4.17, CI 1.43-12.19). The odds of unmet health system and information needs in women who had external radiotherapy were higher than for women who had not had radiotherapy (OR 4.35, CI 1.26-15.03). The odds of unmet health system and information needs in women who had lymph nodes removed were higher than for women who had not had lymph nodes removed (OR 3.38, CI 1.36-8.41).

The odds of unmet health system and information needs in, women whose disease was still present were considerably higher than for those whose disease was absent (OR 3.62, CI 1.24-10.52). Relative to women who had treatment more than 2 years ago, the odds of unmet health system and information needs in women who were administered treatment 1-12 months ago and women who were administered treatment 1-2 years ago were significantly higher (OR 5.71, CI 1.31-24.91, and OR 4.10, CI 1.33-12.63 respectively). The odds of unmet health system and information needs in women who had not been hospitalised since completing treatment for gynaecological cancer were higher than for women who had been hospitalised (OR 3.57, CI 1.46-8.74). There was a negative linear relationship of higher emotional wellbeing with decreasing health system/ information needs.

TABLE 5.18 STATISTICALLY AND CLINICALLY SIGNIFICANT CORRELATES OF REPORTING "SOME NEED" IN THE HEALTH SYSTEM/ INFORMATION DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [c] OR (95% CI)	p value
Type of gynaecological Cancer				
Cervical	116	Referent	Referent	0.026
Uterine	126	0.73 (0.44-1.22)	6.14 (1.65-22.81)	
Ovarian	136	0.93 (0.56-1.52)	5.62 (1.50-21.09)	
Other	55	0.84 (0.44-1.60)	6.56 (1.27-33.80)	
Stage				
Early stage	307	0.78 (0.50-1.21)	3.60 (1.15-11.31)	0.014 [a]
Late stage	108	Referent	Referent	
Chemotherapy				
Yes	166	2.05 (1.39-3.03)	4.17 (1.43-12.19)	0.009
No	267	Referent	Referent	

	N	Crude OR (95% CI)	Adjusted [c] OR (95% CI)	p value
Radiotherapy				
No radium	330	Referent	Referent	0.027
Internal brachytherapy	16	0.97 (0.34-2.83)	0.24 (0.02-2.76)	
External radium beam therapy ± brachytherapy	87	2.01 (1.26-3.20)	4.35 (1.26-15.03)	
Lymph nodes removed				
No	230	Referent	Referent	0.009
Yes	203	1.65 (1.12-2.42)	3.38 (1.36-8.41)	
Disease presence				
Disease absent	369	Referent	Referent	0.018
Disease present	64	2.47 (1.48-4.14)	3.62 (1.24-10.52)	
Last administration of treatment				
Within the last month	16	3.27 (1.25-8.50)	0.98 (0.10-10.18)	0.030
1-12 months ago	124	2.19 (1.37-3.50)	5.71 (1.31-24.91)	
1-2 years ago	85	1.69 (1.00-2.88)	4.10 (1.33-12.63)	
>2 years ago	178	Referent	Referent	
Hospitalisation since completing treatment for gynaecological cancer				
No	335	1.16 (0.73-1.83)	3.57 (1.46-8.74)	0.001
Yes	98	Referent	Referent	
Emotional wellbeing				
Lowest quartile	97	12.02 (6.35-22.74)	32.59 (7.89-134.55)	0.001 [b]
2nd quartile	135	3.73 (2.02-6.87)	4.70 (1.50-14.72)	
3rd quartile	76	2.03 (0.99-4.17)	2.19 (0.64-7.51)	
Highest quartile	125	Referent	Referent	

[a] significance value when missing category of this variable was removed from the model

[b] significance value when the variable is treated as continuous and fitted as a linear trend

[c] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

A number of other subgroup comparisons within variables in the following table were considered clinically important. Relative to women aged 18-39, the odds of unmet health system and information needs in women who were aged 50-59 and 60-69 were substantially lower (OR 0.17, CI 0.04-0.72 and OR 0.34, CI 0.06-2.04 respectively). As indicated in figure 5.12, the odds in these two groups were consistently below 0.5 and hence these subgroup differences are plausible.

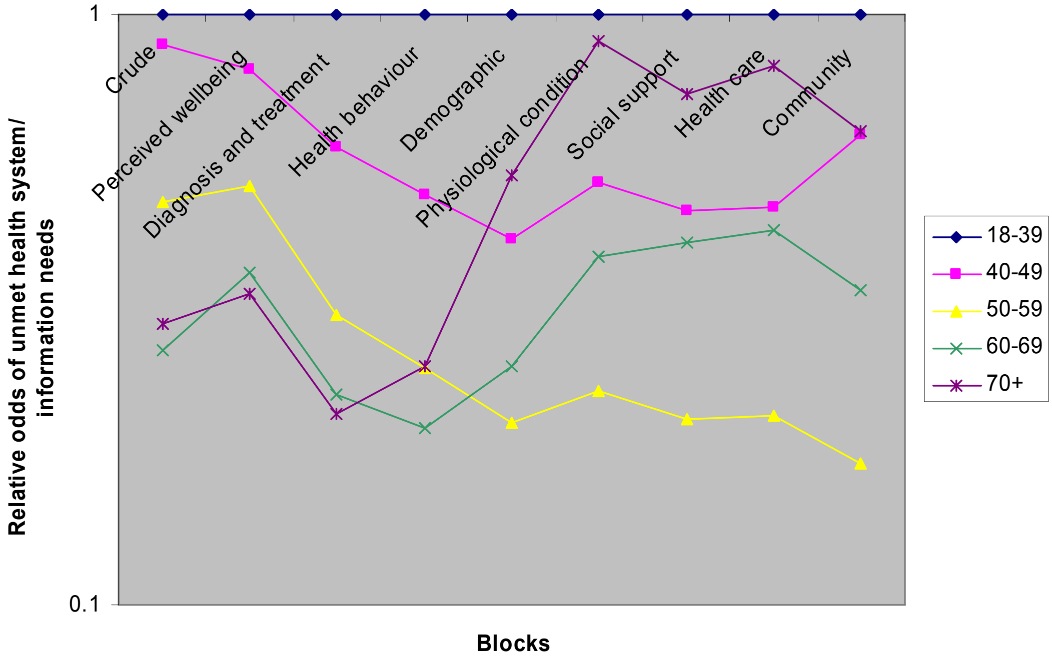


FIGURE 5.12 HEALTH SYSTEM AND INFORMATION NEEDS BY AGE AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

The odds of unmet health system and information needs for women who were unable to work due to illness were higher than for all other employment categories (relative to women who perform home duties OR 5.41, CI 1.13-25.92). A weak negative linear relationship of higher physical wellbeing with decreasing unmet health system and information needs existed.

The odds of unmet health system and information needs in women who lived in other metropolitan centres of Queensland relative to the capital city were possibly lower (OR 0.48, CI 0.12-1.89). Figure 5.13 indicated that after the addition of the fifth block, the odds ratio was less than 0.5 with a reasonable confidence interval at that point (OR 0.47, CI 0.14-1.36). Therefore, this subgroup difference is likely. There was no meaningful difference in the odds of unmet health system and information needs in women living in the capital city or in rural and remote regions of Queensland.

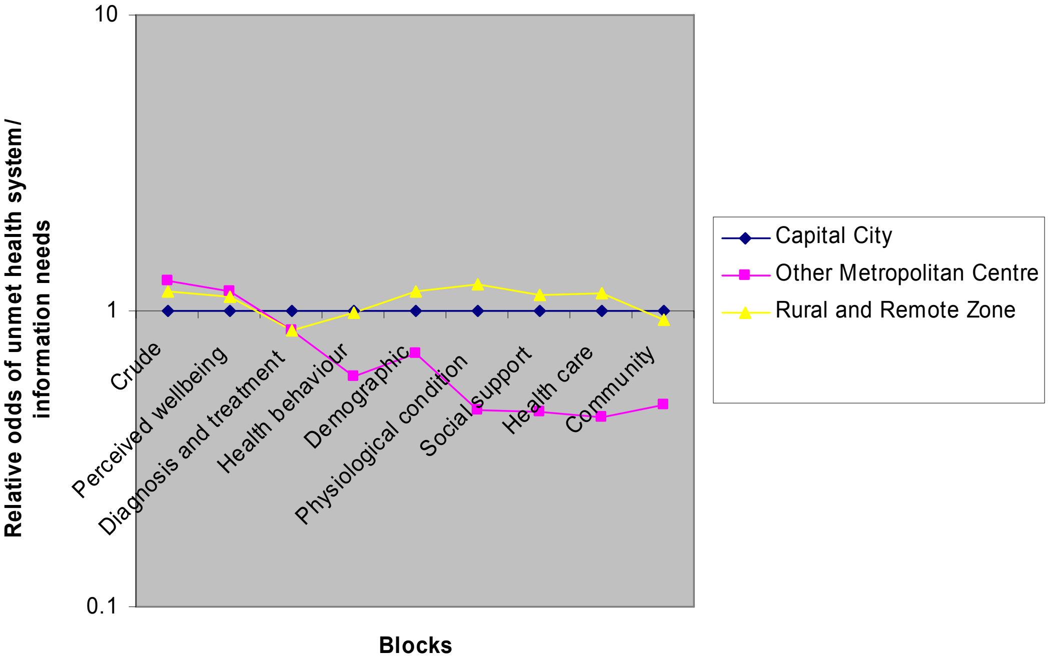


FIGURE 5.13 HEALTH SYSTEM AND INFORMATION NEEDS BY RURAL, REMOTE OR METROPOLITAN AREA AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

Relative to women who lived in high socio-economic areas, the odds of unmet health system and information needs in women who lived in moderately high and moderate socio-economic areas were substantially lower (OR 0.36, CI 0.10-1.37 and OR 0.50, CI 0.13-1.91 respectively). However, there was no meaningful difference in the odds of unmet health system and information needs in women who lived in high and moderately low socio-economic areas. The low number of cases in the low socio-economic area rendered this subgroup unable to be considered with confidence.

TABLE 5.19 REMAINING NON-STATISTICALLY SIGNIFICANT BUT CLINICALLY IMPORTANT CORRELATES OF REPORTING "SOME NEED" IN THE HEALTH SYSTEM/ INFORMATION DOMAIN (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted ^{c} OR (95% CI)	p value
Age (years)				
18-39	54	Referent	Referent	0.056
40-49	76	0.89 (0.46-1.71)	0.63 (0.18-2.17)	
50-59	139	0.48 (0.26-0.87)	0.17 (0.04-0.72)	
60-69	112	0.27 (0.14-0.53)	0.34 (0.06-2.04)	
70+	52	0.30 (0.13-0.65)	0.63 (0.08-4.99)	
Employment type				
Paid full- time	87	1.42 (0.84-2.41)	1.03 (0.28-3.73)	0.100
Paid part time or casual	88	1.46 (0.86-2.50)	1.83 (0.54-6.17)	
Home duties	70	Referent	Referent	
Retired	114	0.70 (0.42-1.17)	0.50 (0.15-1.60)	
Unable to work because of illness	40	3.66 (1.95-6.87)	5.41 (1.13-25.92)	
Other	34	1.39 (0.72-2.69)	1.52 (0.36-6.42)	

	N	Crude OR (95% CI)	Adjusted [c] OR (95% CI)	p value
Physical wellbeing				
Lowest quartile	119	9.25 (4.63-18.51)	2.49 (0.69-9.03)	0.134 [b]
2nd quartile	90	5.49 (2.67-11.29)	2.23 (0.71-7.02)	
3rd quartile	126	2.19 (1.07-4.49)	1.51 (0.51-4.51)	
Highest quartile	98	Referent	Referent	
Rural Remote and Metropolitan Area Classification				
Capital City	206	Referent	Referent	0.813 [a]
Other Metropolitan Centre	60	0.92 (0.50-1.69)	0.48 (0.12-1.89)	
Rural and Remote Zone	128	1.12 (0.72-1.74)	0.93 (0.27-3.14)	
Socio-economic status for areas				
High SES	69	Referent	Referent	0.175
Moderately high SES	96	0.57 (0.31-1.08)	0.36 (0.10-1.37)	
Moderate SES	83	0.78 (0.41-1.47)	0.50 (0.13-1.91)	
Moderately low SES	134	0.89 (0.51-1.58)	0.74 (0.20-2.70)	
Low SES	51	0.88 (0.44-1.77)	1.10 (0.27-4.57)	

[a] significance value when missing category of this variable was removed from the model

[b] significance value when the variable is treated as continuous and fitted as a linear trend

[c] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, service or organisation use, complementary therapy support, service or organisation awareness, provider referral, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.2.3.5 *SUMMARY OF CORRELATES ACROSS MULTIPLE SUPPORTIVE CARE DOMAINS*

As indicated in the literature review (section 2.6.4), many support services offer multiple types of support and for this reason it was worth considering correlates that indicated particular groups of gynaecological cancer survivors that had multi-dimensional unmet needs. Groups identified with higher odds of reporting ‘some’ unmet needs across multiple supportive care domains, relative to their corresponding comparison group, included: Survivors born in another country, survivors in paid work or unable to work due to illness, survivors who were diagnosed with a gynaecological cancer other than cervical, survivors diagnosed with early stage disease, survivors who had open surgery, survivors who had chemotherapy, survivors more recently administered cancer treatment, survivors whose disease was still present, survivors with diagnosed lymphoedema, survivors who experienced treatment related menopause, survivors with lower emotional and physical wellbeing, service users, survivors aware of support services and, survivors who live outside the capital city. These correlates mainly fell within the personal level of the social-ecological model, but also include the health care and community levels of influence.

5.2.3.6 EFFECT MODIFICATION BY CANCER TYPE OR SURVIVAL PHASE

At the bivariate level of analysis, unmet needs were different across a number of variables' categories when stratified by types of gynaecological cancer and survival phase post-diagnosis (see appendix 16). Effect modification was further explored at the multivariable level of analysis, with limited power. Only one interaction term was able to be entered into the model at a time, and even then subgroup estimates became unstable with very wide confidence intervals due to limited cases in some categories. A number of relationships were modified by type of cancer and survival phase post-diagnosis. Statistical significance was noted for these; however, precision of the estimates were indistinct for most, with overlapping confidence intervals. Thus it was difficult to discern if the results were real or just a statistical finding due to an over-specified model.

Two scenarios with stronger and consistent effect modification trends emerged from this analysis. Firstly, for cervical cancer survivors who had chemotherapy, radiotherapy or who were not in remission, the odds of unmet psychological needs were significantly higher than for respectively cervical cancer survivors who had no chemotherapy, no radiotherapy or who were in remission. In contrast, the odds of unmet psychological needs among all other gynaecological cancer survivors who had adjunctive treatments or who were not in remission, were not associated with significantly higher unmet psychological needs. To describe this cluster of women with disease severity more, a new variable was created, which combined women who had chemotherapy and radiotherapy or women who were not in remission. The outcome of this new variables' relationship with psychological needs, stratified by type of cancer, presents a similar conclusion to the three initial stratified relationships, with narrower confidence intervals (see figure 5.14). The final model, including 479 cases, had 32% of women in this disease severity subgroup. Reasonable numbers of such cases were within each cancer type, and hence this was likely to be a plausible conclusion.

To determine if the characteristics of cervical cancer survivors in this subgroup were different from all other gynaecological cancer survivors in this subgroup, bivariate crosstabulation by key variables was conducted. Results showed that in the cervical cancer subgroup relative to all other gynaecological cancer survivors, there were proportionately more women above 50 years of age, more women within their first twelve months post-treatment, more women who had been diagnosed with other physical and emotional illnesses, and more women who lived outside the capital city.

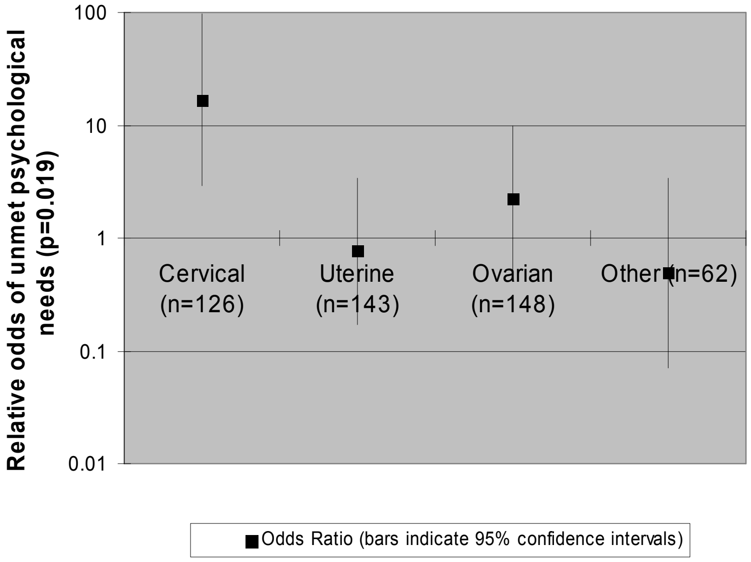


FIGURE 5.14 THE RELATIVE ODDS OF PSYCHOLOGICAL NEEDS AMONGST WOMEN WHO HAD EXTENSIVE TREATMENT/DISEASE COMPARED TO WOMEN WHO DID NOT, STRATIFIED BY TYPE OF GYNAECOLOGICAL CANCER (MULTIVARIABLE MODEL). ODDS SCALE IS LOGARITHMIC.

The second trend observed within the effect modification analysis was that for cervical cancer survivors, lymphoedema status was not associated with higher unmet needs whereas, for all other gynaecological cancer survivors, unmet needs were mainly higher across multiple supportive care needs domains for women who had lymphoedema or undiagnosed swelling relative to women who had no lower limb swelling (see figure 5.15).

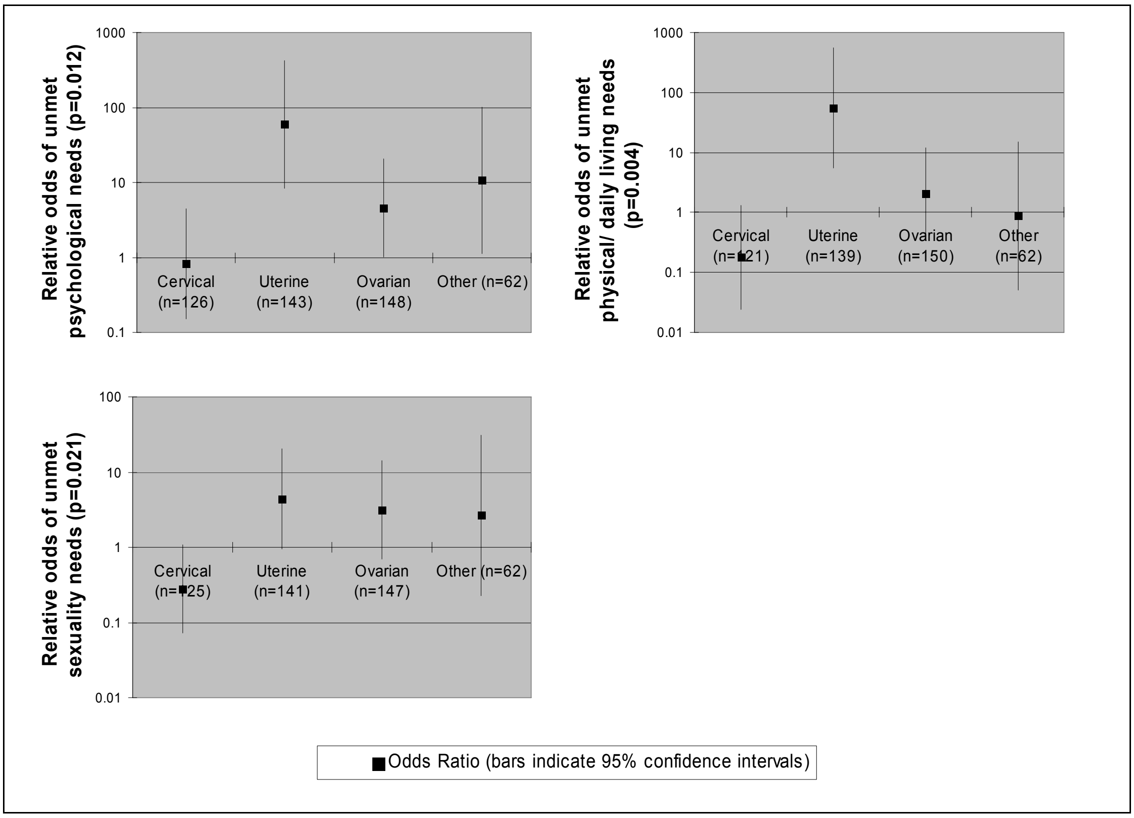


FIGURE 5.15 THE RELATIVE ODDS OF UNMET PSYCHOLOGICAL, PHYSICAL/DAILY LIVING AND SEXUALITY NEEDS AMONGST WOMEN WHO HAD LYMPHOEDEMA OR UNDIAGNOSED SWELLING COMPARED TO WOMEN WHO HAD NO LOWER LIMB SWELLING, STRATIFIED BY TYPE OF GYNAECOLOGICAL CANCER (MULTIVARIABLE MODEL). ODDS SCALE IS LOGARITHMIC.

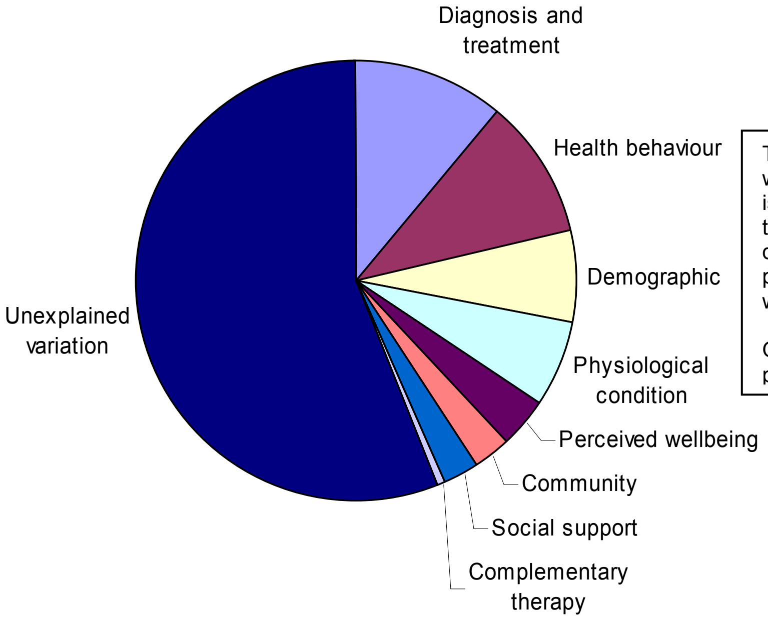
5.3 CORRELATES OF SUPPORT SERVICE USE

The focus of this study was to assess unmet needs of cancer survivors so that health services and health care professionals can tailor their initiatives and resources to those groups of survivors who require them. In addition, it was considered useful to consider the correlates of service use to determine the profile of service users and whether the groups of women with higher odds of unmet needs were also the groups of women who were less or more likely to use services.

The analysis of correlates of service use was conducted in the same way as the supportive care needs analysis. Almost all the same social-ecological correlates, plus the addition of unmet psychological, sexuality, physical/ daily living, health system/ information, and patient care/ support needs as correlates of service use, were considered at bivariate and multivariable levels of analysis. The exception of two variables, “service awareness” and “service referral”, from the multivariable analysis was made, as they were so highly correlated with service use. The bivariate analysis showed that of those women who were aware of support services, 67% used at least one, and obviously, women who were not aware of any support services did not use them. Furthermore, of the women who received a referral, 86% used a service. As the profile of services users was a secondary consideration to needs, only the adjusted multivariable results are presented within this thesis from here in. Crude results can be view in appendix 17.

5.3.1 VARIATION EXPLAINED

Factors included in the final support service use model explained 44% (Nagelkerke R Square = 0.439) of the variation. Figure 5.10 presents the relative contribution to variation explained by each block of factors within the social-ecological model, standardised to 100%. Within the social-ecological model, six blocks make up the personal level of influence service use. One of these blocks, "support needs", did not account for any variation. However, the remaining five blocks in the personal level of influence accounted for 40% of the variation. Social support, complementary therapy support and community levels of influence accounted for negligible variation.



The personal level of influence within the social-ecological model is made up of: diagnosis and treatment, health behaviours, demographic characteristics, physiological condition, personal wellbeing and support needs.

Other levels of influence are presented as individual blocks

FIGURE 5.16 VARIATION IN SUPPORT SERVICE USE EXPLAINED BY INDEPENDENT VARIABLES WITHIN THE FINAL MODEL (SCALED TO 100%), REFLECTING A SOCIAL-ECOLOGICAL THEORETICAL FRAMEWORK.

5.3.2 ADJUSTED CORRELATES OF SERVICE USE

Table 5.20 outlines correlates of service use determined to have robust estimates of odds ratios and confidence intervals. Of these variables, most indicate that the association with service use was evident in both the crude and fully adjusted models. However, remission status and BMI showed a significant association with service use in the adjusted model and no association in the crude models.

Age and employment type were identified as potential correlates. However, due to wide confidence intervals and limited cases within categories, it was necessary to conduct further analyses to verify that final odds ratios were imprecise but stable. Figure 5.17 indicated that while age lost its linear relationship with service use after the first few blocks of variables were added, women aged 18-59 consistently maintained higher odds of service use with the addition of each block of variables, with reasonably precise confidence intervals right up until the addition of the second last block (*i.e.* up to complementary therapy support). Therefore, the conclusion was declared with confidence. That is, the odds of using a support service amongst women aged 18-59 were substantially higher than the odds for women aged 70 years or more.

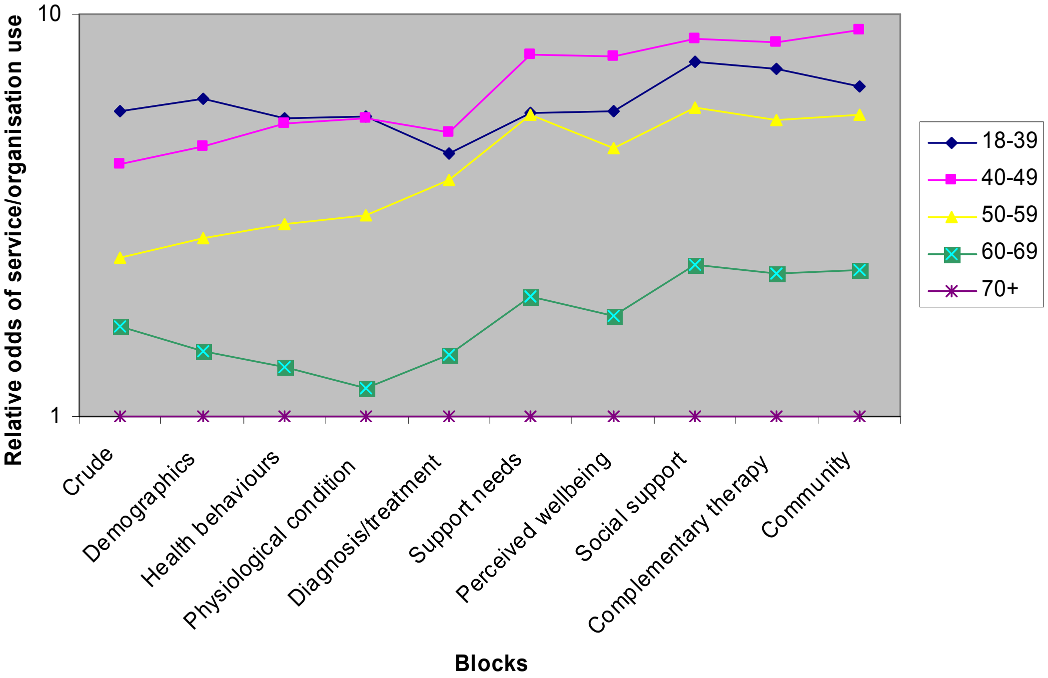


FIGURE 5.17 SUPPORT SERVICE/ ORGANISATION USE BY AGE GROUP AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

As is illustrated in figure 5.18, from the addition of block five, the odds of using a support service amongst retired women were substantially higher than for working women. When only five blocks were included, the confidence intervals were reasonably precise. After this, the point estimate remains above two with wider confidence intervals and hence, the conclusions of this relationship were declared with confidence. Women who were unable to work due to illness also had a point estimate that was significantly different from working women however, cases were limited in this group and the precision of the estimates were not convincing.

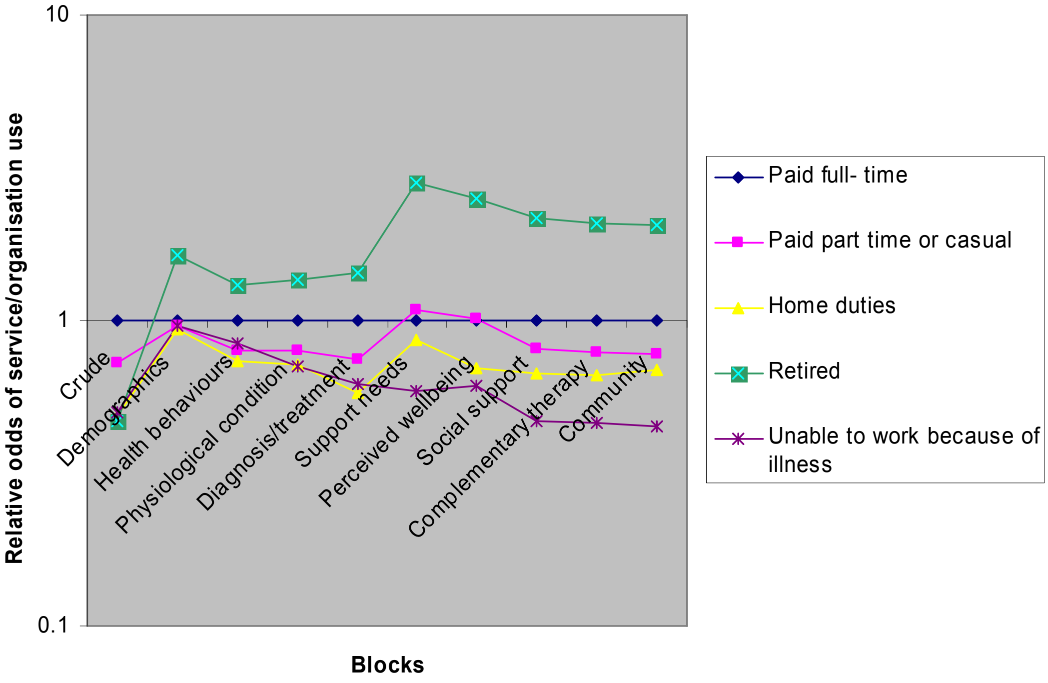


FIGURE 5.18 SUPPORT SERVICE/ ORGANISATION USE BY EMPLOYMENT AT CRUDE THEN WITH CUMULATIVE BLOCKS ADDED UNTIL FINAL ADJUSTMENT WHICH IS AT THE COMMUNITY BLOCK

Relative to uterine cancer survivors, the odds of using a support service amongst all other gynaecological cancer survivors were substantially higher (OR 2.24, CI 0.84-6.00, OR 3.16, CI 1.12-8.94 and OR 3.22, CI 1.03-10.07). The odds of using a support service amongst women who had an open bowel resection were significantly higher than for women who had open abdominal surgery or vaginal or laparoscopic surgery (OR 4.15, CI 0.92-18.82). Although cases were limited within the subgroup that had an open bowel resection, the confidence interval was reasonably precise and also the crude relationship supported this conclusion. Hence this conclusion was plausible.

Relative to women in treatment centre A, B or C, the odds of using a support service amongst survivors who attended multiple treatment centres were considerably higher (relative to treatment centre A: OR 4.03, CI 1.42-11.41). Relative to gynaecological cancer survivors not in remission, the odds of using a support service amongst survivors in remission were considerably higher (OR 3.60, CI 1.57-8.25). The odds of using a support service amongst obese gynaecological cancer survivors were significantly higher than for survivors in the normal and overweight body mass index subgroups (relative to normal class: OR 2.97, CI 1.26-6.97).

TABLE 5.20 CORRELATES OF REPORTING SERVICE USE SINCE CANCER DIAGNOSIS (FINAL MAIN EFFECTS MODEL)

	N	Crude OR (95% CI)	Adjusted [b] OR (95% CI)	p value
Age (years)				
18-39	60	3.29 (1.44-7.49)	6.61 (1.10-39.92)	0.098
40-49	79	2.95 (1.38-6.31)	9.16 (1.70-49.29)	
50-59	133	1.56 (0.80-3.03)	5.62 (1.49-21.21)	
60-69	105	1.23 (0.62-2.45)	2.32 (0.77-7.04)	
70+	48	Referent	Referent	
Employment type				
Paid full- time	83	Referent	Referent	0.221
Paid part time or casual	93	0.82 (0.44-1.55)	0.78 (0.30-2.04)	
Home duties	70	0.61 (0.31-1.19)	0.69 (0.23-2.12)	
Retired	110	0.73 (0.40-1.33)	2.05 (0.66-6.34)	
Unable to work because of illness	35	0.58 (0.25-1.30)	0.45 (0.11-1.78)	
Other	34	0.55 (0.24-1.24)	1.06 (0.31-3.65)	
Type of gynaecological Cancer				
Cervical	116	2.51 (1.48-4.29)	2.24 (0.84-6.00)	0.097
Uterine	121	Referent	Referent	
Ovarian	135	2.49 (1.49-4.15)	3.16 (1.12-8.94)	
Other	53	2.11 (1.08-4.13)	3.22 (1.03-10.07)	
Surgery				
None	7	0.81 (0.18-3.69)	0.37 (0.04-3.69)	0.193
Vaginal or laparoscopic	53	0.74 (0.41-1.32)	0.68 (0.23-1.98)	
Open abdominal	325	Referent	Referent	
Open bowel resection	40	2.87 (1.23-6.69)	4.15 (0.92-18.82)	
Treatment centre				
Treatment hospital A	125	Referent	Referent	0.046 [a]
Treatment hospital B	90	1.06 (0.61-1.85)	1.38 (0.47-4.11)	
Treatment hospital C	75	0.82 (0.46-1.47)	0.95 (0.37-2.44)	
Other hospitals	54	1.01 (0.53-1.95)	0.91 (0.31-2.67)	
Multi-treatment centres	78	2.00 (1.07-3.76)	4.03 (1.42-11.41)	
Remission				
Yes	324	1.23 (0.78-1.94)	3.60 (1.57-8.25)	0.003
No/don't know	101	Referent	Referent	
Body Mass Index				
Underweight	11	0.59 (0.17-2.03)	1.77 (0.26-12.23)	0.002 [a]
Normal weight	131	Referent	Referent	
Overweight	116	0.60 (0.36-1.01)	0.66 (0.31-1.39)	
Obese	126	1.01 (0.60-1.71)	2.97 (1.26-6.97)	

[a] significance value when missing category of this variable was removed from the model

[b] all variables mutually adjusted for age, marital status, education levels, employment status, household income, country of origin, children living at home, cancer type, survival phase, stage, treatment centre, insurance, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed, last admission for treatment, remission status, disease presence, lymphedema status, stoma status, hospitalised since completing treatment for gynaecological cancer, ever diagnosed with a physical or emotional illness, menopausal status, HRT, sexual activity, physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, spiritual wellbeing,

psychological needs, sexuality needs, physical/ daily living needs, patient care/ support needs, health system/ information needs, alcohol consumption, smoking, physical activity, vegetable intake, fruit intake, BMI, social support, complementary therapy support, geographic location, Accessibility/Remoteness Index of Australia (ARIA), Rural Remote and Metropolitan Area Classification (RRMA), and Socio-Economic Indexes of Areas (SEIFA).
Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

5.3.3 EFFECT MODIFICATION BY TYPE OF CANCER

Effect modification by type of cancer was found to be statistically significant of the relationship of services use to chemotherapy and physical/ daily living needs at the multivariable level of analysis. These were the only relationships with statistical support for a difference across groups and hence were the only relationships explored further with subgroup estimates and confidence intervals being calculated. Other non-significant possible modification by cancer type was likely to have severely overlapping confidence intervals and thus lack plausible conclusions.

When considering the relationship of physical/ daily living needs with service use, stratified by cancer type, there was a distinct difference between cervical and uterine cancer survivors (see figure 5.19). For uterine cancer survivors, the odds of service use were higher in women who had unmet physical and daily living needs compared to uterine cancer survivors with no unmet physical and daily living needs, whereas for cervical cancer survivors, the opposite effect was observed. For ovarian gynaecological cancer survivors less distinguishable differences were observed in service use by physical and daily needs. The “other” gynaecological cancer subgroup was not considered in either of these comparisons due to exorbitantly wide confidence intervals.

Due to very few women diagnosed with uterine cancer having chemotherapy, this subgroup was not possible to consider in the stratification of type of cancer, of the relationship of service use with chemotherapy. For ovarian cancer survivors, the odds of service use were higher in women who had chemotherapy compared to ovarian cancer survivors who did not have chemotherapy. The opposite effect was observed within the cervical cancer subgroup.

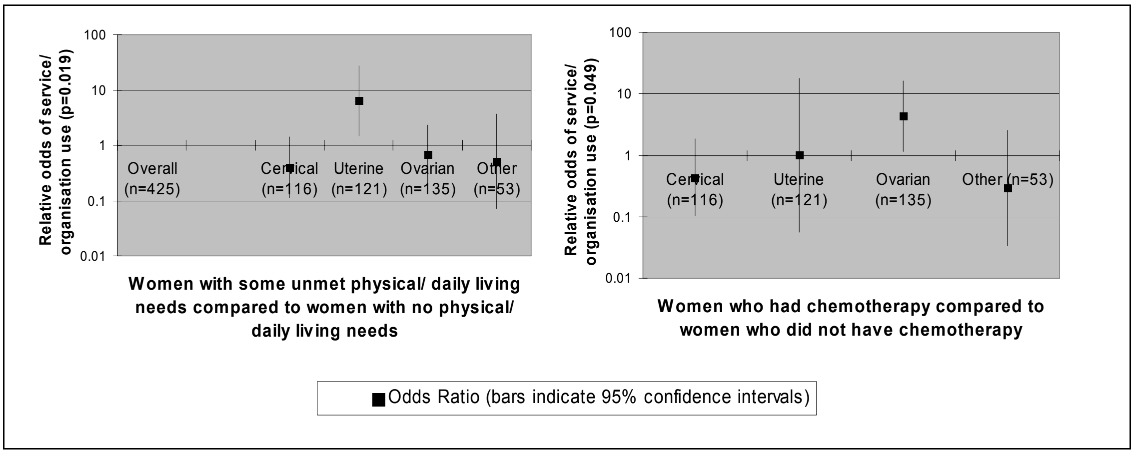


FIGURE 5.19 CORRELATES OF SUPPORT SERVICE OR ORGANISATION USE STRATIFIED BY TYPE OF GYNAECOLOGICAL CANCER (MULTIVARIABLE MODEL). ODDS SCALE IS LOGARITHMIC.

5.4 MISSING VALUES SENSITIVITY ANALYSIS

Due to missing data attrition in the multivariable models, the adjusted results of supportive care needs and service use were not completely representative of all survey participants. As each of the supportive care needs models contained the same independent variables, thus the same cases were dropped within each needs model, under or over representation was almost exactly the same for each needs domain when comparing missing data with complete data. Therefore, the following missing values analysis was applied to one needs domain (psychological needs) and is inferential to all other needs domains.

Results showed that the models included more younger women, more educated women, more employed women, more women who experienced iatrogenic menopause, more women who had HRT in the past three months, more women with higher levels of social support and more women who were aware of at least one support service or organisation (see table 5.21). Results of the multivariable models are reflective of these over-represented subgroups.

A similar sensitivity analysis was carried out for the service use model. As almost the same independent variables were included in the service use mode, the same patterns of representativeness were observed. The exception of course was that service awareness was not included in the multivariable service use model and therefore was not considered in the sensitivity analysis.

TABLE 5.21 COMPARISON OF WOMEN WHO WERE INCLUDED IN THE FINAL USE MULTIVARIABLE MODEL WITH THOSE WHO HAD MISSING DATA FOR AT LEASE ONE ITEM (PSYCHOLOGICAL NEEDS MODEL EXAMPLE).

Characteristics	Complete Data		Missing Data	
	N	%	N	%
Age (years)				
18-39	62	12.9	15	4.6
40-49	83	17.3	51	15.8
50-59	148	30.9	68	21.1
60-69	126	26.3	95	29.4
70+	60	12.5	94	29.1
Employment type				
Paid full- time	93	19.4	46	14.2
Paid part time or casual	97	20.3	35	10.8
Home duties	79	16.5	52	16.1
Retired	127	26.5	120	37.2
Unable to work because of illness	45	9.4	29	9.0
Other	38	7.9	24	7.4
Missing			17	5.3
Menopausal status				
Pre/ peri menopausal	15	3.1	18	5.6
Post menopause	269	56.2	176	54.5
Iatrogenic menopause	173	36.1	59	18.3
missing	22	4.6	70	21.7
HRT in the 3 past months				
Yes	105	21.9	35	10.8
No	374	78.1	259	80.2
Missing			29	9.0
Social support				
Lowest quartile	119	24.8	55	17.0
2nd quartile	113	23.6	53	16.4
3rd quartile	90	18.8	32	9.9
Highest quartile	157	32.8	77	23.8
Missing			106	32.8
Awareness of at least 1 support service or organisation(excluding QCF)				
Yes	409	85.4	200	61.9
No	47	9.8	56	17.3
Missing	23	4.8	67	20.7

5.5 RELATIONSHIP OF SUPPORTIVE CARE NEEDS TO QUALITY OF LIFE

In addition to the main research questions, this study also considered the relationship of supportive care needs to quality of life with a view to informing the discussion. Supportive care needs and quality of life have been considered conceptually similar within the literature. As was indicated earlier in Table 5.7 (Associations between quality of life variables and reporting “some need” within each of the supportive care domains – bivariate analysis), that median physical, social/ family, emotional, functional and spiritual wellbeing scores were significantly lower in those women who reported having any need for help compared with those who reported no unmet needs. This association was evident across all of the supportive care needs domains and was considered clinically and statistically significant.

A further analysis was conducted looking at the association between overall quality of life with each of the supportive care domains and showed (see figure 5.20) that approximately 75% of the distribution of women who reported no psychological, physical/daily living and patient care/ support needs was exclusively the women who reported having a higher quality of life than the women with some psychological, physical/daily living and patient care/ support needs. There was some additional overlap between women who reported some or no sexuality and health system/ information needs however, most women who had no sexuality and health system/ information needs reported a higher quality of life than those who had needs. Across all needs domains, medians were clinically and statistically significantly lower in those women who reported having a need for help compared with those who had no unmet needs. Hence, while it is likely that correlates of supportive care needs and quality of life are similar, they are unlikely to be completely so. It is beyond the scope of this thesis to examine all the correlates of quality of life in addition to all the correlates of each supportive care needs domain, but this section helps interpretation.

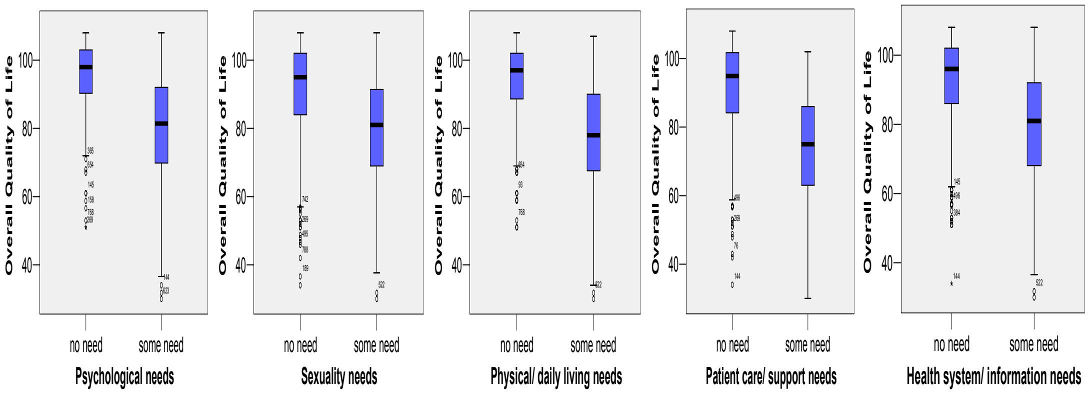


FIGURE 5.20 THE ASSOCIATION BETWEEN SUPPORTIVE CANCER NEEDS AND QUALITY OF LIFE

5.6 SUPPORTIVE CARE NEEDS DISCUSSION

5.6.1 PREVALENCE OF UNMET NEEDS

The prevalence of unmet need items reported by participants in this study were considerably lower than those reported by most other Australian studies for which highest moderate or high need items were between 34%-49% (Foot & Sanson-Fisher, 1995; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001; Aranda *et al*, 2005) compared with 17% in this study. The difference in prevalence of reported unmet needs between this study and the earlier studies is possibly due to the improved quality of care and health information since the other studies were conducted, or the particular cancer groups being studied. However, this is unlikely to explain such a large reduction of prevalence in these findings. Furthermore, there were a few Australian studies that reported similar levels of unmet need items (17% and 22% respectively) that were conducted five years prior to this study (Bonevski *et al*, 1999; Newell *et al*, 1999).

Sampling in Girgis *et al*'s (2000) study who had higher levels of needs, was conducted similarly to this study, where patients were between three months and six years post-diagnosis and randomly selected *via* a registry. Other studies with higher levels of needs selected outpatients attending treatment centres (Foot & Sanson-Fisher, 1995; Sanson-Fisher *et al*, 2000; Aranda *et al*, 2005) or cancer self-help groups (Steginga *et al*, 2001). The latter two methods of sample selection may lend towards higher needs as patients in the treatment phase are different from patients post-treatment and patients attending self-help groups have acknowledged their needs by seeking help. Girgis *et al*'s (2000) study may have found an inflated level of unmet needs compared to this study, due to it's location in a different state (New South Wales) and the variation in provision of support services between New South Wales and Queensland, inclusion of survivors from a distinct cancer type (breast) or the use of an earlier version of the survey that did not anchor the need for help to a specific time period. This study's survey instrument was revised to assess perceived needs in the last month. The two studies that had a similar prevalence of needs also possessed the same differences in sampling, location, and cancer types from this study as the studies with inflated levels of unmet needs did. That is, they were conducted in New South Wales with outpatients diagnosed with a non-gynaecological cancer. Hence, it is difficult to determine if the generally lower prevalence of reported unmet need items by Queensland gynaecological cancer survivors is a product of the study design, location, cancer type or all of the above.

We can however reasonably compare the highest ranking need items between studies. In this study the top three unmet need items related to the psychological domain. Similarly, in Sanson-Fisher *et al*'s (2000) study which included a mix of cancer types and in Aranda *et al*'s (2005) breast cancer study, psychological need items were predominant. However, other studies primarily ranked information need items highest (Foot & Sanson-Fisher, 1995; Bonevski *et al*, 1999; Girgis *et al*, 2000) or physical needs highest (Newell *et al*, 1999). Apart from this study Steginga *et al*'s (2001) study was the only other Australian research to report sexuality needs in the top ten ranked need items. This was mainly because only a few other Australian studies (Sanson-Fisher *et al*, 2000; Aranda *et al*, 2005) have utilised the newer adapted supportive care needs measure which includes the sexuality domain. However, it may also be because Steginga *et al*'s (2001) study is the only other genital-cancer based study of needs.

5.6.2 CORRELATES OF UNMET NEEDS WITHIN A SOCIAL-ECOLOGICAL FRAMEWORK

To identify target groups with higher odds of unmet needs and thus direct service providers to focus their resources appropriately, this study considered multiple factors within a social-ecological framework that potentially influenced the reporting of unmet supportive care needs. The social-ecological model is a more extensive framework of levels of influence on needs than has been considered in previous research. Other supportive care needs research has limited their consideration of correlates to disease and treatment variables and patients age, gender and marital status and in some cases geographical location. The social-ecological model considers factors beyond the biomedical approach that has been used to date, which are particularly important to cancer survivors who are past the treatment phase and assimilating back into a life within a community. Factors such as current physiological condition and wellbeing, health behaviours, social support, use of complementary therapy support, community support service awareness, referral and use and some additional treatment and demographic characteristics, were included within the framework of this study's needs analysis.

Considering a more holistic picture of factors that influence a person's needs enables the explanation of more variation within the statistical modelling, thus teasing out a more sophisticated adjustment of which factors were associated with higher odds of unmet needs. The use of the social-ecological framework within this study explained between 53-74% of the variation across the supportive care needs domains, demonstrating that this framework captured an appropriate range of factors associated with reporting unmet needs. Still, this is not a predictive model as we are only 53-74% sure that a women with the characteristics within this model will have the outcome we predict. There were a few factors within the social-ecological model that were beyond measurement within this study, that may explain more variation including: spiritual beliefs, pharmaceutical support, particular care delivery professionals, exercise programs, special devices and media/policy and cultural influences on needs. Future studies may wish to include these factors. However, with such a specified model, huge sample sizes are required otherwise, precision and robustness of the final estimates are an issue that requires careful consideration to ensure the final conclusions are credible and not just a random statistical finding due to an over-specified model. Confirmation of credible estimates, in this study was done by building the statistical model one block of similar variables after another, in the order of personal, social support, health care and then community factors, similarly to the levels of influence within the social-ecological framework.

5.6.3 DEMOGRAPHIC CHARACTERISTIC ASSOCIATED WITH UNMET NEEDS

Multivariable modelling revealed that several demographic characteristics were associated with gynaecological cancer survivors reporting some unmet need within supportive care domains examined. These included age, marital status, country of origin, children living in the home and type of employment. Unmet sexuality needs decreased with age, whereas, it was survivors aged 60 and older who had higher odds of reporting physical and daily living needs compared with those younger than 60. Age had a similar relationship with sexuality needs in other research (Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001) but was not found to be important in other research when considering physical and daily living needs (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001; Aranda *et al*, 2005). While the women in some age brackets did have two fold higher odds of unmet psychological and health system/information needs, than for women in other age brackets in this study, no meaningful relationship of age with these needs domains was concluded. In contrast, some other needs research identified age as a correlate of psychological needs (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-

Fisher *et al*, 2000) and health system/information (Sanson-Fisher *et al*, 2000) needs, with generally higher odds of reporting needs in younger groups.

Women living with a partner had higher odds of reporting sexuality needs compared to women in other marital subgroups. Marital status was not significantly associated with any supportive care needs domains in other research (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001; Aranda *et al*, 2005).

Differences in identified correlates of needs between studies is likely to be in part due to the same factors discussed above in section 5.6.1, which explained the differences in level of perceived needs (*i.e.* study design, location and cancer type). In addition, part of the difference is probably due to the inclusion of varying factors within the statistical model, which affects the amount of adjustment of correlations between independent variables included. Most other needs studies adjusted for some demographic, disease and treatment variables whereas, this study included a broarder range of factor from a social-ecological model. However, Bonevski *et al* (1999) was only able to conduct univariate analysis due to a small and relatively low prevalence of needs. Unadjusted associations within Bonevski *et al's* (1999) study are considered with little certainty. Furthermore, in the case of marital status, the limited numbers of participants in marital subgroups other than living with a partner and the statistical significant criterion of p<0.050 in other research would not find this variable significant due to wide confidence intervals. To specifically consider marital status as a correlate of needs stratified sampling by marital subgroup would be necessary to facilitate adequate cases.

Other demographic characteristics, including country of origin, children living in the home and type of employment, identified as correlated of unmet needs in this study were not considered by other research, however may serve as important target for service providers. Survivors born in another country had higher odds of unmet needs within the psychological and sexuality supportive care domains, compared to women born in Australia. Within other research women from other ethnicities have had higher levels of cancer related burden (Ashing-Giwa *et al*, 2004). Women born in other countries may have less close social support to discuss psychosexual concerns with or they may be reluctant to go to their family for support as culturally families may not be used to facing the reality of their diagnoses.

Women with children living in the home had higher odds of physical and daily living needs relative to women without children in the home. This makes sense as women with children at home generally have a higher physical demand.

Relative to women who performed home duties, women who were unable to work due to illness had higher odds of unmet psychological, sexuality, physical/ daily living and health system/ information needs, and women in paid work had higher odds of unmet sexuality and health system/ information needs. A woman whose illness has affected their ability to work is likely to affect multiple domains of their life. Women in paid work often have competing demand (work, household chores, finance and commitment to family) which places considerable stress on the women (Ashing-Giwa *et al*, 2004). Working women may have less time to address health system/ information needs and may be under additional work stress that can affect their libido.

5.6.4 DIAGNOSIS AND TREATMENT VARIABLES ASSOCIATED WITH UNMET NEEDS

Type of gynaecological cancer, disease stage, type of surgery, chemotherapy, radiotherapy, lymph nodes removed, time since last administration of treatment and insurance were associated with reporting some unmet need within supportive care domains examined. Relative to cervical cancer survivors, uterine, ovarian and "other" gynaecological cancer survivors had higher odds of psychological and health system/ information needs. This is an unusual finding since cervical cancer survivors have a younger mean age, and are much more likely to experience treatment-related menopause, than other gynaecological cancer survivors. Most other research has found that psychosocial impact of cancer is greater on younger patients than older patients (Mor *et al*, 1992; Foot & Sanson-Fisher, 1995; Bonevski *et al*, 1999; Sanson-Fisher *et al*, 2000) and that iatrogenic menopause worsens the quality of life (Biglia *et al*, 2004). Perhaps it has something to do with cervical cancer survivors being diagnosed with proportionally less aggressive disease stages than other gynaecological cancer survivors. Although disease stage information has not been collected in most supportive care needs studies (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001), increasing stage has been associated with increasing prevalence of depression (Massie, 1989; McDaniel *et al*, 1995). On the contrary, survivors diagnosed with early stage disease had higher odds of physical/ daily living needs and health system/ information needs than survivors diagnosed with late stage in this study. Further qualitative research to determine why cervical cancer survivors report less unmet needs than other gynaecological cancer survivors would be useful to understand these subgroup differences.

Women who had open abdominal or open bowel surgery had higher odds of unmet psychological and physical/ daily living needs than survivors who had vaginal or laparoscopic surgery. This was expected due to the extensiveness of the procedures. Women who had chemotherapy had higher odds of unmet psychological, physical/ daily living, and health system/ information needs than survivors who did not have chemotherapy. Women who had external beam radiation therapy or who had lymph nodes removed had higher odds of health system/ information needs than women who had no radiation or no nodes removed. Girgis *et al* (2000) confirmed that women who had chemotherapy had higher odds of unmet physical/ daily living needs, however did not replicated the other treatment associations with needs. Other needs studies have either measure type of treatments relative to each other (Sanson-Fisher *et al*, 2000) or have not clearly specified how (Steginga *et al*, 2001) or whether they have measured treatment at all (Bonevski *et al*, 1999).

Interestingly this study also found that for cervical cancer survivors who had chemotherapy, radiotherapy or who were not in remission, the odds of unmet psychological needs were significantly higher than for than for cervical cancer survivors who had no chemotherapy, no radiotherapy or who were in remission. Where as, this association was non-existent within other gynaecological cancer subgroups. Therefore, in particular cervical cancer survivors who are diagnosed with more aggressive disease are more likely to report a need for help with psychological issues than other types of cancer. This maybe because this particular cluster of cervical cancer survivors were older, closer to treatment, had other illnesses and lived outside the capital city.

Gynaecological cancer survivors more recently admitted for treatment had higher odds of unmet psychological, physical/ daily living and health system/ information needs. This relationship of time since last administration of treatment with unmet physical and daily living needs was confirmed within other cancer populations however, no association was observed with psychological and health system/ information needs (Sanson-Fisher *et al*, 2000). Steginga *et al* (2001) measured time since diagnosis and found a similar trend of increasing physical/ daily living needs with decreasing time. Other research did not measure time since treatment (Girgis *et al*, 2000; Steginga *et al*, 2001) or have adequate cases across compatible timeframes (Bonevski *et al*, 1999).

This study also observed that women who had private insurance had higher odds of unmet psychological needs than women who had accesses to Medicare only. Medical insurance was not considered within most other needs analyses (Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001) or was considered at an unadjusted level (Bonevski *et al*, 1999). Within the unadjusted results of both this and Bonevski *et al's* (1999) study, cancer survivors supported by the public insurance system (Medicare) had higher odds of unmet physical and daily living needs, however no association was observed after adjustment in this study.

5.6.5 CURRENT PHYSIOLOGICAL CONDITIONS ASSOCIATION WITH UNMET NEEDS

Disease presence, remission status, lymphoedema status, menopausal status, HRT use, hospitalisation since cancer treatment completion and ever diagnosed with another illness were associated with reporting some unmet need. While other studies do not consider both disease presence and remission status, this study acknowledges the difference between the two theoretically, as well as statistically when considering multi-collinearly tests. Remission is a self reported variable as to whether the signs and symptoms of cancer have completely or partially disappeared, whereas, disease presence or absence is registry recorded, at follow-up intervals by specialist. The latter does not take into account partial disappearance of disease. This study found that the odds of psychological, physical/ daily living and health system/ information needs were higher in women whose disease was still present compared to women whose disease was absent, and that the odds of sexuality needs were higher in women not in remission compared to women in remission. Within needs research, varying associations exist of remission status to supportive care domains. In samples of breast cancer (Girgis *et al*, 2000) and prostate cancer survivors (Steginga *et al*, 2001), remission status was not associated with any of the four need domains considered in this study whereas, in Sanson-Fisher *et al's* (2000) study women not in remission had higher odds of having unmet needs in all domains except sexuality, compare to women in remission.

Other variables measuring current physiological conditions have not been considered in needs research to date. As expected, this study showed that overall women with diagnosed lymphoedema or who experienced treatment-related menopause had higher odds of psychological, sexuality, and physical/ daily living needs than women with no lower limb swelling or who were post menopause prior to treatment. However, when the relationship of lymphoedema status with needs was stratified by type of gynaecological cancer, diagnosed lymphoedema was not associated with having higher needs within the cervical cancer subgroup. This is an unusual finding that warrants further research to explore possible reason for this subgroup difference.

In addition, survivors who had HRT in the past three months had higher odds of sexuality needs than those who did not, survivors diagnoses with another illness had higher odds of physical/ daily living needs than those who were not, and survivors who had not been hospitalised since completing cancer treatment had higher odds of health system/ information needs than those who had been.

5.6.6 ASSOCIATION OF CURRENT WELLBEING, HEALTH BEHAVIOURS AND SOCIAL SUPPORT WITH UNMET NEEDS

Perceived wellbeing, health behaviours and social support has not been considered for their association with unmet needs before. This study found that all wellbeing scales, smoking and drinking were associated with one or more supportive care needs domains. In particular, lower emotional wellbeing was associated with higher unmet psychological, sexuality and health system/ information needs. Lower physical wellbeing was associated with higher unmet physical/ daily living and health system/ information needs. Lower functional wellbeing was associated with higher unmet psychological needs and lower social/ family wellbeing was associated with higher unmet sexuality needs. These wellbeing associations were as expected. Survivors who smoked cigarettes or who drank alcohol less regularly than five days per week, had higher odds of unmet psychological needs, than survivors who did not smoke or drank five or more days per week. Other health behaviours such as meeting the fruit, vegetable, physical activity and body mass index recommendations were not associated with any of the supportive care needs domains considered.

Social support has been claimed by many authors to have positive effects on cancer patients physical health, mental well-being, and social functioning (Funch & Mettlin, 1982; Wortman, 1984; Goodwin *et al*, 1991; Waxler-Morrison *et al*, 1991; Leiberich *et al*, 1993b). Surprisingly, this study found no meaningful association of level of social support with unmet needs.

5.6.7 HEALTH CARE AND COMMUNITY FACTORS ASSOCIATION WITH UNMET NEEDS

Women's use or awareness of community support services and women's rural, remote or metropolitan area classification was associated with unmet needs. Survivors who were aware of services had higher odds of psychological and physical/ daily living needs. Survivors who used a services had higher sexuality needs than non-users. These women were possibly seeking support for these issues in the first place, but it is interesting that there needs either remain unmet or become unmet needs after using support services.

Relative to survivors who lived in the capital city, survivors who lived outside the capital city had higher odds of psychological and physical and daily living needs, survivor who lived in a rural or remote area had higher unmet sexuality needs and survivors who lived in a metropolitan city outside the capital city had higher odds of health system/ information needs. Classification of geographical location were different between this study and other needs research that considered this potential correlate (Girgis *et al*, 2000; Steginga *et al*, 2001). Girgis *et al* (2000) supported the finding that the odds of unmet physical and daily living needs in cancer survivors residing in a rural location were higher than survivors living in an urban centres. However, in contrast Steginga *et al* (2001) identified that the odds of unmet psychological needs in cancer survivors residing in an urban centre close to the capital city were higher than in survivors living in regional centres.

5.6.8 VALIDITY OF THE SUPPORTIVE CARE NEEDS SURVEY

The items within the supportive care needs survey were piloted initially within a sample of medical and radiation oncology outpatients (Foot & Sanson-Fisher, 1995) and then later a modified version was piloted within a sample of patients attending surgical, radiation or medical oncology treatment cancers (Bonevski *et al*, 2000). This study includes mainly patients post-treatment, who are disease-free or stable, and are adjusting to life after cancer. The instrument has not been validated within a post-treatment population, and therefore, some of the items may not be relevant or appropriate. Certainly the results of this study were indicative of the items within the patient care and support domain being irrelevant, as the prevalence of any needs in this domain was minimal. Consequently, this domain was not considered in the regression analysis of correlates in this study. It is not recommended that future research with cancer survivors post-treatment are administered any items within this domain as they are confusing and an unnecessary respondent burden. A new support service and care domain would be useful to measure the level of unmet needs within the community service continuum of care.

While the supportive care needs survey has been deemed a valid and reliable measure of multiple needs domains, face validity of this instrument is a concern. The wording is convoluted and confusing. The questionnaire has an initial statement “In the last month, what was your level of need for help with:”, and then has a list of items. With items such as “not being able to do the things you used to do” and “being adequately informed about the benefits and side-effect of treatments before you have chosen them”, it is difficult to determine what exactly is implied by a “need” for help with such items. Also the former requires interpretation of the negative wording.

During data entry it was observed that some participants simply circled “no need” or “not applicable” at the top of the page and did not answer individual items. Furthermore, some participants circled the whole “not applicable” column in one loop. In these cases it is questionable as to whether respondents actually considered every item. Analysis of domain items also showed that between six and ten percent of participants did not answer all items within each domain and therefore had missing outcome data.

5.6.9 CLASSIFICATION OF THE NEEDS OUTCOME

The Supportive Care Needs Survey guide to administration, scoring and analysis (McElduff *et al*, 2004) instructs that need outcomes for logistic regression analysis be classified as they have been in this study, that is if an individual scored 3,4 or 5 to any item on the domain, that is they indicated 'some need' to any item, then they were allocated a score of 1, otherwise they scored a 0 indicating ‘no need’. It is debatable whether this method of classifying needs domains is the most meaningful and truly reflective classification of representing needs scores or if it makes maximum use of the refinement of the scoring scale as designed. In this system of classification, those domains with more questions per domain have an elevated likelihood of registering some needs within that domain. For example, the psychological needs domain with ten items, only has to have one in ten items with a need to be classified as some need, compared with the sexual needs domain, which has to have at least one in three items to be classified as some need. Therefore, it is invalid to compare the prevalence of needs in one needs domain to another needs domain.

The guide to administration, scoring and analysis suggests it is possible to utilise a continuous outcome when the aim is to identify factors influencing population variation. In this study 41% of participants reported having no unmet supportive care needs overall and between 50% and 79% of participants reported no needs within each of the six supportive care domains. Other studies participants have reported between 18% and 60% (Foot & Sanson-Fisher, 1995) and between 45% and 72% (Bonevski *et al*, 1999) of participants indicating they had no need within each of the five main domains. Therefore, certainly in this study and most likely in other supportive care needs research, a continuous outcome variable would not be meaningful or possible to look at correlates of some needs as the large proportion of participants with no needs would render this variable not Normally distributed and not likely to be transformable to Normality, hence violating the assumptions of linear regression modelling.

Another way of classifying needs would be to sum the responses to each of the need items within the domain and divide by the total number of items in the domain to form an average domain score, then dichotomise this score using a cut off of either 2.5 (which is mid way between the no needs and some needs individual items scale) or 3 (the point where participants are averaging at least a low need across all items). Using this classification would allow meaningful comparison between domains and enable the identification of a priority need domain for action rather than a priority item within a domain.

Prior research reports that cancer patients' perceived needs are highest in the psychological, health information and physical and daily living domains because most of the highest reported moderate or high need items relate to these domains (Bonevski *et al*, 1999; Girgis *et al*, 2000; Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001). These studies consider of the ten or fifteen highest need items, that most were related to a particular domain. Using this reporting style for identifying priorities for action, it is unlikely that domains with few items such as sexuality needs which have only three items, will ever be reported as priority needs domains, even when participants may have high unmet needs across all items in this domain. In this study, four out of the top ten ranked moderate or high needs were in the psychological needs domain, three were in the physical/ daily living needs domain, two were in the sexuality needs domain and two were in the health system/ information needs domain. Hence using this method of identifying a priority need domain, no clear domain for action is identified, as there was no real dominant domain. The dichotomised average domain score may be a better way to identify priority need domains for action, by enabling meaningful comparison between domain scores. When needs were classified this suggested way in this study, unmet psychological needs were reported most frequently with 19.4% of women reporting some psychological needs. The next most prevalent unmet needs domain was sexuality needs (16.2%), followed by physical/ daily living needs (14.2%), health system/ information domain (11.6%) and finally patient care and support domain (8.9%). Further exploration and validation of this method of classification is suggested. The validated standard approach to use of the instrument was used here to permit comparison with other studies.

6 DISCUSSION

This research project makes an important contribution to exploring the supportive care needs of a particular group of cancer survivors that have not been examined with validated multi-domain measures in previous research. To contextualise the interconnected picture of supportive care issues, needs, and use, the social-ecological framework was used. The investigation of service awareness, service use and geographical location as community level influences on supportive care needs was shown to be an important consideration unique to the social-ecological perspective. While the traditional biomedical model, used in prior research, explains most of the variation associated with unmet needs, this study indicated that future research should also include measures of these community variables to both explain and adjust for the effect of this factor.

A number of correlates of need were considered for the first time in this research project. Of particular importance, it was identified that being diagnosed with lymphoedema, experiencing treatment-related menopause, or being unable to work due to illness were associated with higher odds of unmet needs across all supportive care domains examined. These findings were not unexpected, but the evidence provided here for first time is valuable.

Of considerable consequence, it was identified that uterine cancer survivors reported higher levels of unmet psychological and health system/information needs compared to cervical cancer survivors, as well as being less likely to use support services. The inclusion of women with gynaecological cancers of multiple tumour sites presents an intricate understanding of the specific sequelae of this group of cancer survivors who are often pooled together in other research.

This study also highlighted the prevalence of lower limb lymphoedema as well as its undiagnosed symptoms. This was the first study to do so using a population-based methodology and as such was also able to quantify the magnitude of lymphoedema-specific unmet needs within an entire geographical location. This new knowledge is crucial in informing health care organisations about priority support needed for this most disabling side-effect of gynaecological cancer treatment.

Furthermore, a population comparison of health behaviours between gynaecological cancer survivors and Queensland women highlighted the significantly lower level of sufficient physical activity and higher level of obesity in the cancer survivor population. This comparison analysis provided new insight into the differences in supportive health behaviours between gynaecological cancer survivors and the general population and justifies the need to invest considerable resources into addressing the elevated obesity issue specific to this group.

This was an extensive research project exploring quality of life, site-specific morbidities, support use, unmet support needs, and the groups of women with relatively higher levels of supportive care needs and use. The following sections put results from this study into context with other research. The meaning of these findings and their implications are also discussed herein.

6.1 QUALITY OF LIFE

To gauge the overall picture of wellbeing of gynaecological cancer survivors, research question one assessed perceived level of quality of life. Overall, most women coped well with their condition. On average, self-perceived overall quality of life was very good and individual wellbeing subscales (physical, social/family, emotional and functional) were correspondingly also very good; with physical wellbeing rating exceptionally well, on average. This supports previous findings that female cancer survivors report relatively high levels of quality of life that are similar to that of the general population (Ganz *et al*, 1998; Bower *et al*, 2000; Bardwell *et al*, 2004).

Some meaningful cancer type subgroup differences between scales did exist. In addition, differences between the gynaecological cancer populations (cervical, ovarian, uterine and other) compared to the general female population in Queensland also existed. On average, uterine, ovarian and vulval cancer survivors had significantly higher social/family wellbeing score than did cervical cancer survivors or compared to the general female population in Queensland. Women post-treatment for breast cancer have similarly reported better social functioning than women in the general population (Ganz *et al*, 1998; Bower *et al*, 2000; Bardwell *et al*, 2004). The way people respond to questions about social support or emotional well-being has been shown to be related to their age and expectations about how "common" their situation is, and how this relates to what they experience in their social surroundings (Ambron & Brodzinsky, 1982; Schroevers *et al*, 2004; Arndt *et al*, 2005). Given that uterine, ovarian and vulval cancers mostly affect older women compared with cervical cancer and that illness is a sort of "common" or "expected" life event in the older generation; there is no real barrier for women to tell others about their illness and to seek social support and people seem to respond reflecting these “expected” support needs. Cervical cancer survivors are younger on average than the other gynaecological cancer populations and treatment-related menopause and other side effects of cancer may be harder to adjust to (Ganz *et al*, 2003). After treatment, which is mainly curative for this group, some family members expect survivors to "get on with life" (Beesley, 2003), and so cervical cancer survivors may continue to deal with the sequelae of cancer while their younger social network has an expectation that they should be back to “normal” after being treated.

Not surprisingly, this current study found that vulval cancer survivors had lower functional wellbeing on average than uterine cancer survivors. This is most likely due to two main factors: the external site of this cancer is often associated with ongoing pain and sexual dysfunction, and the much higher prevalence of lymphoedema development in this subgroup. Uterine cancer survivors also had, on average, significantly higher functional wellbeing and overall quality of life than the general female population in Queensland. This was an unexpected finding. Very few uterine cancer survivors received chemotherapy (whereas a third to three-quarters of women diagnosed with other gynaecological cancers received chemotherapy) and other research has indicated that women undergoing chemotherapy have poorer perceived quality of life than those who do not have chemotherapy (Jones *et al*, 2006). However, longitudinal studies that incorporate assessment of ongoing symptom burden and perceived quality of life after chemotherapy are rare and no definitive conclusions can be drawn about the lasting effects after treatment completion.

Other research using the same quality of life measure in a gynaecological cancer survivor population in a similar timeframe post-diagnosis (Miller *et al*, 2002), presented similar scores to this current study for overall quality of life, emotional wellbeing, and functional wellbeing. However, physical wellbeing and social/ family wellbeing were considerably lower within Miller *et al’s* (2002) study. They presented means and standard deviations, without establishing whether the scales were

Normally distributed. If their data were not Normal, like those in this current study, this might account for the difference in physical wellbeing and social/ family wellbeing averages between studies. Miller *et al* (2002), did find that ovarian cancer survivors had statistically significantly lower emotional wellbeing and clinically significantly lower overall quality of life than cervical and uterine cancer survivors, whereas this current study did not. No differences across time post-diagnosis were observed in either this or Miller *et al's* (2002) study. This uniformity in wellbeing over time, more than 6 months after completion of treatment, is consistent with other studies on female cancer patients (Andersen *et al*, 1989b; Klee *et al*, 2000a; Chan *et al*, 2001a).

Other quality of life research within the gynaecological cancer population has been conducted during treatment or shortly after, or has used instruments other than the FACT-G to assess quality of life. The other most commonly used instrument is the European Organisation for Research and Treatment of Cancer (EORTC) quality of life questionnaire (QLQ-30). It is difficult to compare directly between the FACT-G and EORTC QLQ-30, as it has been established that the overall agreement between the two instruments is only moderate and only physical well-being in the FACT-G is well represented by the EORTC QLQ-30 (Kemmler *et al*, 1999).

Chan *et al* (2001a) conducted longitudinal quality of life research within a Chinese population of gynaecological cancer survivors, using the European Organisation for Research and Treatment of Cancer (EORTC) quality of life questionnaire (QLQ-30). Considering only global quality and life and physical wellbeing, this current study showed comparable overall quality of life to survivors in Chan *et al's* (2001a) study, when considering the score of time points within both studies (6-24 months post-treatment). However, physical wellbeing appeared significantly higher in this study when compared to the approximation of physical wellbeing represented in Chan *et al's* (2001a) figure. This observed difference could be a function of the differences in survey instruments, the Chinese *versus* Australian perception of physical wellbeing, and/or the treatment or support administered within these different countries to cause or meet physical needs.

6.2 QUALITY OF LIFE AND UNMET NEEDS

This study considered both quality of life and supportive care needs as important morbidity outcomes of cancer survivors. It has been argued in the literature that unmet needs are conceptually related to quality of life (Mor *et al*, 1991) but to date these measures have not been compared statistically. To inform discussion of the main research questions, this study considered the relationship between these measures and found the level of correlations between quality of life and psychological, physical/ daily living and patient care/ support needs were high. For sexuality and health system/ information needs, the level of correlations with quality of life were only moderate. This study confirms that these outcomes to some degree measure conceptually similar constructs, however not to the point where one is a surrogate for the other. For this reason, these measures should be considered independently. Quality of life measures are recommended in all clinical trials (Kiebert & Kaasa, 1996). They provide important insight into the multiple dimensions of health and are sensitive to changes over time (Jones *et al*, 2006). Sensitivity to changes over time has not been psychometrically tested within the supportive care needs measure. When the study's intention is to inform service delivery, the supportive care needs measure could be used alone or in conjunction with the quality of life measure. The supportive care needs measure is beneficial in this scenario as it directly measure the participant's desire for help with specific unmet needs (Sanson-Fisher *et al*, 2000).

6.3 SITE-SPECIFIC MORBIDITIES AND UNMET NEEDS

While quality of life was high on average, some women did experience debilitating site-specific conditions following treatment. Research questions two and three assessed the prevalence of diagnosed and symptomatic lymphoedema and sexual dysfunction. Ten percent of survivors were diagnosed with the lower limb swelling condition, lymphoedema, and an additional 14% reported lower limb swelling that had not been medically diagnosed. Eight percent of all women reported that they were not engaging in sexual activity because their gynaecological cancer had made sexual relations difficult or uncomfortable.

6.3.1 LYMPHOEDEMA

There are few other studies that focus on lower limb lymphoedema (LLL) following gynaecological cancer. This study generally reported a lower prevalence of diagnosed lymphoedema and symptomatic cases than other studies. Ryan *et al* (2003b) reported that 36% of Australian women treated for gynaecological cancer reported swelling of their legs and 18% were clinically diagnosed with LLL. Werngren-Elgstrom and Lidman (1994) found that 22% of cervical cancer survivors had lymphoedema. The lower proportions in the study described in this thesis may have been due to the differences in study design. Diagnosis of the women in the above studies included definitive diagnosis by a lymphoedema management specialist. This contact with a specialist may have seen more cases diagnosed than just non-specialist self-reported data explained in this study.

Of particular importance, it was identified in both this and Ryan *et al's* (2003b) study, that diagnosed lymphoedema was far more prevalent in vulval cancer survivors than all other gynaecological cancer types, with 35% of vulval cancer survivors being diagnosed in this study and 47% in Ryan *et al's* (2003b) study. Also of interest was the time of lymphoedema onset. Both Ryan *et al* (2003b) and this study confirmed that most lymphoedema diagnoses occurred within the first year post-cancer diagnosis (84% and 75% respectively) which is much sooner than the breast cancer experience with upper limb lymphoedema (Clark *et al*, 2005).

Ryan *et al* (2003b) deduced from their findings that there was a need for more awareness of LLL and the possibility of onset, strengthening continuity of care between professionals in hospitals and those in the community, and information for women on what to observe and to where to refer if LLL manifests. This study looked specifically to the women experiencing these symptoms to determine where the supportive care system needs improvement. A quarter of women reported a moderate or high need for help to be more informed about the causes, prevention and treatment of lymphoedema, and to be given written information about ways to manage symptoms of lymphoedema. Thirty-four percent of women were not informed about lymphoedema until they were diagnosed. Also, about a fifth of women reported a moderate or high need for help with pain or discomfort in the legs or groin and with managing the symptoms of lymphoedema.

To help support the physical burden of lymphoedema it is important that women are aware of, and are treated with the most up-to-date treatment regimen. Complex Physical Therapy (CPT), consisting of lymphatic massage, special exercises, compression bandages and garments, and skin care is advocated by the Lymphoedema Association of Australia (2001), who have run many training courses over the recent few years to teach some 500 therapists from all over Australia, New Zealand, U.S.A. and some other countries. It is important that women have access to physiotherapists trained in lymphatic massage and special exercises (Casley-Smith & Casley-Smith, 1992). A recent initiative of the Lymphoedema Association of Queensland (2005) was to develop a lymphoedema resource directory. However, at the time of data collection in this current study, the help seeking path may not have been as accessible, and consequently unmet needs may have reduced since this study was implemented.

In addition to receiving professional help, it is acknowledged that many women may use self-management techniques to help reduce the swelling or provide comfort. Ryan *et al* (2003a) observed that 73% of women with lower limb lymphoedema after gynaecological cancer treatment utilised techniques such as rest and elevation of legs, gentle walking, tai chi, line dancing, self-massage and exercises seen in pictures of people with lymphoedema. The adoption of personal strategies to relieve symptoms and the use of existing health care are both important influential factors on unmet supportive care needs, which make up two important levels of influence (personal and health care) within the social-ecological framework. Also within the health care level of influence is the option of pharmaceutical support. While Complex Physical Therapy is a fast treatment, many people cannot afford it or find it difficult to wear compression garments (Lymphoedema Association of Australia, 2001). Benzopyrones were deemed successful in trials, with infrequent use of compression garments (Casley-Smith, 1999). However, a Cochrane review has concluded that it is not possible to deduce the effectiveness of benzopyrones in reducing limb volume, pain, or discomfort in lymphoedematous limbs due to the poor quality of existing trials (Badger *et al*, 2004). These questionable prescription medication are being endorsed by the Lymphoedema Association of Australia (2001) as a safe and slow but effective treatment. In light of the recent Cochrane review it is recommended that the Lymphoedema Association inform lymphoedema sufferers of the possible benefits of benzopyrones, rather than guaranteeing the effectiveness of this treatment.

Social support networks could be another important influence on relieving the physical burden of lymphoedema. Help with physical chores and tasks that require lymphoedema sufferers to be on their feet for long periods of time may reduce the onset or severity of pain or discomfort in the legs or groin.

At a more peripheral level of influence of the social-ecological model, community factors such as having access to professional care may influence supportive care needs. The recently developed lymphoedema resource directory (Lymphoedema Association of Queensland, 2005) indicates that treatment facilities cluster around urban locations and therefore women living in rural and remote locations are more likely to have poorer professional support.

6.3.2 SEXUAL DYSFUNCTION

Another morbidity that commonly affects gynaecological cancer survivors due to the site of disease is sexual dysfunction. Other research has estimated 20–90% of gynaecological cancer patients experience significant sexual difficulties (Andersen, 1993). Elevated rates of sexual dysfunction in the areas of desire, excitement, orgasm, and dyspareunia (Andersen *et al*, 1989a) have been reported to be still evident at 12 months post-treatment. Of the 43% of gynaecological cancer survivors in this study who were sexually active, 35% noticed quite a bit or very much dryness of the vagina, 22% had little to no desire, and 17% reported quite a bit or very much pain or discomfort during penetration. This study found no significant difference in sexual activity or unmet sexuality needs across survival phases post-diagnosis. However, after adjustment for age, it was observed that cervical cancer survivors were more likely to engage in sexual activity than uterine or ovarian cancer survivors. This may be due to the less extensive surgery associated with cervical cancer treatment.

In addition to medical outcomes impacting on sexuality, sexual dysfunction is often associated with cancer-related psychological problems such as anxiety, depression relating to feelings of loss of desirability, attractiveness and fertility (Laganà *et al*, 2001). This study considered whether women had a need for help with: changes in sexual feelings, changes in sexual relationship, and to be given information about sexual relationships. While the majority of women were satisfied with the existing information on sexual relationships, survivors rated the former two need items as their sixth and seventh highest ranked unmet needs out of 45 need items across multiple need domains. Moreover, cervical cancer survivors had a significantly higher proportion of moderate or high need for help with changes in sexual feelings than uterine and ovarian cancer survivors.

6.4 SUPPORTIVE CARE USE

It is clear that some site-specific morbidities exist in a substantial proportion of the gynaecological cancer population of survivors, for which support is required. In addition to these morbidities, women require support for the common issues that accompany any cancer diagnosis. Steginga and Dunn (1997) noted that the most common difficulties that persisted after the treatment phase for Queensland gynaecological cancer survivors were, fear of dying (23%), anxiety (15%), pain (15%), depression (13%), sexual problems (12%), fatigue (12%), bladder dysfunction (11%), and vaginal problems (e.g., recurrent infections) (10%).

In Queensland, women access multiple sources of support within their communities including: services and organisations, complementary therapy support, participation in positive health behaviours and utilisation of social support. Research question four sought to determine the prevalence of supportive care use of the types of support mentioned above. This research question conceptualised support within the multiple layers of the social-ecological model. At a personal level it was recognised that healthy lifestyle practices can provide physical and psychological health benefits and may be taken up by cancer survivors as a way of supporting their health (Demark-Wahnefried *et al*, 2005). At a social level, support from family and friends has long been recognised as an important supportive care resource that has been associated with psychological wellbeing (Thoits, 1995). At a health care level for survivors who are beyond the treatment phase, community-based organisations and services provide the ideal setting for evidence-based support practices (Steginga *et al*, 2006). Also, complementary therapy support is a highly visible part of contemporary health care (Vickers & Cassileth, 2001). It may sit within both the health care and personal levels of support in the conceptual model, depending on whether cancer survivors sought an alterative therapist or were prescribed a remedy, or whether they spontaneously adopted a complementary therapy in hope of achieving improved health. Assessing multiple levels of support within a social-ecological context provided a broader understanding of the experience of a person's life as a whole by including the broader worksite/organisational/community and media/policy/cultural influences that other models do not consider. This model also provides an understanding of the levels of uptake of different types of support on a population basis.

6.4.1 COMMUNITY SUPPORT SERVICE USE

With the exception of uterine cancer survivors, over 60% of gynaecological cancer survivors utilised at least one community support service or organisation. Uterine cancer survivors' use of services was significantly lower (43% use). As women were asked if they had "ever used a support service or organisation", the level of use within each survival phase was not appropriate to consider. Part of research question six was to determine the correlates of service use. The user profile showed that women were more likely to use a support service if they were younger, retired, diagnosed with a gynaecological cancer other than uterine, had open bowel resection, were treated at multiple centres, in remission or were obese.

Predominantly women utilised cancer support services for information, with information booklets (37%), information on the internet (23%) and, information and support telephone lines (20%), being the top three services used. The provision of information is at the front-line of service provision. Hutchison *et al* (2006), in their tiered, psychosocial, community-based intervention model, identified cancer-related information as a resource that should be provided universally to anyone affected by cancer. Other types of cancer support services were used less frequently. Psycho-educational and peer support represent level two supportive care in Hutchison *et al's* (2006) model and are targeted to cancer survivors with mild distress. Accordingly, support groups and workshops on topics such as coping with cancer, had less participation (11-12%) compared to the information-based services. Face-to-face counselling was utilised by 11% of this study's participants, indicating that a significant proportion of gynaecological cancer survivors were triaged to extended levels of care where moderate to severe distress levels were identified. However, this is not to say that all women who experienced heightened levels of distress received appropriate supportive care.

Referral from health care providers to services is low according to the participants in this current study. Only 31% of women were referred to information that was designed to be universally available to all cancer survivors, and less than 15% were referred to other services. Clinicians do not always see it as their role to address psychosocial needs and hence may overlook distress and appropriate referral (Ford *et al*, 1994; Söllner *et al*, 2001). In addition, clinicians may not be aware of all the available services or local care referral networks. Consequently, available services may be underutilised. Some services may not be available to all women in Queensland due to the geographic barriers of this State. Queensland has a population of four million in an area nearly seven times the geographical size of the United Kingdom, which has approximately 60 million people (Steginga *et al*, 2006). Thirty percent of people live outside the relatively more populous south-east corner (Steginga *et al*, 2006) where most support services and organisations are based.

On the whole, survivors appear to be satisfied with the health system and information provision. Less than ten percent of survivors reported a moderate or high unmet need across ten out of eleven health system and information need items. The only exception was that eleven percent of gynaecological cancer survivors reported a moderate or high unmet need for “being informed about things you can do to get yourself well”.

Psychosocial and physiological support services are also very important in the care of cancer survivors. A study of Sydney women diagnosed with breast cancer found that over 40% utilised support groups, about a third of women utilised physiotherapy, nearly 30% utilised social workers, and a quarter of women utilised community nurses (Chisholm *et al*, 2000). Service utilisation was much higher in Chisholm *et al’s* (2000) breast cancer population than gynaecological cancer survivors in this current study with respectively 11%, 15%, 11% and 7% use of these services by gynaecological cancer survivors. This is probably due to the fact that Chisholm *et al’s* (2000) study was metropolitan-based and included women with breast cancer, which has been the focus of much more research and consequently service provision. An American national-based sample reported that 9% of female cancer survivors utilised professional counselling or a clinical social worker for psychosocial support (Hewitt & Rowland, 2002), confirming a similar level of use as this female population sample. However, Hewitt and Roland (2002) also showed that if all cancer survivors with mental health problems received such care, use would increase by 62%. Certainly, this current study showed that unmet psychological needs were a top priority for help needed, with 50% of women reporting one or more of ten unmet psychological need items. However, when women were asked about a need for access to professional counselling (eg psychologist, social worker, counsellor or nurse specialist) less than 10% of women reported this as being a moderate or high need of theirs. This may be because of misconceptions about what takes place in these therapies (Taylor *et al*, 2004) or the stigma that is associated with mental health (Corrigan, 2004).

Patients' desire for support does not correlate to the level of their distress (Söllner *et al*, 2004). It is important that cancer survivors are able to navigate health services to ensure that they get what they want and need. While it is clear in this current study that women report a need for help with psychological issues, it is indistinguishable what exact help they would prefer to address this. This is a limitation of the supportive care needs survey which is able to identify specific unmet needs but not the specific type of support that a woman desires to meet the need. Qualitative research in a United Kingdom group of cancer survivors who had been discharged from a support program consisting of education, social interaction, psychological support, exercise and complementary therapy found that cancer survivors reported that sharing their experiences with others in the same situation was the most beneficial means of psychosocial support (Taylor *et al*, 2004). Taylor et al's (2004) study indicated that patients were confused about what to expect with counselling and that most patients would prefer the option of group therapy in addition to peer support. However, many patients were reluctant to take advantage of the peer support service offered because of the misconception that they would be matched up with bed-ridden patients (Taylor *et al*, 2004). More specific information about what to expect with peer-support and other psycho-social support initiatives is recommended to be provided *via* support organisation websites and pamphlets that can be explained and mailed when a telephone enquiry is made.

The Queensland Cancer Fund was the highest-ranked organisation utilised for support by this Queensland population, with about one fifth of women reporting accessing their material or services. In addition to a wide variety of services, this organisation provides a helpline, staffed by health professionals with specialised training in understanding and referring patients to other appropriate services *via* the assistance of a database that lists a compendium of Queensland cancer support services. Hence, the Queensland Cancer Fund helpline is an important tool for triaging cancer survivors to services which meet their specific needs and level of distress. When considering Hutchison *et al's* (2006) tiered model of psychosocial intervention, the Queensland Cancer Fund helpline in its capacity to orientate survivors to services is identified as level one universal care that should be made available to all cancer survivors. However, awareness of the organisation is a barrier to the provision of universal care. Only three-quarters of women in this current study reported being aware of the Queensland Cancer Fund and only 15% reported being referred to the organisation by a health care provider.

6.4.2 COMPLEMENTARY THERAPY SUPPORT

Another increasingly popular form of cancer care is complementary therapy (Girgis *et al*, 2005). Research indicates that complementary therapy use by cancer patients is between 7% to 64% use (Ernst & Cassileth, 1998), depending on which type of cancer the patients had, which country the studies were conducted in, whether therapies were used in an adjunctive mode and/or as "curative" treatment, and how the studies defined complementary and alternative therapies. This current study found a substantial proportion (29%) of gynaecological cancer survivors used complementary therapy or alternative therapists to cope with their cancer or reducing the risk of cancer spreading or returning. This proportion was significantly higher in ovarian cancer survivors (36%) compared to uterine cancer survivors (24%). This was possibly due to women diagnosed with ovarian cancer perceiving their disease as a terminal illness (Wenzel *et al*, 2002) and consequently turning to anything including unsubstantiated, but potentially effective therapies, that might help prolong survival. Yet-to-be-published data from a Queensland study of ovarian cancer patients with similarly worded questions, found that around 40% of patients use complementary and alternative therapies to help with their cancer (Webb *et al*, 2004), thus confirming prevalence rates of this current research.

In this study, meditation, naturopaths and massage therapists were the most common modalities, with approximately ten percent use for each. In addition, women consumed a wide variety of dietary and nutritional complementary therapies (21%) as a self-management strategy; however, the prevalence of use for each of the individual therapies was quite low. This is probably because for many dietary supplements and special foods there is little or no evidence supporting the use of these therapies among cancer survivors (Brown *et al*, 2003). However, for a number of other complementary therapies such as hypnotherapy, relaxation therapy, music therapy, massage and acupuncture, there is demonstrated evidence of decreased symptoms and better quality of life (Vickers & Cassileth, 2001).

Research has just begun to evaluate the many complementary therapies available to cancer survivors. Given the substantial number of cancer survivors who are seeking and utilising complementary therapies as part of their supportive care, it is important that an evidence base is established for these therapies (Girgis *et al*, 2005). Further randomised control trials are needed, and based on these, it is important that survivors interested in these therapies and health professionals, are informed of the appropriate uses and effectiveness of these therapies. The challenge for clinicians and service providers is to promote beneficial complementary therapies and oppose disproved or implausible therapies. For cancer survivors post-treatment, the aim of complementary therapy use is often to promote quality of life and prevent recurrence (Brown *et al*, 2003). With limited contact to medical staff in this post-treatment phase, accessing evidence-based information about beneficial complementary therapies from trusted sources is a challenge for cancer survivors (Vickers & Cassileth, 2001). The American Cancer Society (2004) has developed guidelines for complementary and alternative therapies to inform patients about how to approach the use of these therapies and the Queensland Cancer Fund has just developed a similar resource that is now available electronically (Queensland Cancer Fund, 2006). The American Cancer Society (2005) also has a website that lists a comprehensive range of therapies and for each provides a description, what it involves, its history, the evidence for its effectiveness, and possible problems or complications. Australia cancer support organisations only have limited information about therapies that may be effective mainly for the management of symptoms during treatment. The development of guidelines represents an organisational level influence within the social-ecological model; however, they enable self-management, which is a personal level of influence. The provision of evidence-based written information by community support organisations is another important aspect of supportive care that represents the health care level of the social-ecological model. Each of these levels are important in meeting the challenge to accessing reliable complementary therapy information post-treatment.

6.4.3 SUPPORTIVE HEALTH BEHAVIOURS

In addition to complementary therapies, cancer survivors are often highly motivated to seek information about, and participate in, healthy behaviours to support their health, improve their quality of life and survival (Brown *et al*, 2003). Being diagnosed with cancer is often a life changing experience, and after treatment, when most survivors are free of disease or stable, they may be motivated to change their health behaviours or set life-long goals for appropriate weight, and participation in healthy lifestyle choices (Patterson *et al*, 2003). According to data in the current study, many Queensland gynaecological cancer survivors have made healthy lifestyle changes after being diagnosed with gynaecological cancer. About one quarter (23%) of women improved their eating habits by increasing their fruit and vegetable intake, 10% increased their physical activity levels, about a quarter (24%) decreased their alcohol consumption and 10% decreased their cigarette smoking. However, notable proportions regressed in their consumption of fruits and vegetables (8%) or their level of physical activity (44%). Some of this decrease in physical activity may be explained by cancer-related conditions such as fatigue or lymphoedema. While physical activity is difficult in these circumstances, there is strong evidence for its effectiveness in relieving fatigue (Mock *et al*, 1997). Current evidence indicates that physical activity does not lead to the development of lymphoedema or worsen pre-existing lymphoedema within breast cancer survivors (Lane *et al*, 2005) and that physical activity may lead to reductions in total leg volume and subjective leg symptoms in cancer survivors with lower limb lymphoedema (Moseley *et al*, 2004). Education by health care providers and support organisations about the benefits of physical activity, especially with conditions such as fatigue and lymphoedema, are important. Mass media campaigns have been utilised to promote the general adult physical activity guidelines. More targeted health promotion to cancer survivors is necessary that deals with the types of activity that are safe and beneficial to this group and subgroups who experience other conditions post-treatment.

The recommended daily intake of fruit and vegetables for Australians is two serves of fruit and five serves of vegetables (Cashel & Jeffreson, 1995). The National Physical Activity Guidelines recommend 30 minutes of at least moderate-intensity physical activity on most days of the week (DHAC, 1999). These physical activity and eating guidelines are also important for cancer survivors, for improving quality of life and for reducing the risk of cancer recurrence as well as the risk of other chronic conditions such as diabetes and heart disease (Dixon *et al*, 2005). Many women surveyed were not meeting these guidelines. One-third did not meet the fruit recommendations. More than 80% did not meet the vegetable recommendations and over a half do not meet the physical activity guidelines. However, when compared with the general female population in Queensland (DiSipio *et al*, 2006), gynaecological cancer survivors were doing significantly better at meeting the recommendations for fruit (51% *vs.* 66%, aged 20-75 years). Consumption of recommended vegetables was similarly very low in both populations (14-18%). A recent Queensland study of gynaecological cancer patients undergoing treatment found that malnutrition in this group was a significant problem especially amongst ovarian cancer survivors of whom 14% were malnourished (Laky *et al*, 2006). While evidence from some recent prospective studies have not indicated that fruit and vegetable consumption reduces the risk of cancer (Bingham *et al*, 2003; Hung *et al*, 2004), they have an important role as a low energy density source of nutrients and contribute to weight management, as well as their probably cancer protective effects (Dixon *et al*, 2005).

Overall, gynaecological cancer survivors were significantly less active than the general female population of the same age; however most of this difference was observed within the 60-75 age group, with 43% who met the sufficient physical activity recommendation relative to 55%. Also, gynaecological cancer survivors aged 40-75, had proportionately 1.7 times more obese women than Queensland females in the same age group. Other research has shown that overweight and obese women have a three fold increase risk of developing uterine cancer (WHO/FAO, 2003) and that obese women with gynaecological cancer have decreased survival compared to women within a healthy weight range (Modesitt & van Nagell, 2005). Regular physical activity can protect against weight gain, decrease cancer risk, and potentially improve cancer prognosis (Brown *et al*, 2003), as well as possibly reduce some of the morbidities associated with gynaecological cancer, such as fatigue (Mock *et al*, 1997) and lymphoedema (Moseley *et al*, 2004).

6.4.4 SOCIAL SUPPORT

In addition to the self-management health strategies utilised by cancer survivors, the importance of social networks for cancer survivors coping with difficulties after treatment has been well established (Funch & Mettlin, 1982; Wortman, 1984; Goodwin *et al*, 1991; Waxler-Morrison *et al*, 1991; Leiberich *et al*, 1993b; Zacharias *et al*, 1994). This current study showed that most Queensland gynaecological cancer survivors perceived their social support to be excellent. In another Queensland study of gynaecological cancer survivors, the most commonly cited form of social support was emotional support from families (Steginga & Dunn, 1997).

This research suggests that, in general, existing social support networks seem adequate. Outside of gynaecological cancer survivors' existing network of family and friends, considerable avenues exist in Queensland for survivors to converse with each other or with health professionals, for example, the gynaecological cancer support group at Royal Brisbane and Women's Hospital, the lymphoedema support groups across the state, the Queensland Cancer Fund peer support program, Queensland Cancer Fund and Gynaecological Cancer Society telephone support lines, the Gynaecological Cancer Society and the Association of Online Cancer Resources, and gynaecological cancers online support groups.

6.5 MEETING SUPPORTIVE CARE NEEDS

A substantial proportion of Queensland women are utilising multiple sources of support within their communities to cope with the sequelae of gynaecological cancer. On average, women were completely satisfied with the support services that they used, yet there remained a considerable level of reported unmet supportive care need (research question five). Results showed that 43% of gynaecological cancer survivors reported having at least one moderate or high level unmet supportive care need. The five issues that concerned the group the most were "fear about the cancer spreading", "concerns about the worries of those close" "uncertainty about the future", "lack of energy/tiredness", and "not being able to do things you used to do". Therefore, assistance with addressing these psychological and physical/ daily living concerns are priorities for gynaecological cancer survivors.

A range of interventions, such as cognitive behavioural therapy, psycho-educational interventions, anxiety reductions and relaxation strategies, supportive psychotherapy, peer support and family and couples therapy have been proven useful for decreasing distress in cancer patients (Devine & Westlake, 1995; Canadian Association of Psychosocial Oncology, 1999; National Comprehensive Cancer Network, 2002; Carlson & Bultz, 2003; National Breast Cancer Centre and National Cancer Control Initiative, 2003). Numerous strategies including nutritional behaviour (Kalman & Villani, 1997) and physical activity (Schain *et al*, 1994; Mock *et al*, 1997; Pinto *et al*, 2002) can be effective in improving energy levels and fatigue.

In practice, it is important to assess individuals' preferences in supportive care needs (Turton & Cooke, 2000; Carlson & Bultz, 2003; Steginga *et al*, 2006). This assessment may be part of the hospital discharge procedure or when women telephone support organisation helplines and may be done using a range of methods from clinical interviews to psychometric screening with question(s) assessing level of distress (Steginga *et al*, 2006). Cancer survivors may attempt to meet their support needs with self-management strategies such as attempting to improve health and symptoms with complementary therapies, healthy eating or attending self-help centres (Turton & Cooke, 2000). Self-management strategies empower people to take an active role, assisting their sense of control (Turton & Cooke, 2000). Cancer survivors will often turn to their family and friends as an important source of social and emotional support (Steginga & Dunn, 1997). For cancer survivors seeking service support, it is important to systematically refer them to types of services that would be expected to most closely match their needs and level of distress (Carlson & Bultz, 2003; Steginga *et al*, 2006). However, this population-based study did not consider individuals' needs, as it was not intended, nor were the resources available, to provide individualised management plans for the 800 plus women who participated. Rather this study provides evidence for targeted implementation of such programs or interventions to the identified groups of survivors with higher levels of unmet need. Presumably, these people had not met all their support needs within the personal and social levels of influence which are intrinsic to their day-to-day life. Therefore, the healthcare level of influence is the next level of care to consider. Accordingly, the second part of research question six was to determine the social-ecological correlates of unmet supportive care needs, so that healthcare can target its resource to those groups in most need of support.

Most cancer survivors do well with standard care (Hutchison *et al*, 2006). However, there are a few groups of women who are at risk for poor adjustment and unmet supportive care needs. Of considerable importance, it was identified in this current study that uterine cancer survivors were at a much higher risk of having unmet psychological needs relative to women with all other types of gynaecological cancer, especially cervical cancer, and that women who utilised a support service were more likely to have unmet psychological needs. These strong correlations are puzzling as there is no clear reason why uterine cancer survivors would have elevated psychological issues, except that they are significantly less likely to utilise any support services. However the latter finding, that indicates psychological needs remain unmet after service use, further points to the possibility that even if cancer survivors seek service support, they are either not being triaged to the appropriate type of psychological care for their level of distress, or that the appropriate care does not exist. During this study's data collection the Queensland Cancer Fund introduced a free telephone-based counselling service with a clinical psychologist that was available to all people in Queensland. Questions in this current study about unmet needs were anchored to the "last month" and asked in 2004. However, this recent psychological support service may not have been available when distress initially presented amongst participants. Consequently, women in this cross-sectional study may still have had high levels of distress despite reporting that they utilised support services, due to Queensland-wide free qualified psychological support being unavailable before this time.

In addition to cancer type and service use variables, a few key physiological, treatment and diagnosis variables from the personal level of influence within the social-ecological model were associated with both unmet psychological and physical/ daily living needs. Women whose last administration of treatment was within the preceding 12 months and women who had more aggressive disease (*i.e.* disease still present, or who had open surgery or chemotherapy) were at higher risk for both unmet psychological and physical/ daily living needs. Furthermore, women who continued to experience day-to-day difficulties with lymphoedema, iatrogenic menopause or the inability to work due to illness were also at higher risk for both unmet psychological and physical/ daily living needs.

Another important personal factor that specifically influenced physical/ daily living needs was women with children living at home. Approximately 20% of women diagnosed with gynaecological cancer do have children living at home and this study indicated that they were at much greater risk for unmet physical/ daily living needs. In the United States, research has shown that 24% of adults with cancer are parenting children younger than 18 years (National Cancer Institute, 1992). Despite the number of families affected, little information exists about the challenges and needs of parenting with cancer (Rauch & Muriel, 2004). At the time of data collection in this current study, no specific resources for parenting by cancer survivors were administered by Australian cancer support organisations. An information book (The Cancer Council NSW, 2005) has since been developed, which focuses on how to communicate with children. Coping with physical/ daily living needs as a parent is another aspect of parenting that needs consideration and is given little attention in the above information resource. Information about how to manage fatigue when also faced with parenting duties and where to get help with managing the tasks that are associated with looking after children when survivors are no longer able to, are a priority. These physical needs may be influenced by the amount of social support and health care cancer survivors are able to utilise.

At a community level of influence, the women who were at risk for unmet psychological and physical/ daily living needs were identified as women who did not live in the capital city and in particular, for physical/ daily living needs, women who lived in rural and remote areas were at increased risk. This finding is not surprising in Queensland given this state's large geographical area and the location of 56% of the population being outside the capital city (Steginga *et al*, 2006) where less resources are based. At the time of data collection in this study, cancer specific face-to-face counselling by a trained psychologist was only available in Brisbane via the Cancer Support Centre at Griffith University. This service has now been replaced by a similar free face-to-face service provided directly through the Queensland Cancer Fund, but is still only available in Brisbane. Other psychosocial resources limited to Brisbane include an outpatient clinic-based social work service and a gynaecological oncology support group at the Royal Brisbane and Women's Hospital provided by the Queensland Centre for Gynaecological Cancer. In terms of physical/daily living needs being higher in rural and remote locations, in addition to limited resources, women in these locations may suffer heightened physical/ daily living needs due to the physically demanding agricultural, forestry and fishing employment sectors being the single largest employment sector for rural women (17%), compared with urban women who had negligible women working in the sectors (1%) (Commonwealth Office of the Status of Women, 2002).

After psychological and physical and daily living needs, sexuality needs were ranked next highest for gynaecological cancer survivors. Interventions such as personal and/or couple therapy have proved effective in improving sexual adjustment (Christensen, 1983; Scott *et al*, 2004). To address the moderate or high unmet needs for help with changes in sexual feelings and relationships, which were identified by over ten percent of women in this study, the implementation of this type of therapy for target groups may be of benefit. Specifically, this study identified at a personal level of influence, that younger women living with a partner, should be targeted for psycho-sexual support. Also women living with cancer and women who continued to experience day-to-day difficulties with lymphoedema, iatrogenic menopause or the inability to work due to illness were also at higher risk for unmet sexuality needs. At a community level of influence, women living in rural and remote areas were identified as targets for psycho-sexual support.

6.6 ADDRESSING SUPPORTIVE CARE NEEDS FROM A SOCIAL-ECOLOGICAL PERSPECTIVE

For the study of supportive care needs, it is evident that all levels of the social-ecological model, including personal, social support, health care, worksite/organisational/community and media/policy/culture, impact on the reporting of unmet needs. Other models of morbidity outcomes have generally limited themselves to the personal and social influences on health and therefore the social-ecological perspective enables the identification of several new variables that sit within the broader levels of influence that have a significant impact on the reporting of unmet needs. This current study shows that key personal factors were associated with reporting higher levels of support needs. Personal factors were also utilised as a means of self-management to improve health and symptoms.

In this study, social support was not associated with higher levels of unmet needs, never-the-less, it has been well established as an important means of support of wellbeing (Leiberich *et al*, 1993a; Zacharias *et al*, 1994), as well as a means of psychological support (National Breast Cancer Centre and National Cancer Control Initiative, 2003) and physical and daily living support (Goodwin *et al*, 1991; The Cancer Council NSW, 2005). The use of healthcare services was associated with unmet psychological and sexuality needs in this study. Community-based support organisations provide an ideal setting for the dissemination of evidence-based practices and information (Steginga *et al*, 2006) and are a crucial level of influence on supportive care needs.

At a worksite/community/organisation level of influence, this study found that unmet needs were associated with geographical location. The communities in which we live in often determine the level of access we have to health care professionals, services, social networks, and environments that are supportive to healthy behaviours (Australian Institute of Health and Welfare, 2003b). The administration of a continuum of care plan is another factor that may have an impact on morbidity outcomes within this “exosystem” level of influence. Women who have access to discharge planning are possibly more likely to receive the appropriate referrals and be triaged to the services that are suitably matched to address their level of distress (Fenerty, 1993; Carlson & Bultz, 2003; Shepperd *et al*, 2004; Hutchison *et al*, 2006). The level of discharge planning a women received was not directly measured in this current study, as it was not considered in the design stage of this project. However, the hospital in which women were treated may provide some indication of care planning ability to meet supportive care needs post-treatment. This study showed that depending on which hospital women were treated at, there was a significant difference in the level of unmet psychological and physical/ daily living needs. However, it is impossible to determine from this study whether this difference is a result of care planning or other factors such as the demographic characteristics of the women attending the different hospitals. Geographical location and level of care planning are both part of the worksite/organisational/community level of influence. Geographical location alone demonstrates the importance of this level of influence in the consideration of cancer morbidity research.

Finally, the recent development of clinical practice guidelines for psychosocial care of cancer survivors (National Breast Cancer Centre and National Cancer Control Initiative, 2003) is a welcome step forward in ensuring the cancer care continuum is implemented. Guidelines such as these influence evidence-based values, practices and role expectations, from the very outer levels or "macrosystems" of society (Bronfenbrenner, 1979). The filtering effect of these guidelines is seen through the guideline's translation into action of clinical practice and service provision. In the Queensland climate this translation is starting to take place through the implementation of workshop training programs for health professionals in understanding the guidelines and in the reorientation of service provision inline with the guidelines (Steginga *et al*, 2006). To specifically measure the impact of such guidelines on morbidity outcomes, a repeated measures study design would be required with pre- and post-analysis around guideline development. This current study does not include any measurement of the influences such as guidelines that exist in the macrosystems of society. However, the filtered influence of their effect on morbidity outcomes are likely to be captured within the variables measured within the more internal levels of the social-ecological model, as these guidelines should directly influence the provision of support services, and services should provide resources that improve the self-management practices of individuals. Thus, the measurement of unmet needs should be accordingly affected. Guidelines such as these form a 'top-down' public health approach and are important in synthesising the existing evidence-base into recommended actions. However, it is equally important to adopt a 'bottom-up' approach where cancer survivors are asked about their needs, rather than it being assumed that they require particular resources. These two approaches can be effectively linked to ensure both evidence-based resources exist, as per recommendation guidelines, and that individual women are referred to the type of support they desire by appropriate questioning of needs and levels of distress.

6.7 STRENGTHS AND LIMITATIONS

The current study represents a cross-sectional view of gynaecological cancer survivors' specific morbidity issues, supportive care needs and use. It is one of a few population-based studies to consider lower limb lymphoedema after cancer treatment. It is the only study to utilise a broader social-ecological perspective in considering the supportive care needs and use of cancer survivors. Unlike many other studies which focus on supportive care of cancer survivors during the treatment process, this study acknowledges that cancer survivors may need community support for issues well after their treatment has finished. It targets these survivors and the communities they live in, to determine community-based support beyond the medical paradigm. In line with a broader view of support, which not only includes services, but also a range of lifestyle activities and complementary therapies, this research considers the use and usefulness of multiple support modalities available to people within their communities. This study is one of a few studies to consider the many issues across gynaecological cancer types and survival phases. It is the first study of gynaecological cancer survivors to consider unmet needs across more than two areas of need using a validated measure, and the first Australian study of supportive care needs and use within a gynaecological cancer population. There are, however, a number of limitations that need to be considered in the interpretation of results.

6.7.1 STUDY DESIGN

While cross-sectional survey designs are not ranked highly on the "quality continuum" for research design, for most of the research questions within this descriptive study, the cross-sectional design was appropriate, as the questions aimed to determine prevalence or difference between groups at one point in time. However, to consider differences across survival phases post-diagnosis, a longitudinal design would have been ideal to enable the measurement of individuals' change over time. Within the current design, it is difficult to tell how much of the differences between survival phases were attributed to different cohorts within the cross-sectional survival phases.

6.7.2 REPRESENTATIVENESS

A comparison of this study's sampling frame, which captures 85% of the gynaecological cancer survivors population, with the population-based registry (Queensland Cancer Registry) indicated that ovarian cancer survivors were under-represented within the sampling frame. Age, geographical location and cancer type were the only available comparable characteristics between registries. Therefore, it is difficult to tell if other gynaecological cancer population characteristics are under- or over-represented, except to speculate that characteristics associated with ovarian cancer such as a more aggressive disease stage, patients having chemotherapy and not having radiation therapy, may also be under-represented in the sampling frame. Chemotherapy was associated with higher levels of unmet psychological, physical/daily living and health system/information needs. Hence the prevalence of supportive care needs is likely to be under-estimated for need items within these domains and the effect size of chemotherapy group differences of supportive care needs is likely to be under-estimated. However, more aggressive disease stage and not having radiation therapy was associated with lower levels of physical/ daily living and/or health system/ information needs thus possibly over-estimating the prevalence of need items in these domains and group differences of supportive care needs in disease stage and radiation groups.

This study achieved a 57% response rate, which was considered reasonable within this cancer population who are between three months and five years post-diagnosis. The other Australia supportive care needs study that was conducted in a cancer population sampling frame where patients were between three months and six years post-diagnosis achieved a 53% response rate (Girgis *et al*, 2000). Studies conducted in a timeframe closer to treatment have achieved 61-65% response rates (Sanson-Fisher *et al*, 2000; Steginga *et al*, 2001; Aranda *et al*, 2005).

The comparison of study participants to the sampling frame revealed that older women (70+) were slightly under-represented in the sample. Cancer stage, disease presence, geographical locations of Queensland, the accessibility/remoteness index and the socio-economic index were representative of the sampling frame. However, the exclusion of patients considered too ill too participate and unable to speak adequate English, likely resulted in under-representation of the specific needs of these cancer survivors. Unmet needs in these groups were likely to be higher on average than the general gynaecological cancer population as similar characteristics in this study were indicative of higher odds of unmet need. That is, women who were unable to work due to illness and women who were not born in Australia had higher unmet needs than working/retired women or Australian born women respectively.

Further consideration of the representativeness of results from the statistical modelling analyses was also necessary due to substantial missing values eliminating cases from the multivariable models. Since all models were built using the same social-ecological factors, one overarching missing values sensitivity analysis was conducted which found that all models over-represented younger women, more educated women, employed women, women who experienced iatrogenic menopause, women who had HRT in the past three months, more socially supported women and women who were aware of at least one support service. Results showed that younger women, employed women, women who experienced iatrogenic menopause and women who had HRT had higher sexuality needs than their respective counterparts. Women who experienced iatrogenic menopause or who were aware of at least one support service had higher psychological and physical/ daily living needs, and employed women also had higher health/ system and information needs. Accordingly, the reported prevalence of unmet needs across these domains is likely to be inflated slightly.

This was a Queensland-based study and therefore may be limited in its generalisability to other states and territories. While disease characteristics of gynaecological cancer survivors in Queensland are likely to be similar across most parts of Australia, service provision and access to support modalities for survivors post-treatment are different.

6.7.3 RECALL BIAS

Most questions included in the survey asked about women's current experience or experience in a recent time frame (eg in the last month), thus minimising the potential for recall bias. Self-reported diagnosis and treatment data were substituted for registry variables to remove recall bias. However, there were several sections that asked women to recall whether they had experienced lymphoedema symptoms, used support services, organisations, or complementary therapies, or changed health behaviour, since being diagnosed with cancer. For some women this could be up to a five year period. Within the modelling where variables were recoded in to “ever used any support services or organisations” or “ever used any complementary therapies”, recall bias was not likely to be a problem as it is unlikely that women would forget all support modalities.

Generally, only the severe symptom of swelling was discussed within this research and it is also unlikely that women would forget this due to the impact of swollen legs on many facets of their lives. However, prevalence of each lymphoedema symptom, individual support services and organisations and complementary therapies may be under-reported as women may forget less severe symptoms or all of the particular services or therapies they utilised. Recall bias is most likely to affect reported behaviour changes, due to regular changes in behaviour patterns and the inability of people to accurately remember their behaviour for periods in their distant past. Results could possibly over-report an increase in healthy behaviours (*i.e.* vegetable intake and physical activity) and over-report a decrease in unhealthy behaviours (*i.e.* alcohol consumption and cigarette smoking) when comparing “current behaviour” to “just prior to cancer diagnosis”, as survivors may have felt the pressure to report a healthier lifestyle after cancer.

6.7.4 MEASUREMENTS ISSUES

This study utilised standardised and validated survey instruments where available, including the supportive care needs survey – Short Form 34 (SCNS-SF34) (McElduff *et al*, 2004), the Functional Assessment of Cancer Therapy – General (FACT-G) (Cella *et al*, 1993), the Active Australia Survey (Australian Institute of Health and Welfare, 2003a) and the Duke-UNC Functional Social Support Questionnaire (Broadhead *et al*, 1988). Commonly used questions, mainly derived from the Queensland Cancer Risk Study, were also used to enable direct comparison between gynaecological cancer survivors and the Queensland population. Some variables did require the development of new questions, in particular the lymphoedema questions, support service or organisation use questions and the complementary therapy use question. Piloting of this questionnaire helped to establish the face and content validity of these new items.

Some hesitation is reserved as to the sensitivity of the support service or organisation use and complementary therapy use questions, due to the overwhelming tabular format, which may have caused some respondents to just skip part or all of the questions in these sections. Some busyness was reduced after pilot data indicated that the tables may be overwhelming for some people, but a second pilot was not conducted. Therefore, under-reporting of use of services, organisations and complementary therapies is possible.

Within the Active Australia Survey, recall bias and variability of physical activity patterns contribute to measurement error (Bauman & Merom, 2002), with most people over-reporting their level of physical activity. To minimise this, any cases who reported participating in greater than fourteen hours of activity in the previous week are recoded to fourteen hours. This cap may not remove the over-reporting that is likely to exist for many cases. If a person rounds up their physical activity to what they would do on a good week, then they may be classified as sufficiently active when more accurately they should have been in the insufficient category. One of the objectives of this study was to report the proportion of gynaecological cancer survivors participating in sufficient physical activity. In this context, the results here may be an over-estimate. However, another objective was to compare the difference in the level of physical activity between cancer survivors and the general population. Any error would be expected to occur equally within both populations and therefore is not likely to be an issue for the latter objective, unless the different populations had different motivations for completing the survey.

6.7.5 USEFULNESS OF THE SUPPORTIVE CARE NEEDS SURVEY

This study was based on the premise that it is important to assess unmet needs of cancer survivors so that health services and health care professionals can tailor their interventions and resources to those groups of survivors who require them. While it is acknowledged that the needs of some cancer survivors will never be met, it is questionable whether this approach will actually translate into better outcomes for survivors. When individuals have been identified with unmet needs or higher levels of distress and provided with corresponding individualised management plans they have either not had better outcomes than those in standard care (McLachlan *et al*, 2001) or they have been no more likely than those with mild distress to be interested in or utilise the supportive counselling offered (Söllner *et al*, 2004). This current population study also suggests that it is not quite as simple as providing a service to meet a need or an issue. Women with diagnosed lymphoedema and women who experienced treatment-related menopause, and hence were dealing with issues such as loss of fertility, ability to have children, changing levels of hormones, and symptoms belonging to women of an older age group, were more likely to report unmet psychological, sexuality and physical/ daily living needs. Yet these same women were no more likely to utilise support services than women with no lower limb swelling or women who were post-menopause prior to their cancer treatment. Furthermore, unmet psychological and sexuality needs were more often reported in women who did utilise support services.

Women who seek support may have a higher level of awareness of their own supportive care needs and thus may explain why service users are more likely to report unmet needs. However, the questions remain; 1) Why aren't more women with morbidity such as lymphoedema and issues associated with treatment-related menopause using existing support services to meet their needs? 2) Are the existing support services providing the type of support that remains unmet in this group? and 3) Will reorientation of support services based on needs assessment findings improve the level of unmet needs on a population basis? Further qualitative research focusing on women with these gynaecological morbidities is necessary to answer the first two questions. Answering the third question involves more systematic study of unmet needs pre- and post-service provision. However, sensitivity to change of the needs assessment tool is also currently unknown, and so further psychometric testing would be necessary.

6.8 SUMMARY AND RECOMMENDATIONS

The current descriptive study is valuable as it supplies service providers and health care professionals with specialised knowledge of the particular needs and identifies subgroups of patients with relatively higher levels of need, as well as the patterns of use of a wide variety of supportive care modalities and the prevalence of site-specific morbidities. This increased knowledge should be informative in the development of resources and interventions by support organisations for these specific groups of survivors.

The results from this survey tell us that, while women with gynaecological cancer in Queensland are doing quite well overall, there is still room for improvement in a few key areas of public health importance, namely, the support of psychological issues including fear about the cancer spreading, concerns about the worries of those close to you and uncertainty about the future, and the support of physical/daily living issues including lack of energy/tiredness and not being able to do things you used to do.

While there is evidence for a range of psychological interventions and taught self-management techniques in improving adjustment and reducing distress in people affected by cancer (Meyer & Mark, 1995; Cunningham, 2000; Carlson & Bultz, 2003; Rehse & Pukrop, 2003), this study showed that very few women actually had the desire for counselling services or relaxation classes even though 50% reported unmet psychological needs. Further qualitative research of women who report moderate to high unmet psychological needs is recommended to determine why they do not desire counselling, their perception of counselling and what they would prefer to address their psychological needs. Such finding would be very important in complementing needs research to informing health care about both what women both need and want. In addition to informing health care, a study of this nature would be useful in addressing psychological support perceptions at the macrosystematic levels of society. Mental illness is often attached to a stigma that prevents many people from seeking help (Corrigan, 2004). The Australian government have developed the National Mental Health Strategy and set up the Mindframe Media Strategy, which seek to encourage responsible reporting of mental health issues, however, they admit that there is still progress to be made (Australian Government Dept of Health and Ageing, 2004). Reducing the stigma *via* a mass media campaign about mental illnesses and mental health issues in the context of chronic illness may be a useful strategy to ensure that existing care is utilised to its full potential.

In terms of addressing the reported physical needs, in particular improving energy levels and tiredness, nutritional and physical activity interventions have been proven effective (Schain *et al*, 1994; Kalman & Villani, 1997; Mock *et al*, 1997; Pinto *et al*, 2002). Interestingly this current study showed that 11% of women reported a moderate or high need to be informed about things you can do to help yourself get well, thus suggesting that on a personal level, women are interested in accessing more self-management information. At a health care level of influence, women would also probably be receptive to nutritional and physical activity interventions to address their unmet physical and daily living needs, given their desire to be informed about personal health improvement strategies. The social support level of influence is also an important layer of the social-ecological model to consider the unmet need for help with both improving energy levels and tiredness and not being able to do things they used to do. For many people, friends and family will be keen to help, to reduce the burden of fatigue and take over the things that they are unable to do (The Cancer Council NSW, 2005). However, often they may not know the best way to help (The Cancer Council NSW, 2005). To facilitate this help, it is important that cancer survivors let friends and family know what exactly they need help with to relive their physical burden. Support organisations, either through their written information or verbal helplines, are best positioned to educate women with cancer, their families and friends, about the way to communicate with each other to facilitate required support.

In addition to self-management and social support, community health care is an important source of support for many women. This current study identified that gynaecological cancer survivors had higher levels of unmet needs in the period closely following treatment completion, otherwise known as the re-entry phase (Stanton *et al*, 2005). It is recommended that desired and evidenced-based psychological and physical/daily living initiatives be implemented in that period by community support organisations. A number of initiatives should be considered that are targeted to the circumstances of women who have higher odds of unmet needs, that is, designed initiatives should consider the issues associated with living with cancer, living with children after cancer treatment, living with lymphoedema, the sequelae of treatment induced menopause and the issues associated with being unable to work. At a universal level of health care, information resources about each of these topics that address the psychological and physical/ daily living consequences are crucial. If an individual’s distress is moderate to severe, they may require and/or desire more intensive support initiatives. The Queensland Cancer Fund currently have a “Living with Cancer” program held in metropolitan centres throughout Queensland. This program discusses topics such as understanding cancer, diagnosis, treatment, communicating with others and lifestyle behaviours. However, once women have moved past the treatment phase this study shows that other psychological and physical/daily living issues are priorities. The development of a number of programs or workshops are recommended that discuss the specific psychological and physical/ daily living outcomes of women who a) live with cancer, b) live with children after cancer treatment, c) live with lymphoedema, d) have had treatment-related menopause and e) are unable to work due to illness, and how and where women can get help with managing these.

This study also showed that women living in rural and remote regions of Queensland had higher odds of unmet supportive care needs than women living in the capital city. Universal care, the bottom tier in the model for community support service delivery (Steginga *et al*, 2006), ensures that women living in these locations are at least able to access telephone and mail-based support services. Since this study was conducted telephone counselling by trained psychologists has been implemented. However, for women with severe distress, more intensive support may be required. Mental health services have been identified as one of the most significant deficiencies in rural and remote Australia (Australian Institute of Health and Welfare, 2003b). Specialist therapy may be hundreds of kilometres away, or services like respite care for daily living support may not be available at all in these areas. Queensland's geographical barriers is a key issue that needs to be given consideration. One strategy that has been implemented in rural and remote areas for mental health is videoconferencing (Capner, 2000; Haythornthwaite, 2002; Jong, 2004; Thomas *et al*, 2005; Griffiths *et al*, 2006). Women's Health Queensland Wide provides regular videoconferences on a range of health issues to sites throughout the state via Queensland Health's Telehealth network and services (Women's Health Queensland Wide, 2006). A program for cancer survivors could be implemented in rural and remote locations using this technology. It could also be used to improve the support and training of local health professionals who provide service to this population.

Some unmet sexuality needs also existed in this group of gynaecological cancer survivors, namely the need for help with changes in sexual feelings and relationships. In addition, to the groups identified as having higher levels of psychological and physical/ daily living needs, this study also identified that younger women living with a partner also had higher levels of unmet sexuality needs. Therefore, supportive care of sexuality should be sensitive to the issues of younger cancer survivors. Interventions that are inclusive of couples and not just individuals are also recommended for psycho-sexual support. Such interventions have been proven effective for sexual adjustment after the female of the relationship has been diagnosed with cancer (Scott *et al*, 2004).

The only unmet health system/ information need that affected this group to a significant degree was the need to be informed about things they could do to help themselves get well. This study also indicated that a large number of women could use support for healthy living, that is, getting more physical activity and eating a healthy diet. In particular, this study highlighted the significantly lower levels of physical activity and higher levels of obesity in gynaecological cancer survivors compared to the general female population in Queensland. A great opportunity exists for health promotion of lifestyle changes after cancer treatment when women are motivated to manage their long-term health (Brown *et al*, 2003). Other research has shown that exercise interventions among patients with cancer and cancer survivors has improved functional capacity, reduced fatigue, weight, pain and sleeping problems, as well as improved psychological outcomes (Pinto & Trunzo, 2005). Programs have also documented that it is safe and feasible for patients with cancer to participate in supervised exercise programs (Winningham *et al*, 1986). To manage the weight concerns in this population of gynaecological cancer survivors, as well as possibly address some of the unmet physical and psychological supportive care needs, the implementation of an evidenced-based physical activity intervention is recommended. In particular, this intervention should target overweight and obese women, who account for 55% of this population.

Moreover, at a universal level of care, it is important that cancer support organisations provide access to evidence-based information about the value of particular dietary items, complementary therapies and types of physical activities that are safe and beneficial to their quality of life. Currently in Australia, only general dietary and physical activity guidelines are promoted for all adults, regardless of whether they have had a major illness or not. Other research has suggested that cancer survivors find it difficult to answer even the simplest of questions about appropriate lifestyle activities after diagnosis and after treatment (Brown *et al*, 2001). A few reports have been written and published in scientific journals to guide informed choices by cancer survivors (Brown *et al*, 2001; Brown *et al*, 2003). With permission, the Queensland Cancer Fund helpline staff sends out these borrowed resources, however, they maybe perceived by some to be quite technical and lengthy. The Queensland Cancer Fund holds healthy living workshops in some areas of Queensland. However, these are inaccessible to a proportion of the population and require commitment to a workshop to become informed. This research suggests that more specific written information, that is lay-person friendly, for cancer survivors particularly after treatment, is needed. It should be disseminated by support organisations when requested.

To facilitate the triage of gynaecological cancer survivors to appropriate health care information and other support initiatives, cancer survivors' awareness of the

Queensland Cancer Fund needs to be raised from three-quarters to population saturation to ensure that lack of awareness is not a barrier to the provision of universal care. Having a referral is strongly associated with service use. In this current study, 86% of women who received a referral, used a support service. This study showed that patient reported referrals to the Queensland Cancer Fund were minimal (15%) and need to be increased to connect the network of care from clinicians to the community setting. Other research has shown that many health professionals have a low appreciation of patients' support needs and infrequently provide referrals to psychosocial support services (Ford *et al*, 1994; Fallowfield *et al*, 2001; Söllner *et al*, 2001). Clinical practice guidelines for cancer care in Australia were introduced for psychosocial care of cancer patients in 2003 (National Breast Cancer Centre and National Cancer Control Initiative, 2003). To increase health professionals' understanding of the guidelines and improve referral to community psychosocial care, Steginga *et al* (2006) are currently implementing a training program.

Steginga *et al's* (2006) program is targeting the problem of limited awareness and referral to community support services at the "health care" level of the social-ecological model. More peripheral levels of the social-ecological model could also be utilised to address this issue. Within the worksite/organisational/ community level, this issue should be considered from the perspective of hospital administration. Most Australian studies reveal gaps in the discharge management practices of hospitals (Department of Health NSW, 2001). Discharge planning is described as the critical link between hospitals, community-based services, non-government organisations and carers (Department of Health NSW, 2005). Yet despite recent advances in electronic records, patient pathways and technology-assisted decision support, poor communication exists between the hospital and providers of services in the community (Shepperd *et al*, 2004). In 1997, only 42% of Queensland hospitals had a written discharge policy and only 44% of Queensland hospitals employ a community liaison or discharge nurse (Department of Health NSW, 2001). At the most peripheral level of the social-ecological model, the media/policy/culture level, this issue could be addressed by the development of a discharge planning policy directive that ensures discharge planning is an integral part of everyone's hospital care and that information is provided about services and programs available in the community following hospital discharge. The New South Wales Department of Health developed a policy of this nature; however, it has since been rescinded for unknown reasons.

American documentation is starting to advocate the growing need to promote and support long-term health of cancer survivors (National Cancer Institute *et al*, 2004; Hewitt *et al*, 2005; National Cancer Institute *et al*, 2005). Policy in Australia needs to expand its focus from acute care to managing the long-term health consequences of cancer. Hudson (2005) has defined the stage following cancer treatment as the second stage in the cancer care continuum where the objective is to maintain cancer free survival and prevent cancer-related morbidities. Hutchison *et al* (2006) recently initiated this expansion of the existing clinical practice guidelines for psychosocial cancer care, to a community based model for psychosocial service delivery. This current study indicated that psychological, physical/ daily living and sexuality needs were a significant concern to gynaecological cancer survivors post-treatment. Thus clinical practice guidelines and their application in a community setting need to extend further into addressing the physical/ daily living and sexuality needs of cancer survivors. In addition, the consideration of a model of care for specific cancer morbidities that are correlated with higher levels of unmet needs is recommended. Cancer morbidities can be site-specific. Current policy only extends to the similar themes that exist for needs across all cancer types. However, some site-specific implications for care exist and should be included.

Specifically, one condition that may develop as a result of gynaecological cancer treatment is lower limb lymphoedema. There is an urgent need to expand research on this secondary condition and the effects it has on survivors' lives. This study has highlighted the prevalence of this condition as well as its undiagnosed symptoms, particularly for vulval cancer survivors. This study also found that many women experiencing lymphoedema or its symptoms have unmet needs for information support and help with the physical burden of this condition. Follow-up of high-risk women is pertinent, that is, those treated for vulval cancer and those within the first year post-treatment when most cases present. It is recommended that self-management information and referral information for suppliers and services for lymphoedema management are given to high lymphoedema risk groups as part of the hospital discharge procedure, as well as when symptoms occur, to ensure a continuum of care is maintained. For women who live in rural and remote locations professional lymphoedema management may not be available (Lymphoedema Association of Queensland, 2005). Training courses in lymphoedema management are offered to health professionals by the Lymphoedema Association of Australia

(2001). For general practitioners and other therapist operating in these locations, the consideration of video-conferencing training courses is recommended.

In addition to lymphoedema, impaired sexuality was also found to affect a significant proportion of gynaecological cancer survivors following treatment. At a personal level of care, information booklets that consider sexuality after cancer diagnosis and treatment are already available to inform women about what to expect. At a social level of care, partner support is integral to the management of psychosexual wellbeing (Steginga & Dunn, 1997). At a health care level of support, psychosocial support for survivors and their partners, particularly cervical cancer survivors, with sexuality changes should be a critical subject of future program development and evaluation. A recent Brisbane-based study of early stage breast and gynaecological cancer survivors found that a counselling intervention for couples coping produced significant improvement in sexual adjustment as well as communication, reduced distress and coping, compared with individual coping training or the provision of medical information education (Scott *et al*, 2004). Similarly to Hutchison *et al's* (2006) tiered model of psychosocial support, a model of psychosexual support could be adopted which provides sexuality information to all cancer survivors and further triages sexuality and relationship distress to various psychosexual interventions depending on severity.

In addition to the distinction between gynaecological cancer and other cancers highlighted in the literature, this current study also reveals a detectable difference in supportive care needs and use within gynaecological cancer types. Perhaps the most interesting finding uncovered from this research is the pattern of supportive care needs and use within the uterine cancer survivor subgroup. Survivors of this particular cancer were less likely to use support services yet more likely to report unmet psychological needs relative to all other gynaecological cancer survivors and also more likely to report unmet health system and information needs relative to cervical cancer survivors. It is possible that unmet needs exist in this group because of the lack of exposure to support services. The system of care would benefit from further qualitative research to identify why these particular cancer survivors are not seeking appropriate support when they report a need for help.

The social-ecological model provided new insight into the broader range of variables that are important in determining the unmet needs of cancer survivors. This model also provided a holistic framework in which initiatives were considered at multiple levels of the model, with the aim of reducing the morbidity and unmet needs burden in this gynaecological cancer population. This approach was conducive to both 'top-down' and 'bottom-up' initiatives in addressing morbidity and unmet needs. This approach was also linked in with Hutchison *et al's* (2006) recently developed community-based approach to service provision of tiered psychosocial support. When considering the provision of support services, which map exclusively to the health care level of the social-ecological model, Hutchison *et al's* (2006) model was applied to further facilitate the consideration of the levels of interventions or initiatives that match the level of need or distress an individual may experience. The approach of considering social-ecological correlates of supportive care needs and a range of initiatives to meet these needs from within the different levels of the social-ecological model is rich and comprehensive and is recommended in future research.

REFERENCE

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., de Haes, J. C., & et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85*(5), 365-376.

Abang, M., Lopes, A., Regnard, C., & Monoghan, J. (1999). Lymphoedema following surgical treatment for vulva cancer: short-term follow up. *Int J Gynecol Cancer, 9*, 130.

Allen, S. M., & Mor, V. (1997). The prevalence and consequences of unmet need. Contrasts between older and younger adults with disability. *Medical Care, 35*(11), 1132-1148.

Ambron, S. R., & Brodzinsky, D. (1982). Family life, retirement and the final years. In *Lifespan human development*. New York: Holt,Rinehart and Winston.

American Cancer Society. (2004). *Guidelines For Using Complementary and Alternative Methods*. Retrieved from http://www.cancer.org/docroot/ETO/content/ETO_5_3x_Guidelines_For_Using_Complementary_and_Alternative_Methods.asp

American Cancer Society. (2005). *Complementary and Alternative Therapies*. Retrieved from http://www.cancer.org/docroot/ETO/ETO_5.asp?sitearea=ETO

Andersen, B. L. (1993). Predicting sexual and psychologic morbidity and improving the quality of life for women with gynecologic cancer. *Cancer, 71 suppl.*, 1678-1690.

Andersen, B. L., Anderson, B., & deProsse, C. (1989a). Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. *Journal of Consulting and Clinical Psychology, 57*(6), 683-691.

Andersen, B. L., Anderson, B., & deProsse, C. (1989b). Controlled prospective longitudinal study of women with cancer: II. Psychological outcomes. *Journal of Consulting and Clinical Psychology, 57*(6), 692-697.

Andersen, B. L., & Hacker, N. F. (1983). Psychosexual adjustment after vulvar surgery. *Obstetrics and Gynecology, 62*, 457-462.

Andersen, B. L., & Turnquist, D. C. (1989). Psychological issues. In J. S. B. a. N. F. Hacker (Ed.), *Practical gynecologic oncology* (pp. 631-656). Baltimore, Maryland: Williams & Wilkins.

Andersen, B. L., & van der Does, J. (1994). Surviving gynecologic cancer and coping with sexual morbidity: an international problem. *Int J Gynecol Cancer, 4*, 225-240.

Anderson, D., Yoshizawa, T., Gollschewski, S., Atogami, F., & Courtney, M. (2004). Relationship between menopausal symptoms and menopausal status in Australian and Japanese women: Preliminary analysis. *Nursing & Health Sciences, 6*(3), 173-180.

Aranda, S., Schofield, P., Weih, L., Yates, P., Milne, D., Faulkner, R., & Voudouris, N. (2005). Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *European Journal of Cancer Care (English Language Edition), 14*(3), 211-222.

Araujo, J. A., Curbelo, J. G., Mayol, A. L., Pascal, G. G., Vignale, R. A., & Fleurquin, F. (1997). Effective management of marked lymphedema of the leg. *International Journal of Dermatology, 36*(5), 389-392.

Arndt, V., Merx, H., Stegmaier, C., Ziegler, H., & Brenner, H. (2005). Persistence of restrictions in quality of life from the first to the third year after diagnosis in women with breast cancer. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 23*(22 (Print)), 4945-4953.

Arnold, E. M. (1999). The cessation of cancer treatment as a crisis. *Social Work in Health Care, 29*(2), 21-38.

Ashing-Giwa, K. T., Kagawa-Singer, M., Padilla, G. V., Tejero, J. S., Hsiao, E., Chhabra, R., Martinez, L., & Tucker, M. B. (2004). The impact of cervical cancer and dysplasia: a qualitative, multiethnic study. *Psycho-Oncology, 13*(10), 709-728.

Astin, J. A., Shapiro, S. L., Eisenberg, D. M., & Forys, K. L. (2003). Mind-body medicine: state of the science, implications for practice. *Journal of the American Board of Family Practice, 16*(2), 131-147.

Auchincloss, S. S. (1995). After treatment. Psychosocial issues in gynecologic cancer survivorship. *Cancer, 76*(10 Suppl), 2117-2124.

Australian Bureau of Statistics. (2004). *Causes of Death (2004)*. Australia: Australian Bureau of Statistics.

Australian Council of Stoma Associations. (2003). *Australian Council of Stoma Associations*. Retrieved from http://www.australianstoma.org.au/

Australian Government Dept of Health and Ageing. (2004). *Mindframe: a resource for media professionals*. Retrieved from http://www.mindframe-media.info/index.php

Australian Institute of Health and Welfare. (2001). *Number of new cases and age-specific rates for selected cancers by year of registration, sex and 5 year-age groups*. Retrieved from http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Cancer/canceragerratesv7

Australian Institute of Health and Welfare. (2003a). *The Active Australia Survey: a guide and manual for implementation, analysis and reporting*. Canberra: AIHW.

Australian Institute of Health and Welfare. (2003b). *Rural, Regional and Remote Health*. Canberra: Australian Institute of Health and Welfare.

Baade, P., & Coory, M. (2002). *Update on Mortality and Incidence Trends for Leading Cancers in Queensland, 1982 to 2000.* (No. Information Circular 63): Queensland Health.

Badger, C., Preston, N., Seers, K., & Mortimer, P. (2004). Benzo-pyrones for reducing and controlling lymphoedema of the limbs. *Cochrane database of systematic reviews (Online)*(2), CD003140.

Bandura, A. (1986). *Social foundations of thought and action: a social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.

Bardwell, W. A., Major, J. M., Rock, C. L., Newman, V. A., Thomson, C. A., Chilton, J. A., Dimsdale, J. E., & Pierce, J. P. (2004). Health-related quality of life in women previously treated for early-stage breast cancer. *Psycho-Oncology, 13*(9 (Print)), 595-604.

Basen-Engquist, K., Bodurka-Bevers, D., Fitzgerald, M., Webster, K., Cella, D., Hu, S., & Gershenson, D. (2001). Reliability and validity of the Functional Assessment of Cancer Therapy-Ovarian. *Journal of Clinical Oncology, 19*(6), 1809-1817.

Bauman, A., & Merom, D. (2002). Measurement and surveillance of physical activity in Australia - an introductory guide. *Australasian Epidemiologist, 9*(2), 2-6.

Beaton, D. E., Katz, J. N., Fossel, A. H., Wright, J. G., Tarasuk, V., & Bombardier, C. (2001). Measuring the whole or the parts? Validity, reliability, and responsiveness of the Disabilities of the Arm, Shoulder and Hand outcome measure in different regions of the upper extremity. *Journal of Hand Therapy, 14*(2), 128-146.

Beaufort, F., Drofenik, M., & Pleyer, K. (1988). Evaluation of drugs with questionable effectiveness and so-called natural preparations in oncology by patients. Results of a survey. *Wiener Medizinische Wochenschrift, 138*(4), 85-91.

Beesley, V. (2003). *Prostate, Gynaecological and Colorectal Cancer Survivor Issues and Support: A Qualitative Pilot Study*. Brisbane: Queensland University of Technology and Queensland Cancer Fund.

Bergmark, K., Avall-Lundqvist, E., Dickman, P. W., Henningsohn, L., & Steineck, G. (1999). Vaginal Changes and Sexuality in Women With a History of Cervical Cancer. *New England Journal of Medicine, 340*(18), 1383.

Biegel, D. E., Petchers, M. K., Snyder, A., & Beisgen, B. (1989). Unmet needs and barriers to service delivery for the blind and visually impaired elderly. *Gerontologist, 29*(1), 86-91.

Biglia, N., Gadducci, A., Ponzone, R., Roagna, R., & Sismondi, P. (2004). Hormone replacement therapy in cancer survivors. *Maturitas., 48*(4), 333-346.

Bingham, S. A., Day, N. E., Luben, R., Ferrari, P., Slimani, N., Norat, T., Clavel-Chapelon, F. o., Kesse, E., Nieters, A., Boeing, H., TjÃ¸nneland, A., Overvad, K., Martinez, C., Dorronsoro, M., Gonzalez, C. A., Key, T. J., Trichopoulou, A., Naska, A., Vineis, P., Tumino, R., Krogh, V., Bueno-de-Mesquita, H. B., Peeters, P. H. M., Berglund, G. r., Hallmans, G. r., Lund, E., Skeie, G., Kaaks, R., & Riboli, E. (2003). Dietary fibre in food and protection against colorectal cancer in the European Prospective Investigation into Cancer and Nutrition (EPIC): an observational study. *Lancet., 361*(9368), 1496-1501.

Blanchard, C. G., Albrecht, T. L., Ruckdeschel, J. C., Grant, C. H., & Hemmick, R. M. (1995). The role of social support in adaptation to cancer and to survival. *Journal of Psychosocial Oncology, 13*, 75-95.

Blanchard, C. M., McGannon, K. R., Spence, J. C., Rhodes, R. E., Nehl, E., Baker, F., & Bostwick, J. (2005). Social ecological correlates of physical activity in normal weight, overweight, and obese individuals. *International Journal of Obesity, 29*(6), 720-726.

Bloom, J. R. (2002). Surviving and thriving? *Psycho-Oncology, 11*(2), 89-92.

Bloomhill Cancer Help. (2005). Retrieved from www.bloomhill.com.au

Blumberg, B. D. (1983). Meeting the educational needs of adolescents with cancer. *Progress in Clinical and Biological Research, 130*, 85-89.

Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Offord, K. P., Koch, C., Wen, K. Y., Kreutz, K., & Salner, A. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counseling, 49*(3), 233-242.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., & Boyes, A. (2000). Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer, 88*(1), 217-225.

Bonevski, B., Sanson-Fisher, R., Hersey, P., Paul, C., & Foot, G. (1999). Assessing the Perceived Needs of Patients Attending an Outpatient Melanoma Clinic. *Journal of Psychosocial Oncology, 17*(3/4), 101-118.

Boon, H., Stewart, M., Kennard, M. A., Gray, R., Sawka, C., Brown, J. B., McWilliam, C., Gavin, A., Baron, R. A., Aaron, D., & Haines-Kamka, T. (2000). Use of complementary/alternative medicine by breast cancer survivors in Ontario: prevalence and perceptions. *Journal of Clinical Oncology, 18*(13), 2515-2521.

Bos-Branolte, G. (1991). Gynaecological Cancer: A Psychotherapy Group. In M. Watson (Ed.), *Cancer Patient Care: Psychosocial Treatment Methods* (pp. 260-280). Leicester: BPS Books.

Bourgeois-law, G. I., & Lotocki, R. (1999). Sexuality and Gynaecological Cancer: A Needs Assessment. *The Canadian journal of human sexuality, 8*(4), 231.

Bower, J. E., Ganz, P. A., Desmond, K. A., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2000). Fatigue in breast cancer survivors: occurrence, correlates, and impact on quality of life. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 18*(4 (Print)), 743-753.

Boyes, A., Girgis, A., & Zucca, A. (2002). *Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of needs assessment in oncology*. Sydney: The Cancer Council NSW & The University of Newcastle.

Boyle, P., Autier, P., Bartelink, H., Baselga, J., Boffetta, P., Burn, J., Burns, H. J. G., Christensen, L., Denis, L., Dicato, M., Diehl, V., Doll, R., Franceschi, S., Gillis, C. R., Gray, N., Griciute, L., Hackshaw, A., Kasler, M., Kogevinas, M., Kvinnsland, S., La Vecchia, C., Levi, F., McVie, J. G., Maisonneuve, P., Martin-Moreno, J. M., Bishop, J. N., Oleari, F., Perrin, P., Quinn, M., Richards, M., Ringborg, U., Scully, C., Siracka, E., Storm, H., Tubiana, M., Tursz, T., Veronesi, U., Wald, N., Weber, W., Zaridze, D. G., Zatonski, W., & zur Hausen, H. (2003). European Code Against Cancer and scientific justification: third version (2003). *Annals of oncology : official journal of the European Society for Medical Oncology., 14*(7), 973-1005.

Bradley, K. A., Badrinath, S., Bush, K., Boyd-Wickizer, J., & Anawalt, B. (1998). Medical risks for women who drink alcohol. *Journal of general internal medicine : official journal of the Society for Research and Education in Primary Care Internal Medicine., 13*(9), 627-639.

Brady, M. J., Peterman, A. H., Fitchett, G., Mo, M., & Cella, D. (1999). A case for including spirituality in quality of life measurement in oncology. *Psycho-Oncology, 8*(5), 417-428.

Bredart, A., Razavi, D., Delvaux, N., Goodman, V., Farvacques, C., & Van Heer, C. (1998). A comprehensive assessment of satisfaction with care for cancer patients. *Supportive Care in Cancer, 6*(6), 518-523.

Bredart, A., Robertson, C., Razavi, D., Batel-Copel, L., Larsson, G., Lichosik, D., Meyza, J., Schraub, S., von Essen, L., & de Haes, J. C. (2003). Patients' satisfaction ratings and their desire for care improvement across oncology settings from France, Italy, Poland and Sweden. *Psycho-Oncology, 12*(1), 68-77.

Brennan, J. (2001). Adjustment to cancer - coping or personal transition? *Psycho-Oncology, 10*(1), 1-18.

Broadhead, W. E., Gehlbach, S. H., de Gruy, F. V., & Kaplan, B. H. (1988). The Duke-UNC Functional Social Support Questionnaire. Measurement of social support in family medicine patients. *Medical Care, 26*(7), 709-723.

Brock, C., & Perry, D. (1995). Report on the social and emotional impact of cancer diagnosis on young adults. *Austral Soc Work, 48*, 29-32.

Bronfenbrenner, U. (1979). *The Ecology of Human Development*. USA: Harvard University Press.

Brown, J., Byers, T., Thompson, K., Eldridge, B., Doyle, C., & Williams, A. M. (2001). Nutrition during and after cancer treatment: a guide for informed choices by cancer survivors. *CA: A Cancer Journal for Clinicians, 51*(3 (Print)), 153.

Brown, J. K., Byers, T., Doyle, C., Coumeya, K. S., Demark-Wahnefried, W., Kushi, L. H., McTieman, A., Rock, C. L., Aziz, N., Bloch, A. S., Eldridge, B., Hamilton, K., Katzin, C., Koonce, A., Main, J., Mobley, C., Morra, M. E., Pierce, M. S., & Sawyer, K. A. (2003). Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices. *CA: a cancer journal for clinicians., 53*(5), 268-291.

Burstein, H. J., Gelber, S., Guadagnoli, E., & Weeks, J. C. (1999). Use of alternative medicine by women with early-stage breast cancer. *New England Journal of Medicine, 340*(22), 1733-1739.

Canadian Association of Psychosocial Oncology. (1999). *Standards: Canadian Association of Psychosocial Oncology*. Toronto, Canada: Canadian Association of Psychosocial Oncology.

Capner, M. (2000). Videoconferencing in the provision of psychological services at a distance. *Journal of Telemedicine and Telecare, 6*(6 (Print)), 311-319.

Carlson, L. E., & Bultz, B. D. (2003). Cancer distress screening. Needs, models, and methods. *Journal of Psychosomatic Research, 55*(5 (Print)), 403-409.

Cashel, K., & Jeffreson, S. (1995). *The Core Food Groups*. Canberra: Endorsed by the National Health and Medical Research Council.

Casley-Smith, J. R. (1999). Benzo-pyrones in the treatment of lymphoedema. *International angiology : a journal of the International Union of Angiology, 18*(1), 31-41.

Casley-Smith, J. R., & Casley-Smith, J. R. (1992). Modern treatment of lymphoedema. I. Complex physical therapy: the first 200 Australian limbs. *The Australasian Journal of Dermatology, 33*(2), 61-68.

Cavanagh, D., Fiorica, J. V., Hoffman, M. S., Roberts, W. S., Bryson, S. C., LaPolla, J. P., & Barton, D. P. (1990). Invasive carcinoma of the vulva. Changing trends in surgical management. *American Journal of Obstetrics and Gynecology, 163*(3), 1007-1015.

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., Brannon, J., & et al. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology, 11*(3), 570-579.

Chan, Y. M., Ngan, H. Y., Li, B. Y., Yip, A. M., Ng, T. Y., Lee, P. W., Yip, P. S., & Wong, L. C. (2001a). A longitudinal study on quality of life after gynecologic cancer treatment. *Gynecologic Oncology, 83*(1), 10-19.

Chan, Y. M., Ngan, H. Y., Yip, P. S., Li, B. Y., Lau, O. W., & Tang, G. W. (2001b). Psychosocial adjustment in gynecologic cancer survivors: a longitudinal study on risk factors for maladjustment. *Gynecologic Oncology, 80*(3), 387-394.

Chisholm, J., Donoghue, J., Dunn, K., Farmer, F., Hannan, R., Introna, K., O'Baugh, J., Mitten-Lewis, S., Rickard, J., & Szwajcer, A. (2000). A comparison of the awareness and utilisation of postoperative health services provided to women with breast cancer in public and private hospitals. *Australian Health Review: A Publication Of The Australian Hospital Association, 23*(2 (Print)), 113-122.

Christensen, D. N. (1983). Postmastectomy couple counseling: an outcome study of a structured treatment protocol. *Journal Of Sex & Marital Therapy, 9*(4 (Print)), 266-275.

Clark, B., Sitzia, J., & Harlow, W. (2005). Incidence and risk of arm oedema following treatment for breast cancer: a three-year follow-up study. *QJM : monthly journal of the Association of Physicians, 98*(5), 343-348.

Clipp, E. C., Hollis, D. R., & Cohen, H. J. (2001). Considerations of psychosocial illness phase in cancer survival. *Psycho-Oncology, 10*(2 (Print)), 166-178.

Commonwealth Office of the Status of Women. (2002). *Women in rural Australia*. Canberra: Commonwealth Office of the Status of Women,.

Corney, R., Everett, H., Howells, A., & Crowther, M. (1992). The care of patients undergoing surgery for gynaecological cancer: the need for information, emotional support and counselling. *Journal of Advanced Nursing, 17*(6), 667-671.

Corney, R. H., Crowther, M. E., Everett, H., Howells, A., & Shepherd, J. H. (1993). Psychosexual dysfunction in women with gynaecological cancer following radical pelvic surgery. *British journal of obstetrics and gynaecology., 100*(1), 73-78.

Corrigan, P. (2004). How stigma interferes with mental health care. *The American Psychologist, 59*(7 (Print)), 614-625.

Courneya, K. S., Keats, M. R., & Turner, R. (2000). Social Cognitive Determinants of Hospital-Based Exercise in Cancer Patients Following High-Dose Chemotherapy and Bone Marrow Transplantation. *International Journal of Behavioral Medicine, 7*(3), 189-203.

Courtens, A. M., Stevens, F. C., Crebolder, H. F., & Philipsen, H. (1996). Longitudinal study on quality of life and social support in cancer patients. *Cancer nursing., 19*(3), 162-169.

Coyne, J. C., Benazon, N. R., Gaba, C. G., Calzone, K., & Weber, B. L. (2000). Distress and Psychiatric Morbidity Among Women From High-Risk Breast and Ovarian Cancer Families. *Journal of Consulting and Clinical Psychology, 68*(5), 864-874.

Crittenden, P. M. (1992). The social ecology of treatment: case study of a service system for maltreated children. *American Journal of Orthopsychiatry, 62*(1), 22-34.

Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: a model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88*(2), 125-138.

Cunningham, A. J. (2000). Adjuvant psychological therapy for cancer patients: putting it on the same footing as adjunctive medical therapies. *Psycho-Oncology, 9*(5 (Print)), 367-371.

Demark-Wahnefried, W., Aziz, N. M., Rowland, J. H., & Pinto, B. M. (2005). Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 23*(24 (Print)), 5814-5830.

Demark-Wahnefried, W., Peterson, B., McBride, C., Lipkus, I., & Clipp, E. (2000). Current Health Behaviours and Readiness to Pursue Life-Style Changes among Men and Women Diagnosed with Early Stage Prostate and Breast Carcinomas. *Cancer, 88*(3), 674-684.

Department of Health NSW. (2001). *Shared Responsibility for Patient Care between Hospitals and the Community - An Effective Discharge Policy*: Department of Health NSW.

Department of Health NSW. (2005). *Discharge Planning Principles*: Department of Health NSW.

Derogatis, L. R. (1980). Breast and gynecological cancers. *Frontiers of Radiation Therapy and Oncology, 14*, 1-11.

Derogatis, L. R., Morrow, G. R., Fetting, J., Penman, S., Piasetsky, S., Schmale, A. M., Henrichs, M., & Carnicke, C. L. M. (1983). The prevalence of psychiatric disorders among cancer patients. *JAMA, 249*, 751-757.

Devine, E. C., & Westlake, S. K. (1995). The effects of psychoeducational care provided to adults with cancer: meta-analysis of 116 studies. *Oncology Nursing Forum, 22*(9 (Print)), 1369-1381.

DHAC, D. o. H. a. A. C. (1999). *National Physical Activity Guidelines for Australians*. Canberra.

Dillman, D. (1978). *Mail and Telephone Surveys: the total design method*. New York: Wiley.

DiSipio, T., Rogers, C., Newman, B., Whiteman, D., Eakin, E., Fritschi, L., & Aitken, J. (2006). The Queensland Cancer Risk Study: Behavioural Risk Factor Results. *Australian and New Zealand Journal of Public Health, 30*(4), 375-382.

Dixon, H., Chapman, K., Hodge, A., & Slevin, T. (2005). *Body Weight, Nutrition, Alcohol and Physical Activity: Key Messages for The Cancer Council Australia*.

Dobkin, P. (1991). Assessment of sexual dysfunction in oncology patients: review, critique, and suggestions. *Journal of Psychosocial Oncology, 9*(1), 43-74.

Drake, D., Falzer, P., Xistris, D., Robinson, G., & Roberge, M. (2004). Physical fitness training: outcomes for adult oncology patients. *Clinical nursing research., 13*(3), 245-264.

Eakin, E. G., & Strycker, L. A. (2001). Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. *Psycho Oncology, 10*(2), 103-113.

Eisenberg, D. M., Davis, R. B., Ettner, S. L., Appel, S., Wilkey, S., Van Rompay, M., & Kessler, R. C. (1998). Trends in alternative medicine use in the United States, 1990-1997: results of a follow-up national survey. *JAMA, 280*(18), 1569-1575.

Eisenberg, D. M., Kessler, R. C., Foster, C., Norlock, F. E., Calkins, D. R., & Delbanco, T. L. (1993). Unconventional medicine in the United States. Prevalence, costs, and patterns of use. *New England Journal of Medicine, 328*(4), 246-252.

Ernst, E. (2000). The role of complementary and alternative medicine in cancer. *The lancet oncology, 1*, 176-180.

Ernst, E., & Cassileth, B. R. (1998). The prevalence of complementary/alternative medicine in cancer: a systematic review. *Cancer, 83*(4), 777-782.

Evans, D. L., McCartney, C. F., Nemeroff, C. B., Raft, D., Quade, D., Golden, R. N., Haggerty, J. J., Holmes, V., Simon, J. S., Droba, M., Mason, G. A., & Fowler, W. C. (1986). Depression in women treated for gynecological cancer: clinical and neuroendocrine assessment. *American Journal of Psychiatry, 143*, 447-452.

Ey, S., Compas, B., Epping-Jordan, J., & Worsham, N. (1998). Stress responses and psychological adjustment in patients with cancer and their spouses. *Journal of Psychosocial Oncology, 16*(2), 59-77.

FACIT. (2004). *Functional Assessment of Chronic Illness Therapy: effect size and clinically meaningful change*. Retrieved from http://www.facit.org/validity/validation_change.aspx

Fallowfield, L., Ratcliffe, D., Jenkins, V., & Saul, J. (2001). Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer, 84*(8 (Print)), 1011-1015.

Fang, C. Y., Manne, S. L., & Pape, S. J. (2001). Functional Impairment, Marital Quality, and Patient Psychological Distress As Predictors of Psychological Distress Among Cancer Patients' Spouses. *Health Psychology, 20*(6), 452-457.

Fehring, R. J., Miller, J. F., & Shaw, C. (1997). Spiritual well-being, religiosity, hope, depression, and other mood states in elderly people coping with cancer. *Oncology Nursing Forum, 24*(4), 663-671.

Fenerty, N. J. (1993). Interdisciplinary discharge planning. A continuing care management model. *Cancer Practice, 1*(2 (Print)), 147-152.

Fernsler, J. I., Klemm, P., & Miller, M. A. (1999). Spiritual well-being and demands of illness in people with colorectal cancer. *Cancer Nursing, 22*(2), 134-140; quiz 141-132.

Ferrell, B., Grant, M., Schmidt, G. M., Rhiner, M., Whitehead, C., Fonbuena, P., & Forman, S. J. (1992). The meaning of quality of life for bone marrow transplant survivors. Part 1. The impact of bone marrow transplant on quality of life. *Cancer Nursing, 15*(3), 153-160.

Ferrell, B. R., Dow, K. H., & Grant, M. (1995a). Measurement of the quality of life in cancer survivors. *Quality of Life Research, 4*(6), 523-531.

Ferrell, B. R., Dow, K. H., Leigh, S., Ly, J., & Gulasekaram, P. (1995b). Quality of life in long-term cancer survivors. *Oncology Nursing Forum, 22*(6), 915-922.

Fillenbaum, G. G. (1988). *Multidimensional Functional Assessment of Older Adults*. Hillsdale: Lawrence Erlbaum.

Fitch, M. I., Gray, R. E., DePetrillo, D., Franssen, E., & Howell, D. (1999). Canadian women's perspectives on ovarian cancer. *Cancer Prevention & Control, 3*(1), 52-60.

Fitchett, G. (1999). Screening for spiritual risk. *Chaplaincy Today, 15*, 1-12.

Fobair, P., Hoppe, R. T., Bloom, J., Cox, R., Varghese, A., & Spiegel, D. (1986). Psychosocial problems among survivors of Hodgkin's disease. *Journal of Clinical Oncology, 4*(5), 805-814.

Foot, G. (1996). *Needs assessment in tertiary and secondary oncology practice: a conceptual and methodological exposition.* University of Newcastle, Newcastle.

Foot, G., & Sanson-Fisher, R. (1995). Measuring the unmet needs of people living with cancer. *Cancer Forum, 19*(2), 131-135.

Ford, S., Fallowfield, L., & Lewis, S. (1994). Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *British Journal of Cancer, 70*(4 (Print)), 767-770.

Funch, D. P., & Mettlin, C. (1982). The role of support in relation to recovery from breast surgery. *Social Science and Medicine, 16*(1), 91-98.

Galloway, S. C., & Graydon, J. E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer nursing., 19*(2), 112-117.

Gamel, C., Hengeveld, M., Davis, B., & Gamel, C. (2000). Informational needs about the effects of gynaecological cancer on sexuality: a review of the literature. *Journal of Clinical Nursing, 9*(5), 678-688.

Ganz, P. A., Greendale, G. A., Petersen, L., Kahn, B., & Bower, J. E. (2003). Breast cancer in younger women: reproductive and late health effects of treatment. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 21*(22 (Print)), 4184-4193.

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E., & Wyatt, G. E. (1998). Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 16*(2 (Print)), 501-514.

Germino, B. B., & Funk, S. G. (1993). Impact of a parent's cancer on adult children: role and relationship issues. *Sem Oncol Nurs, 9*, 101-106.

Gioiella, M. E., Berkman, B., & Robinson, M. (1998). Spirituality and quality of life in gynecologic oncology patients. *Cancer Practice, 6*(6), 333-338.

Girgis, A., Adams, J., & Sibbritt, D. (2005). The use of complementary and alternative therapies by patients with cancer. *Oncology Research, 15*(5 (Print)), 281-289.

Girgis, A., & Boyes, A. (2005). Proactive routine monitoring and intervention to reduce the psychosocial impact of cancer therapy. *Clinical Psychologist, 9*(2), 70-73.

Girgis, A., Boyes, A., Sanson-Fisher, R. W., & Burrows, S. (2000). Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Australian and New Zealand Journal of Public Health, 24*(2), 166-173.

Goodwin, J. S., Hunt, W. C., & Samet, J. M. (1991). A population-based study of functional status and social support networks of elderly patients newly diagnosed with cancer. *Archives of Internal Medicine, 151*(2), 366-370.

Gotay, C. C., & Muraoka, M. Y. (1998). Quality of life in long-term survivors of adult-onset cancers. *Journal of the National Cancer Institute, 90*(9), 656-667.

Green, M. S., Naumann, R. W., Elliot, M., Hall, J. B., Higgins, R. V., & Grigsby, J. H. (2000). Sexual dysfunction following vulvectomy. *Gynecologic Oncology, 77*(1 (Print)), 73-77.

Greer, S. (1994). Psycho-oncology: its aims achievements and future tasks. *Psycho-Oncology, 3*, 87-101.

Greimel, E. R., & Freidl, W. (2000). Functioning in daily living and psychological well-being of female cancer patients. *Journal of psychosomatic obstetrics and gynaecology., 21*(1), 25-30.

Griffiths, L., Blignault, I., & Yellowlees, P. (2006). Telemedicine as a means of delivering cognitive-behavioural therapy to rural and remote mental health clients. *Journal of Telemedicine and Telecare, 12*(3 (Print)), 136-140.

Gross, J. (1989). Emotional expression in cancer onset and progression. *Social Science and Medicine, 28*(12), 1239-1248.

Gustafson, D. H. (1991). Expanding on the role of patient as consumer. *QRB. Quality Review Bulletin, 17*(10), 324-325.

Gustafson, D. H., Taylor, J. O., Thompson, S., & Chesney, P. (1993). Assessing the needs of breast cancer patients and their families. *Quality Management in Health Care, 2*(1), 6-17.

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine, 118*(8 (Print)), 622-629.

Gynaecological Cancer Society. (2000). *Gynaecological Cancer Society*. Retrieved from http://www.gcsau.org/

Gynaecological Cancer Society. (2003). *Gynaecological Cancer - Diagnosis*. Retrieved from http://www.gcsq.org.au/patient/cx_diagnosis.asp#Stages

Hancock, L., Lattimore-Foot, G., Lawrence, J., & Welch, J. (2002). *Cited in Boyes, A. Girgis, A. Zucca, A. Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of* *needs assessment in oncology*. Sydney: The Cancer Council NSW & The University of Newcastle.

Harpur, L. L. (2002). Gynaecological Cancer: Some Suggestions for Counselling Intervention. *Guidance and Counseling, 17*(3), 81.

Haythornthwaite, S. (2002). Videoconferencing training for those working with at-risk young people in rural areas of Western Australia. *Journal of Telemedicine and Telecare, 8 Suppl 3*, S3:29-33.

Hewitt, M., Greenfield, S., & Stovall, E. (2005). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: Institute of Medicine and National Research Council.

Hewitt, M., & Rowland, J. H. (2002). Mental health service use among adult cancer survivors: analyses of the National Health Interview Survey. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 20*(23 (Print)), 4581-4590.

Holland, J. C. (1982). Psychological aspects of cancer. In J. F. Holland & E. Frei (Eds.), *Cancer Medicine* (2nd ed., pp. 1175-1204). Philadelphia: Lea & Febiger.

Holland, J. C., & Lesko, L. M. (1989). Chemotherapy, endocrine therapy, and immunotherapy. In J. C. H. a. J. H. Rowland (Ed.), *Handbook of psychooncology: psychological care of the patient with cancer* (pp. 146-162). New York: Oxford University Press.

Holland, J. C., Passik, S., Kash, K. M., Russak, S. M., Gronert, M. K., Sison, A., Lederberg, M., Fox, B., & Baider, L. (1999). The role of religious and spiritual beliefs in coping with malignant melanoma. *Psycho-Oncology, 8*(1), 14-26.

Holzner, B., Kemmler, G., Kopp, M., Moschen, R., Schweigkofler, H., Duenser, M., Margreiter, R., Fleischhacker, W. W., & Sperner-Unterweger, B. (2001). Quality of life in breast cancer patients: Not enough attention for long-term survivors? *Psychosomatics, 42*(2), 117-123.

Hoskins, C. N., Baker, S., Sherman, D., & Bohlander, J. (1996). Social support and patterns of adjustment to breast cancer. *Scholarly Inquiry for Nursing Practice, 10*(2), 99-123.

Houldin, A. D., & Wasserbauer, N. (1996). Psychosocial needs of older cancer patients: a pilot study abstract. *Medsurg Nursing, 5*(4), 253-256.

Houts, P. S., Yasko, J. M., Harvey, H. A., Kahn, S. B., Hartz, A. J., Hermann, J. F., Schelzel, G. W., & Bartholomew, M. J. (1988). Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. *Cancer, 62*(3), 627-634.

Houts, P. S., Yasko, J. M., Kahn, S. B., Schelzel, G. W., & Marconi, K. M. (1986). Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. *Cancer, 58*(10), 2355-2361.

Hudson, M. M. (2005). A model for care across the cancer continuum. *Cancer, 104*(11 Suppl (Print)), 2638-2642.

Hung, H.-C., Joshipura, K. J., Jiang, R., Hu, F. B., Hunter, D., Smith-Warner, S. A., Colditz, G. A., Rosner, B., Spiegelman, D., & Willett, W. C. (2004). Fruit and vegetable intake and risk of major chronic disease. *Journal of the National Cancer Institute, 96*(21 (Electronic)), 1577-1584.

Hutchison, S. D., Steginga, S. K., & Dunn, J. (2006). The tiered model of psychosocial intervention in cancer: a community based approach. *Psycho-Oncology, 15*(6), 541-546.

International Agency for Research on Cancer. (2002). *Weight control and physical activity*. Lyon, France: WHO.

Irwin, M. L., & Ainsworth, B. E. (2004). Physical activity interventions following cancer diagnosis: methodologic challenges to delivery and assessment. *Cancer investigation., 22*(1), 30-50.

Irwin, M. L., Yasui, Y., Ulrich, C. M., Bowen, D., Rudolph, R. E., Schwartz, R. S., Yukawa, M., Aiello, E., Potter, J. D., & McTiernan, A. (2003). Effect of exercise on total and intra-abdominal body fat in postmenopausal women: a randomized controlled trial. *JAMA : the journal of the American Medical Association., 289*(3), 323-330.

Izsak, F. C., & Medalie, J. H. (1971). Comprehensive follow-up of carcinoma patients. *Journal of Chronic Diseases, 24*(2), 179-191.

Janda, M., Obermair, A., Cella, D., Perrin, L. C., Nicklin, J. L., Ward, B. G., Crandon, A. J., & Trimmel, M. (2005). The functional assessment of cancer-vulvar: reliability and validity. *Gynecologic oncology., 97*(2), 568-575.

Jefferies, H. (2002). Ovarian cancer patients: are their informational and emotional needs being met? *Journal of Clinical Nursing, 11*(1), 41-47.

Jenkins, R., & Kl., P. (1995). Religion and spirituality as resources for coping with cancer. *Journal of Psychosocial Oncology, 13*, 51-74.

Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer, 84*(1), 48-51.

Jones, G. L., Ledger, W., Bonnett, T. J., Radley, S., Parkinson, N., & Kennedy, S. H. (2006). The impact of treatment for gynecological cancer on health-related quality of life (HRQoL): a systematic review. *American Journal of Obstetrics and Gynecology, 194*(1 (Electronic)), 26-42.

Jong, M. (2004). Managing suicides via videoconferencing in a remote northern community in Canada. *International Journal of Circumpolar Health, 63*(4 (Print)), 422-428.

Kaczorowski, J. M. (1989). Spiritual well-being and anxiety in adults diagnosed with cancer. *Hospice Journal, 5*(3-4), 105-116.

Kalman, D., & Villani, L. J. (1997). Nutritional aspects of cancer-related fatigue. *Journal of the American Dietetic Association, 97*(6 (Print)), 650-654.

Kane, R., & Boult, C. (1998). Defining the service needs of frail older persons. In S. Allen & V. Mor (Eds.), *Living in the community with disability: Service needs, use and systems.* New York: Springer.

Karlsson, J. A., & Andersen, B. L. (1986). Radiation therapy and psychological distress in gynecologic cancer patients: outcomes and recommendations for enhancing adjustment. *Journal of Psychosomatic Obstetrics and Gynaecology, 5*, 83-294.

Katz, M., Cunningham, W., Mor, V., Anderson, R., Kellogg, T., Zierler, S., Crystal, S., Stein, M., Cylar, K., Bozzette, S., & Shapiro, M. (2000). Prevalence and predictors of unmet needs for supportive services among HIV-infected persons: Impact of case management. *Medical Care, 38*, 58-69.

Kazak, A. (2001). Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice, and policy. *Children's Services: Social Policy, Research, & Practice, 4*(4), 217-233.

Kazak, A. E. (1989). Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *Journal of Consulting & Clinical Psychology, 57*(1), 25-30.

Kemmler, G., Holzner, B., Kopp, M., Dünser, M., Margreiter, R., Greil, R., & Sperner-Unterweger, B. (1999). Comparison of two quality-of-life instruments for cancer patients: the functional assessment of cancer therapy-general and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology, 17*(9 (Print)), 2932-2940.

Kennedy, B. J., Tellegen, A., Kennedy, S., & Havernick, N. (1976). Psychological response of patients cured of advanced cancer. *Cancer, 38*(5), 2184-2191.

Kessler, R. C., Price, R. H., & Wortman, C. B. (1985). Social factors in psychopathology: stress, social support, and coping processes. *Annual Review of Psychology, 36*, 531-572.

Kiebert, G. M., & Kaasa, S. (1996). Quality of life in clinical cancer trials: experience and perspective of the European Organization for Research and Treatment of Cancer. *Journal Of The National Cancer Institute. Monographs*(20 (Print)), 91-95.

King, A. C. (1991). Community intervention for promotion of physical activity and fitness. *Exercise and sport sciences reviews., 19*, 211-259.

Kirk, M., Hoban, E., Dunne, A., & Manderson, L. (1997). *Barriers to and Appropriate Delivery Systems for Cervical Cancer Screening in Indigenous Communities in Queensland*. Brisbane: Queensland Health.

Kirkwood, B. (1989). *Essentials of Medical Statistics*. London: Blackwell Scientific Publications.

Klee, M., Thranov, I., & Machin, D. (2000a). Life after radiotherapy: the psychological and social effects experienced by women treated for advanced stages of cervical cancer. *Gynecologic Oncology, 76*(1), 5-13.

Klee, M., Thranov, I., & Machin Prof, D. (2000b). The patients' perspective on physical symptoms after radiotherapy for cervical cancer. *Gynecologic Oncology, 76*(1), 14-23.

Knapp, R. C., & Berkowitz , R. S. (1986). *Gynecologic oncology*. New York: Macmillan.

Laganà, L., McGarvey, E. L., Classen, C., & Koopman, C. (2001). Psychosexual dysfunction among gynecological cancer survivors. *Journal of Clinical Psychology in Medical Settings, 8*(2), 73-84.

Laky, B., Janda, M., Bauer, J., Vavra, C., Cleghorn, G., & Obermair, A. (2006). Malnutrition amongst gynaecological cancer patients. *European Journal of Clinical Nutrition*(Oct 4).

Lancaster, T., & Nattress, K. (2005). *Gynaecological cancer care : a guide to practice*. Melbourne: Ausmed Publications.

Lane, K., Worsley, D., & McKenzie, D. (2005). Exercise and the lymphatic system: implications for breast-cancer survivors. *Sports Medicine (Auckland, N.Z.), 35*(6 (Print)), 461-471.

Lazarus, R., & Folkman, S. (1984). *Stress Appraisal and Coping*. New York: Springer.

Lehr, H., & Strosberg, M. (1991). Quality improvement in health care: is the patient still left out? *QRB. Quality Review Bulletin, 17*(10), 326-329.

Leiberich, P., Averbeck, M., Grote-Kusch, M., Schroeder, A., & et al. (1993a). Life quality of cancer patients as a multidimensional concept. *Zeitschrift Fuer Psychosomatische Medizin und Psychoanalyse, 39*(1), 26-37.

Leiberich, P., Averbeck, M., Grote-Kusch, M., Schroeder, A., Olbrich, E., & Kalden, J. R. (1993b). [The quality of life of tumor patients as a multidimensional concept]. *Zeitschrift fur Psychosomatische Medizin und Psychoanalyse, 39*(1), 26-37.

Lepore, S. J., Silver, R. C., Wortman, C. B., & Wayment, H. A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology, 70*(2), 271-282.

Lev, E. L. (1997). Bandura's theory of self-efficacy: applications to oncology. *Scholarly Inquiry for Nursing Practice, 11*(1), 21-37; discussion 39-43.

Lewis, F. M. (1993). Psychosocial transitions and the family's work in adjusting to cancer. *Seminars in Oncology Nursing, 9*, 127-129.

Liang, L. P., Dunn, S. M., Gorman, A., & Stuart-Harris, R. (1990). Identifying priorities of psychosocial need in cancer patients. *British Journal of Cancer, 62*(6), 1000-1003.

Linder-Pelz, S. U. (1982). Toward a theory of patient satisfaction. *Social Science and Medicine, 16*(5), 577-582.

Luecken, L. J., & Compas, B. E. (2002). Stress, coping, and immune function in breast cancer. *Annals of Behavioral Medicine, 24*(4), 336-344.

Lymphoedema Association of Australia. (2001). *Treatment of lymphoedema*. Retrieved from http://www.lymphoedema.org.au/index.html

Lymphoedema Association of Queensland. (2003). *Lymphoedema Association of Queensland*. Retrieved from http://homepage.powerup.com.au/~lymphqld/

Lymphoedema Association of Queensland. (2005). *Lymphoedema Treatment Facilities and Resources Directory: Queensland and Northern NSW, October 2005*. Bracken Ridge: Lymphoedema Association of Queensland.

Maguire, P., Walsh, S., Jeacock, J., & Kingston, R. (1999). Physical and psychological needs of patients dying from colo-rectal cancer. *Palliative Medicine, 13*(1), 45-50.

Maher, E. L. (1982). Anomic aspects of recovery from cancer. *Social Science and Medicine, 16*(8), 907-912.

Markovic, M., Manderson, L., Wray, N., & Quinn, M. (2004). 'He's telling us something': Women's experiences of cancer disclosure and treatment decision making in Australia. *Anthropology & Medicine, 11*(3), 327-341.

Marshall, P. A. (1990). Cultural influences on perceived quality of life. *Seminars in Oncology Nursing, 6*(4), 278-284.

Massie, M. J. (1989). Depression. In J. C. H. a. J. H. Rowland (Ed.), *Handbook of psychooncology: psychological care of the patient with cancer* (pp. 283-290). New York: Oxford University Press.

Matthiesen, L., & Simonsen, E. (1990). Lymphedema of legs and truncus as a complication of cancer colli uteri and treatment. *European Journal of Gynaecological Oncology, 11*(1), 23-25.

Mayer, N. H. (1975). Concepts in cancer rehabilitation. *Seminars in Oncology, 2*(4), 393-398.

McDaniel, J. S., Musselman, D. L., Porter, M. R., Reed, D. A., & Nemeroff, C. B. (1995). Depression in patients with cancer: diagnosis, biology, and treatment. *Archives of General Psychiatry, 52*, 89-99.

McElduff, P., Boyes, A., Zucca, A., & Girgis, A. (2004). *Supportive Care Needs Survey: A guide to administration, scoring and analysis*. Newcastle, Australia: The University of Newcastle.

McLachlan, S. A., Allenby, A., Matthews, J., Wirth, A., Kissane, D., Bishop, M., Beresford, J., & Zalcberg, J. (2001). Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology, 19*(21), 4117-4125.

McMichael, C., Kirk, M., Manderson, L., Hoban, E., & Potts, H. (2000). Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. *Australian & New Zealand Journal of Public Health, 24*(5), 515-519.

Meredith, C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C. R., & Fallowfield, L. (1996). Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ, 313*(7059), 724-726.

Meyer, T. J., & Mark, M. M. (1995). Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomized experiments. *Health Psychology: Official Journal Of The Division Of Health Psychology, American Psychological Association, 14*(2 (Print)), 101-108.

Miller, B. E., Pittman, B., Case, D., & McQuellon, R. P. (2002). Quality of life after treatment for gynecologic malignancies: a pilot study in an outpatient clinic. *Gynecologic Oncology, 87*(2), 178-184.

Miller, B. E., Pittman, B., & Strong, C. (2003). Gynecologic cancer patients' psychosocial needs and their views on the physician's role in meeting those needs. *Int J Gynecol Cancer, 13*(2), 111-119.

Mock, V., Dow, K. H., Meares, C. J., Grimm, P. M., Dienemann, J. A., Haisfield-Wolfe, M. E., Quitasol, W., Mitchell, S., Chakravarthy, A., & Gage, I. (1997). Effects of exercise on fatigue, physical functioning, and emotional distress during radiation therapy for breast cancer. *Oncology nursing forum., 24*(6), 991-1000.

Modesitt, S. C., & van Nagell, J. R., Jr. (2005). The impact of obesity on the incidence and treatment of gynecologic cancers: a review. *Obstetrical & Gynecological Survey, 60*(10 (Print)), 683-692.

Molassiotis, A., Chan, C. W., Yam, B. M., Chan, E. S., & Lam, C. S. (2002). Life after cancer: adaptation issues faced by Chinese gynaecological cancer survivors in Hong Kong. *Psycho-Oncology., 11*(2), 114-123.

Montazeri, A., McEwen, J., & Gillis, C. R. (1996). Quality of life in patients with ovarian cancer: current state of research. *Supportive Care in Cancer, 4*(3), 169-179.

Montoya, I. D., Richard, A. J., Bell, D. C., & Atkinson, J. S. (1997). An analysis of unmet need for HIV services: The Houston Study. *Journal of Health Care for the Poor and Underserved, 8*(4), 446-460.

Mor, V., Guadagnoli, E., & Rosenstein, R. (1991). Cancer patients' unmet support needs as a quality-of-life indicator. In D. Osoba (Ed.), *Effect of cancer on quality of life* (pp. 155-168). Boca Raton: FL: CRC Press.

Mor, V., Guadagnoli, E., & Wool, M. (1988). The role of concrete services in cancer care. In R. J. Goldberg & S. Karger (Eds.), *Psychosocial Aspects of Cancer*. Basel.

Mor, V., Masterson-Allen, S., Houts, P., & Siegel, K. (1992). The changing needs of patients with cancer at home. A longitudinal view. *Cancer, 69*(3), 829-838.

Morales Lopez, A., Grau Fibla, G., Campoy Martinez, P., Benavente Rodriguez, A., & Pascual del Pobil Moreno, J. L. (2002). [Development of the ESCAP-CDV as measuring tool for the assessment of quality of life in prostatic cancer]. *Actas Urologicas Espanolas, 26*(4), 242-249.

Moseley, A. L., Piller, N., Esterman, A., & Carati, C. (2004). The Sun Ancon Chi Machine Aerobic Exerciser: a new patient focused, home based therapy for people with chronic secondary leg lymphedema. *Lymphology, 37*(2 (Print)), 53-61.

Mullin, F. (1990). *Charting the Journey: Almanac of Practical Resources for Cancer Survivors*. New York: Consumer Union.

Munstedt, K., Kirsch, K., Milch, W., Sachsse, S., & Vahrson, H. (1996). Unconventional cancer therapy--survey of patients with gynaecological malignancy. *Archives of Gynecology and Obstetrics, 258*(2), 81-88.

Musick, M., Koenig, H., Larson, D., & Matthews, D. (1998). Religion and spiritual beliefs. In J. C. Holland (Ed.), *Psycho-Oncology*. New York: Oxford University Press.

Mytko, J. J., & Knight, S. J. (1999). Body, mind and spirit: towards the integration of religiosity and spirituality in cancer quality of life research. *Psycho-Oncology, 8*(5), 439-450.

Narsavage, G., & Romeo, E. (2003). Education and support needs of younger and older cancer survivors. *Applied Nursing Research, 16*(2), 103-109.

National Breast Cancer Centre and National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre.

National Cancer Institute. (1992). *National Health Interview Survey*. Bethesda, MD: National Cancer Institute, Division of Cancer Control and Population Sciences, Office of Cancer Survivorship.

National Cancer Institute. (2002). *Transitional Care Planning*. Retrieved from http://www.cancer.gov/cancertopics/pdq/supportivecare/transitionalcare/HealthProfessional/page4

National Cancer Institute, National Institutes of Health, & U.S. Department of Health and Human Services. (2004). *Living Beyond Cancer: Finding a New Balance*.

National Cancer Institute, National Institutes of Health, & U.S. Department of Health and Human Services. (2005). *Assessing Progress, Advancing Change*.

National Comprehensive Cancer Network. (2002). *Practice Guidelines in Oncology: Distress Management*: National Comprehensive Cancer Network Inc.

National Health Service Management Executive. (1991). *Moving Forward: Needs, Services and Contracts*. London.

Nelson, C. W., & Niederberger, J. (1990). Patient satisfaction surveys: an opportunity for total quality improvement. *Hospital & health services administration., 35*(3), 409-427.

Nesvold, I. L., & Fossa, S. D. (2002). Lymphedema after surgical treatment of cervical and vulvar cancer. *Tidsskrift for Den Norske Laegeforening, 122*(26), 2531-2533.

Newell, S., Sanson-Fisher, R. W., Girgis, A., & Ackland, S. (1999). The physical and psycho-social experiences of patients attending an outpatient medical oncology department: a cross-sectional study. *European Journal of Cancer Care (English Language Edition), 8*(2), 73-82.

Nihira, K., Mink, I. T., & Meyers, C. E. (1981). Relationship between home environment and school adjustment of TMR children. *American Journal of Mental Deficiency, 86*(1), 8-15.

Northouse, L. L., & Peters-Golden, H. (1993). Cancer and the family: strategies to assist spouses. *Seminars in Oncology Nursing, 9*, 74-82.

Nutbeam, D., & Harris, E. (2004). *Therory in a Nutshell: A practical guide to health promotion theories*. North Ryde, NSW: McGraw-Hill Australia.

Obermair, A. (2004). Personal communication with Assoc. Prof. Andreas Obermair, gynaecological oncologist at Royal Brisbane and Women's Hospital.

OvCa Australia. (2005). *National Ovarian Cancer Network*. Retrieved from http://www.ovca.org/

Pappas, G. P., Golin, S., & Meyer, D. L. (1990). Reducing symptoms of depression with exercise. *Psychosomatics., 31*(1), 112-113.

Patrick, K., Intille, S. S., & Zabinski, M. F. (2005). An ecological framework for cancer communication: implications for research. *Journal of medical Internet research., 7*(3), e23.

Patterson, R. E., Neuhouser, M. L., Hedderson, M. M., Schwartz, S. M., Standish, L. J., & Bowen, D. J. (2003). Changes in diet, physical activity, and supplement use among adults diagnosed with cancer. *Journal of the American Dietetic Association, 103*(3), 323-328.

Patterson, R. E., Neuhouser, M. L., Hedderson, M. M., Schwartz, S. M., Standish, L. J., Bowen, D. J., & Marshall, L. M. (2002). Types of alternative medicine used by patients with breast, colon, or prostate cancer: predictors, motives, and costs. *Journal of Alternative and Complementary Medicine, 8*(4), 477-485.

Perkins, J., Sanson-Fisher, R., & Giles, R. (2002). *Cited in Boyes, A. Girgis, A. Zucca, A. Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of needs assessment in oncology*. Sydney: The Cancer Council NSW & The University of Newcastle.

Peterman, A. H., Fitchett, G., Brady, M. J., Hernandez, L., Cella, D., & Mo, M. (2002). Measuring spiritual well-being in people with cancer: The Functional Assessment of

Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) A case for including spirituality in quality of life measurement in oncology. *Annals of Behavioral Medicine, 24*(1), 49-58.

Peterson, K. E., Sorensen, G., Pearson, M., Hebert, J. R., Gottlieb, B. R., & McCormick, M. C. (2002). Design of an intervention addressing multiple levels of influence on dietary and activity patterns of low-income, postpartum women. *Health education research., 17*(5), 531-540.

Pierce, J. P., Faerber, S., Wright, F. A., Newman, V., Flatt, S. W., Kealey, S., Rock, C. L., Hryniuk, W., & Greenberg, E. R. (1997). Feasibility of a randomized trial of a high-vegetable diet to prevent breast cancer recurrence. *Nutrition and Cancer, 28*(3 (Print)), 282-288.

Pierce, J. P., Newman, V. A., Flatt, S. W., Faerber, S., Rock, C. L., Natarajan, L., Caan, B. J., Gold, E. B., Hollenbach, K. A., Wasserman, L., Jones, L., Ritenbaugh, C., Stefanick, M. L., Thomson, C. A., & Kealey, S. (2004). Telephone counseling intervention increases intakes of micronutrient- and phytochemical-rich vegetables, fruit and fiber in breast cancer survivors. *The Journal Of Nutrition, 134*(2 (Print)), 452-458.

Pignata, S., Ballatori, E., Favalli, G., & Scambia, G. (2001). Quality of life: gynaecological cancers. *Annals of Oncology, 12*(Suppl 3), S37-42.

Pinchen, K., Inglis, A., & Scott, J. (2002). *Media Releases: Care and Support for Cancer Patients*. Retrieved from http://www.qldcancer.com.au/Whats_New/Media_Releases/Careand.html

Pinto, B. M., & Trunzo, J. J. (2005). Health behaviors during and after a cancer diagnosis. *Cancer, 104*(11 Suppl (Print)), 2614-2623.

Pinto, B. M., Trunzo, J. J., Reiss, P., & Shiu, S.-Y. (2002). Exercise participation after diagnosis of breast cancer: trends and effects on mood and quality of life. *Psycho-oncology., 11*(5), 389-400.

Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. *Social science & medicine., 40*(6), 789-797.

Pistrang, N., & Barker, C. (1998). Partners and fellow patients: Two sources of emotional support for women with breast cancer. *American Journal of Community Psychology, 26*(3), 439-456.

Powell, C., Dibble, S., Dall'Era, J., & Cohen, I. (2002). Use of herbs in women diagnosed with ovarian cancer. *International Journal of Gynecological Cancer, 12*(2), 214-217.

Queensland Cancer Fund. (2004). *Cancer in Queensland: Incidence and Mortality 1982 - 2002 (Statistical Tables)*. Brisbane.

Queensland Cancer Fund. (2006). *Complementary and alternative therapies: making an informed decision*. Retrieved from http://www.qldcancer.com.au/pdf/complementaryalternativetherapies.pdf

Queensland Centre for Gynaecological Cancer. (1997). *Queensland Centre for Gynaecological Cancer Annual Report 1997*. Brisbane: Queensland Centre for Gynaecological Cancer.

Rainbird, K., Perkins, J. J., Sanson-Fisher, R., Rolfe, I., & Anseline, P. (2002). *Cited in Boyes, A. Girgis, A. Zucca, A. Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of needs assessment in oncology*. Sydney: The Cancer Council NSW & The University of Newcastle.

Rait, D., & Lederberg, M. (1989). The family of the cancer patient. In J. C. H. a. J. H. Rowland (Ed.), *Handbook of psychooncology: psychological care of the patient with cancer* (pp. 585-597). New York: Oxford University Press.

Rako, S. (1996). *The Hormone of Desire: The Truth about Sexuality, Menopause and Testosterone*. New York: Harmony Books.

Rankin, N., Williams, P., Davis, C., & Girgis, A. (2004). The use and acceptability of a one-on-one peer support program for Australian women with early breast cancer. *Patient Education and Counseling, 53*(2 (Print)), 141-146.

Rauch, P. K., & Muriel, A. C. (2004). The importance of parenting concerns among patients with cancer. *Critical Reviews in Oncology/Hematology, 49*(1 (Print)), 37-42.

Rehse, B., & Pukrop, R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Education and Counseling, 50*(2 (Print)), 179-186.

Richardson, M. A., Sanders, T., Palmer, J. L., Greisinger, A., & Singletary, S. E. (2000). Complementary/alternative medicine use in a comprehensive cancer center and the implications for oncology. *Journal of Clinical Oncology, 18*(13), 2505-2514.

Richters, J., Grulich, A. E., de Visser, R. O., Smith, A. M. A., & Rissel, C. E. (2003). Sex in Australia: sexual and emotional satisfaction in regular relationships and preferred frequency of sex among a representative sample of adults. *Australian and New Zealand journal of public health., 27*(2), 171-179.

Rieger, E., Touyz, S. W., & Wain, G. V. (1998). The role of the clinical psychologist in gynecological cancer. *Journal of Psychosomatic Research, 45*(3), 201-214.

Rock, C. L., & Demark-Wahnefried, W. (2002). Can lifestyle modification increase survival in women diagnosed with breast cancer? *The Journal of nutrition., 132*(11 Suppl), 3504S-3507s.

Rogers, L., Matevey, C., Hopkins-Price, P., Shah, P., Dunnington, G., & Courneya, K. (2004). Exploring social cognitive theory constructs for promoting exercise among breast cancer patients. *Cancer Nursing, 27*(6), 462-473.

Rogers, L. Q., Shah, P., Dunnington, G., Greive, A., Shanmugham, A., Dawson, B., & Courneya, K. S. (2005). Social Cognitive Theory and Physical Activity During Breast Cancer Treatment. *Oncology Nursing Forum, 32*(4), 807-815.

Rowland, J. H. (1989a). Interpersonal resources: social support. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer* (pp. 58-71). New York: Oxford University Press.

Rowland, J. H. (1989b). Intrapersonal resources: coping. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer* (pp. 44-57). New York: Oxford University Press.

Rumsey, N., & Harcourt, D. (1998). The care of women with breast cancer: research policy and practice. In L. Doyal (Ed.), *Women and Health Services: An Agenda for Change*. Buckingham: Open University Press.

Ryan, M., Stainton, M. C., Jaconelli, C., Watts, S., MacKenzie, P., & Mansberg, T. (2003a). The experience of lower limb lymphedema for women after treatment for gynecologic cancer. *Oncology Nursing Forum, 30*(3), 417-423.

Ryan, M., Stainton, M. C., Slaytor, E. K., Jaconelli, C., Watts, S., Mackenzie, P., Mansberg, T., Esquivias Gomez, J. I., Miranda-Romero, A., Cuadrado Valles, C., Bajo del Pozo, C., Sanchez Sambucety, P., Martinez Fernandez, M., Aragoneses Fraile, H., Garcia Munoz, M., Yasuhara, H., Shigematsu, H., Muto, T., Logan, V., Werngren-Elgstrom, M., Lidman, D., Podhaisky, H., Hansgen, K., Lampe, D., Methfessel, G., Methfessel, H. D., Matthiesen, L., & Simonsen, E. (2003b). Aetiology and prevalence of lower limb lymphoedema following treatment for gynaecological cancer. *Australian and New Zealand Journal of Obstetrics and Gynaecology, 43*(2), 148-151.

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer, 88*(1), 226-237.

Sarason, I., Sarason, B., Shearin, E., & Rice, G. (1987). A Brief Measure of social support: practical and theoretical implications. *Journal of Social and Personal Relationships, 4*, 497-510.

Schain, W. S., d'Angelo, T. M., Dunn, M. E., Lichter, A. S., & Pierce, L. J. (1994). Mastectomy versus conservative surgery and radiation therapy. Psychosocial consequences. *Cancer., 73*(4), 1221-1228.

Schnoll, R. A., Harlow, L. L., & Brower, L. (2000). Spirituality, demographic and disease factors, and adjustment to cancer. *Cancer Practice, 8*(6), 298-304.

Schover, L. R., Fife, M., & Gershenson, D. M. (1989). Sexual dysfunction and treatment for early stage cervical cancer. *Cancer., 63*(1), 204-212.

Schover, L. R., & Jensen, S. B. (1988). *Sexuality and chronic illness: a comprehensive approach*. New York: Guilford Press.

Schroevers, M. J., Ranchor, A. V., & Sanderman, R. (2004). The role of age at the onset of cancer in relation to survivors' long-term adjustment: a controlled comparison over an eight-year period. *Psycho-Oncology, 13*(10 (Print)), 740-752.

Schulz, M., Lahmann, P., Riboli, E., & Boeing, H. (2004). Dietary determinants of epithelial ovarian cancer: a review of the epidemiologic literature. *Nutrition and Cancer, 50*(2), 120-140.

Scott, J. L., Halford, W. K., & Ward, B. G. (2004). United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. *Journal of Consulting and Clinical Psychology, 72*(6 (Print)), 1122-1135.

Shapiro, J., Perez, M., & Warden, M. J. (1998). The importance of family functioning to caregiver adaptation in mothers of child cancer patients: testing a social ecological model. *Journal of Pediatric Oncology Nursing, 15*(1), 47-54.

Sheehan, M. (1997). Spirituality and care at the end of life. *Choices, 6*, 1-5.

Shepperd, S., Parkes, J., McClaren, J., & Phillips, C. (2004). Discharge planning from hospital to home. *Cochrane database of systematic reviews (Online)*(1 (Electronic)), CD000313.

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science and Medicine, 32*(6), 705-714.

Siegel, K., Raveis, V. H., Houts, P., & Mor, V. (1991). Caregiver burden and unmet patient needs. *Cancer, 68*(5), 1131-1140.

Sitzia, J., & Wood, N. (1998). Response rate in patient satisfaction research: an analysis of 210 published studies. *International Journal for Quality in Health Care, 10*(4), 311-317.

Skeel, R. T. (1993). Quality of life dimensions that are most important to cancer patients. *Oncology (Huntingt), 7*(12), 55-61; discussion 65-56, 69-70.

Söllner, W., DeVries, A., Steixner, E., Lukas, P., Sprinzl, G., Rumpold, G., & Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer, 84*(2 (Print)), 179-185.

Sollner, W., Maislinger, S., DeVries, A., Steixner, E., Rumpold, G., & Lukas, P. (2000). Use of complementary and alternative medicine by cancer patients is not associated with perceived distress or poor compliance with standard treatment but with active coping behavior: a survey. *Cancer, 89*(4), 873-880.

Söllner, W., Maislinger, S., König, A., Devries, A., & Lukas, P. (2004). Providing psychosocial support for breast cancer patients based on screening for distress within a consultation-liaison service. *Psycho-Oncology, 13*(12 (Print)), 893-897.

Somerfield, M. R., Stefanek, M. E., Smith, T. J., & Padberg, J. J. (1999). A systems model for adaptation to somatic distress among cancer survivors. *Psycho-Oncology, 8*(4), 334-343.

Sorensen, G., Linnan, L., & Hunt, M. K. (2004). Worksite-based research and initiatives to increase fruit and vegetable consumption. *Preventive medicine., 39 Suppl 2*, S94-100.

Sparber, A., Bauer, L., Curt, G., Eisenberg, D., Levin, T., Parks, S., Steinberg, S. M., & Wootton, J. (2000). Use of complementary medicine by adult patients participating in cancer clinical trials. *Oncology Nursing Forum, 27*(4), 623-630.

Spiegel, D. (1994). Health caring. Psychosocial support for patients with cancer. *Cancer, 74*(4 Suppl), 1453-1457.

Stanton, A. L., Ganz, P. A., Rowland, J. H., Meyerowitz, B. E., Krupnick, J. L., & Sears, S. R. (2005). Promoting adjustment after treatment for cancer. *Cancer, 104*(11 Suppl (Print)), 2608-2613.

Steginga, S. (2002). Personal communication with Dr Suzanne Steginga, Manager of Community Services at Queensland Cancer Fund.

Steginga, S., Hutchison, S., Turner, J., & Dunn, J. (2006). Translating psychosocial care: guidelines into action. *Cancer Forum, 30*(1), 28-31.

Steginga, S. K., & Dunn, J. (1997). Women's experiences following treatment for gynecologic cancer. *Oncology Nursing Forum, 24*(8 (Print)), 1403-1408.

Steginga, S. K., Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer (2000). *Psycho-Oncology, 10*(1), 66-75.

Steinwachs, D. M. (1989). Application of health status assessment measures in policy research. *Medical Care, 27*(3 Suppl), S12-26.

Stengle, W. A., & Eckert, D. (1983). Colorectal cancer patient rehabilitation and continuing care needs: a preliminary assessment of services provided by a voluntary cancer agency. *Progress in Clinical and Biological Research, 130*, 433-442.

Stewart, D. E., Wong, F., Cheung, A. M., Dancey, J., Meana, M., Cameron, J. I., McAndrews, M. P., Bunston, T., Murphy, J., & Rosen, B. (2000). Information needs and decisional preferences among women with ovarian cancer. *Gynecologic Oncology, 77*(3), 357-361.

Streiner, D., & Norman, G. (1995). *Health measurement scales: a practical guide to their development and use*. Oxford: Oxford University Press.

Syrjala, K. L., & Chapko, M. E. (1995). Evidence for a biopsychosocial model of cancer treatment-related pain. *Pain, 61*(1), 69-79.

Tabachnick, B., & Fidell, L. (2001). *Using multivariate statistics*. United States of America, Needham Heights: Allyn & Bacon.

Taylor, E., Ismail, S., Hills, H., & Ainsworth, S. (2004). Multicomponent psychosocial support for newly diagnosed cancer patients: participants' views. *International Journal Of Palliative Nursing, 10*(6 (Print)), 287-295.

Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology, 54*(5), 608-615.

The Cancer Council NSW. (2002). *Health Effects of Smoking*

The Cancer Council NSW. (2005). *When a parent has cancer: how to talk to your kids. A guide for parents with cancer, their families and friends.* Woolloomooloo: The Cancer Council New South Wales.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, P. (2002). *Cited in Boyes, A. Girgis, A. Zucca, A. Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of needs assessment in oncology*. Sydney: The Cancer Council NSW & The University of Newcastle.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004a). Assessment of Unmet Needs Among Survivors of Breast Cancer. *Journal of Psychosocial Oncology, 22*(1), 51-73.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004b). The psychosocial needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology, 13*(3), 177-189.

Thewes, B., Meiser, B., Rickard, J., & Friedlander, M. (2003). The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psycho-Oncology, 12*(5), 500-511.

Thewes, B., Meiser, B., Taylor, A., Phillips, K. A., Pendlebury, S., Capp, A., Dalley, D., Goldstein, D., Baber, R., & Friedlander, M. L. (2005). Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *Journal of Clinical Oncology, 23*(22), 5155-5165.

Thiel, M. M., & Robinson, M. R. (1997). Physicians' collaboration with chaplains: difficulties and benefits. *Journal of Clinical Ethics, 8*(1), 94-103.

Thoits, P. A. (1995). Stress, coping, and social support processes: where are we? What next? *Journal of Health and Social Behavior, Spec No*, 53-79.

Thomas, C. P., & Payne, S. M. (1998). Home alone: unmet need for formal support services among home health clients. *Home Health Care Services Quarterly, 17*(2), 1-20.

Thomas, C. R., Miller, G., Hartshorn, J. C., Speck, N. C., & Walker, G. (2005). Telepsychiatry program for rural victims of domestic violence. *Telemedicine Journal And E-Health: The Official Journal Of The American Telemedicine Association, 11*(5 (Print)), 567-573.

Till, J. (1991). Uses (and some possible abuses) of quality-of-life measures. In D. Osoba (Ed.), *Effect of cancer on quality of life* (pp. 137-154). Boca Raton, Florida: CRC Press Inc.

Turrell, G. (2004). Personal communication with Dr Gavin Turrell, Senior Research Fellow at Queensland University of Technology (pp. Socio-Economic-Status Analysis).

Turton, P., & Cooke, H. (2000). Meeting the needs of people with cancer for support and self-management. *Complementary Therapies in Nursing and Midwifery, 6*(3), 130-137.

U.S. Department of Health and Human Services. (1989). *Reducing the Health Consequences of Smoking: 25 Years of Progress. A Report of the Surgeon General.*: U.S. Department of Health and Human Services.

Uwe, K., Katja, S., Wolfgang, M., Marek, Z., Stefan, S., & Karsten, M. (1999). Self-concept, body image, and use of unconventional therapies in patients with gynaecological malignancies in the state of complete remission and recurrence. *European Journal of Obstetrics & Gynecology and Reproductive Biology, 82*(1), 101 - 106.

Veronesi, U., & Martino, G. (1978). Can life be the same after cancer treatment? *Tumori, 64*(4), 345-351.

Vickers, A. J., & Cassileth, B. R. (2001). Unconventional therapies for cancer and cancer-related symptoms. *The Lancet Oncology, 2*(4 (Print)), 226-232.

Vinton, L., Altholz, J., & Marcus, M. (1997). A survey of unmet needs of homebound elders. *Journal of Genrontological Social Work, 27*, 69-84.

Von Gruenigen, V. E., White, L. J., Kirven, M. S., Showalter, A. L., Hopkins, M. P., & Jenison, E. L. (2001). A comparison of complementary and alternative medicine use by gynecology and gynecologic oncology patients. *International Journal of Gynecological Cancer, 11*(3), 205-209.

Wain, G., Mills, J., Hobbs, K., Maidens, J., Robertson, R., Bush, M., Norris, N., & Draper, J. (2004). *Gynaecological Cancer Support*. Retrieved from http://www.gynaecancersupport.org.au/

Ward, S. E., Carlson-Dakes, K., Hughes, S. H., Kwekkeboom, K. L., & Donovan, H. S. (1998). The impact on quality of life of patient-related barriers to pain management. *Research in nursing & health., 21*(5), 405-413.

Ware, J. E., Jr., Davies-Avery, A., & Stewart, A. L. (1978). The measurement and meaning of patient satisfaction. *Health and Medical Care Services Review, 1*(1), 1, 3-15.

Waxler-Morrison, N., Hislop, T. G., Mears, B., & Kan, L. (1991). Effects of social relationships on survival for women with breast cancer: a prospective study. *Social Science and Medicine, 33*(2), 177-183.

WCRF/AICR. (1997). *Food Nutrition and the Prevention of Cancer: a global perspective*. Washington: World Cancer Research Fund and American Institute for Cancer Research.

Webb, P. (2004). Personal communication with Dr Penny Webb, Queensland Institute of Medical Research (pp. The use of complementary and alternative medicine (Australian Ovarian Cancer Study)). Brisbane.

Webb, P., Loos, C., Olsen, C., Green, A., & Purdie, D. (2004). Queensland Institute of Medical Research epidemiology seminar (pp. Use of complementary and alternative medicine by women with ovarian cancer). Brisbane.

Weijmar Schultz, W. C. M., Bransfield, D. D., van de Wiel, H. B. M., & Bouma, J. (1992a). Sexual outcome following female genital cancer treatment: a critical review of methods of investigation and results. *Sex Marit Ther, 7*, 29-62.

Weijmar Schultz, W. C. M., van de Wiel, H. B. M., Hahn, B. E. E., & Bouma, J. (1992b). Psychosexual functioning after treatment for gynecological cancer: an integrative model, review of determinant factors and clinical guidelines. *Int J Gynecol Cancer, 2*, 281-290.

Wenzel, L. B., Donnelly, J. P., Fowler, J. M., Habbal, R., Taylor, T. H., Aziz, N., & Cella, D. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: a gynecologic oncology group study. *Psycho-Oncology, 11*(2), 142-153.

Werngren-Elgstrom, M., & Lidman, D. (1994). Lymphoedema of the lower extremities after surgery and radiotherapy for cancer of the cervix. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery, 28*(4), 289-293.

Whelan, T. J., Mohide, E. A., Willan, A. R., Arnold, A., Tew, M., Sellick, S., Gafni, A., & Levine, M. N. (1997). The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer, 80*(8), 1518-1524.

WHO/FAO. (2003). *Report of the Joint WHO/FAO Expert Consultation on Diet, Nutrition and the Prevention of Chronic Diseases*. Geneva, Switzerland: World Health Organisation/Food and Agricultural Organisation.

Wing, R. R. (1999). Physical activity in the treatment of the adulthood overweight and obesity: current evidence and research issues. *Medicine and science in sports and exercise., 31*(11 Suppl), S547-552.

Winningham, M. L., MacVicar, M. G., & Burke, C. A. (1986). Exercise for cancer patients: guidelines and precautions. / (L ' exercice pour les cancereux: directives et precautions.). *Physician and sportsmedicine (Minneapolis), 14*(10), 125.

Winstanley, M., Woodward, S., & Walker, N. (1995). *Tobacco in Australia: Facts and Issues.*: Victorian Smoking and Health Program, Australia (Quit Victoria).

Women's Health Queensland Wide. (2006). *Videoconference program 2006*. Retrieved from http://www.womhealth.org.au/events/VC/VCprogram/2006/2006vcprogram.htm

Wong-Kim, E. (2000). Predicting depressive symptoms in breast cancer patients: Racial comparisons. *Dissertation Abstracts International Section A: Humanities & Social Sciences, 61*(3-A), 1166.

Wortman, C. B. (1984). Social support and the cancer patient. Conceptual and methodologic issues. *Cancer., 53*(10 Suppl), 2339-2362.

Wortman, C. B., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer. A theoretical analysis. *Journal of Social Issues, 35*, 120-155.

Wyatt, G., & Friedman, L. L. (1996a). Long-term female cancer survivors: quality of life issues and clinical implications. *Cancer Nursing, 19*(1), 1-7.

Wyatt, G. K., & Friedman, L. L. (1996b). Development and testing of a quality of life model for long-term female cancer survivors. *Quality of Life Research, 5*(3), 387-394.

Youlden, D., Baade, P., & Coory, M. (2005). *Cancer survival in Queensland, 2002*. Brisbane, Queensland: Queensland Health and Queensland Cancer Fund.

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-oncology., 10*(1), 19-28.

Zacharias, D. R., Gilg, C. A., & Foxall, M. J. (1994). Quality of life and coping in patients with gynecologic cancer and their spouses. *Oncology Nursing Forum, 21*(10 (Print)), 1699-1706.

Zastowny, T. R., Stratmann, W. C., Adams, E. H., & Fox, M. L. (1995). Patient satisfaction and experience with health services and quality of care. *Quality Management in Health Care, 3*(3), 50-61.

Zebrack, B. (2000). Cancer survivors and quality of life: a critical review of the literature. *Oncology Nursing Forum, 27*(9), 1395-1401.

LIST OF APPENDICES

Pilot Study Report

By Vanessa Beesley

Prostate, Gynaecological and Colorectal Cancer Survivor Issues and Support: A Qualitative Pilot Study

Introduction

With cancer, there is a path that starts from the often dramatic and shocking experience of initial diagnosis and treatment, through to recovery from treatment, to the phase of watching and waiting to see if the cancer will redevelop. This latter period is also known as survivorship and varies by cancer type and severity. Those with more virulent forms of cancer, or cancers that were diagnosed in later stages may eventually move into the next phase, known as the palliative phase, in which recurrence, dying and death occur (Little et al., 2001). Five-year survival rates indicate that more and more people are living as cancer survivors for longer periods of time, thus it is imperative to address survivorship issues.

After the initial course of cancer treatment, when a team of specialists no longer surrounds the patient, they must learn to cope with day-to-day living. Supportive care is considered important, particularly so in the initial post-treatment phase. Whelan et al. (1997) have defined supportive cancer care as “those health services and related activities designed to help patients and their families with their cancer experience during the diagnostic, treatment, follow-up and palliative phases”. Thus supportive care includes not only issues of physical or symptom support, but other domains, such as instrumental and social care, the need for information, psychologic support and spiritual needs. Sanson-Fisher et al. (2000) found that patients 1-12 months post diagnosis with cancer had significantly higher physical and daily living support needs than those patients 1-5 years, more than 5 years post diagnosis, and within a month of diagnosis. They hypothesises that this may be because patients more that a year post diagnosis are familiar with the treatment process and it’s side-effects.

Supportive care needs are dictated by medical and biologic factors, but also by demographics, setting (urban versus rural), and psychosocial factors (National Cancer Institute, 2002). Thus, supportive care needs can be unique to each patient and family, some aspects differ by cancer site, and some supportive care needs are common to almost all cancer patients.

There is limited Australian site-specific research documenting the support needs of cancer patients who are within the aftermath of the intensively focused whirlwind of treatment and recovery. Survivors are faced with a myriad of emotional, physical and spiritual issues, and issues are often specific to a cancer site. For example prostate cancer survivors have to cope with the impact of disease and treatment on very personal aspects of quality of life, such as impotence and incontinence (Boberg et al., 2003), Gynaecological cancer survivors may face infertility, premature menopause, sexual dysfunction and other problems such as lymphoedema (Li et al., 1999), and colorectal cancer patients both with and without a colostomy, may experience bowel dysfunction, disturbed sleep due to urgency or leakage, and consequent diet modifications and some studies have reported prevalence of sexual dysfunction (Sahay et al., 2000). These side-effects have significant affect on survivors' quality of life and patients supportive care needs.

In Australia several initiatives to provide supportive care exist in the network of cancer councils and other affiliated support organisations such as the Prostate Cancer Foundation of Australia, the Gynaecological Cancer Society, the Lymphoedema Association of Australia and the Australian Council of Stoma Associations. Interventions, such as linking with another person with the same diagnosis, who is at least two years post initial diagnosis and who has been trained – are proving popular and successful (Clinical Oncological Society of Australia et al., 2003). However, it is clear that many potential users of support services miss out because of the lack of integration of these services within the mainstream health care system leading to lack of awareness (Clinical Oncological Society of Australia et al., 2003).

Current support service provision for survivors in Queensland varies depending on the cancer site and geographical location. Site-specific support groups exist for some cancers, eg breast and prostate, however these are run by dedicated survivors and hence only exist in some regions of the state. There are also some organisations that coordinate site-specific support for cancer patients. However, it is unclear as to whether: Queensland patients are aware of the available services; Queensland patients have adequate access to appropriate services, and; the available supportive care is meeting patient needs.

The following pilot study was conducted as a formative evaluation of prostate, gynaecological, and colorectal cancer patients to:

- Further define supportive care from the patient's perspective.

- Explore in depth, cancer site, geographical, and gender-specific supportive care issues
- Map help-seeking pathways, awareness, reasons for use and barriers to use of support care.
- Inform the development of the main study instruments

Methods

Interviews were conducted with prostate, gynaecological, and colorectal cancer ‘key informants’, to gauge a range of patients’ perspectives from individual spokespersons, about supportive care awareness and use, and patients’ needs. Key informants were defined as people who have a lot of ‘on the ground’ experience with cancer patients and who have a good understanding of patients’ support care needs. The three cancer types, prostate, gynaecological, and colorectal, were chosen firstly because they are considered by Queensland Cancer Fund as priority sites in supportive care research, and secondly because these cancer types are feasible in terms of available numbers of cancer patients for recruitment through the Queensland Cancer Registry for the larger population-based study that this pilot study was conducted to inform. During the interviews, it was determined that the site-specific needs and available supportive care for colorectal cancer patients was very different, depending on whether the patient had been fitted with a stoma. A stoma is an artificial opening to or from the intestine on the abdominal wall created by a surgeon to bypass parts of the normal intestine (BUPA, 2002). Hence, n[*] interviews were conducted to inform four patient groups; 4 with prostate cancer key informants, 3 with gynaecological cancer key informants, 2 with colorectal cancer ostomate key informants and n[*] with colorectal cancer non-ostomate key informants. Key informants consisted of trained past-patients who provide support either through a site-specific helpline, support groups or support visitors schemes, professional support providers and patients. Where possible, past-patient support providers were recruited, as it was believed that these survivors would be the best representative spokespeople on patients’ support needs, as they have been through the cancer experience themselves, and they currently associate with many patients seeking support. Site-specific providers who have contact with the patients in the survival phase of cancer were also considered a valuable resource for determining site-specific supportive care needs. If there were no past-patient support providers or professional site-specific support providers identifiable for a particular patient group, then patients were recruited through the Royal Brisbane Hospital. The final number of interviewees was determined by the researcher, who ceased

---

n[*] non-ostomate colorectal cancer interviews still to be conducted to conduct further interviews with informants from each patient group when it was felt that saturation on all topics had been achieved.

Key Informant Recruitment

Recruitment varied somewhat by site, as relationships already existed with some sites service providers and site-specific service providers were non-existent for other sites. For all sites a thorough internet search was performed to identify support groups or organisations that specifically targeted prostate, colorectal or gynaecological cancer patients. To further identify support services in Queensland, a filtered search of OnCall (the Queensland Cancer Fund software package that tracks phone inquiries and lists support services) was conducted to identify support services in each region of Queensland for each cancer type.

Utilising existing Queensland Cancer Fund relationships, the prostate cancer key informants were approached by an email from a Queensland Cancer Fund staff member with whom they are familiar. The email outlined the study, its aims and details of what would be involved if they agreed to participate. The willing participants replied with contact details that were then forwarded on to the researcher to arrange an interview time and, if necessary, a meeting place. The prostate cancer key informants consisted of prostate cancer support group leaders or informants who were part of the management of a prostate cancer support group. All of the prostate cancer key informants were diagnosed with prostate cancer approximately 8 years ago and had received training to conduct support groups for patients of the same diagnosis.

All identified Queensland gynaecological and colorectal cancer support groups and organisations on email were approached with an initial email from the researcher, outlining the study, what would be involved if they agreed to participate, how the researcher had come across their group or organisation and why they would be a fitting key informant. If they didn't reply to the email, they were followed up by telephone a week later. An interview time and meeting place, if necessary, was arranged with willing participants.

The initial gynaecological cancer key informant was recruited through an email to the Gynaecological Cancer Society. As there were no other groups or organisations identified which specifically targeted non-medical gynaecological cancer support, a snowball recruitment strategy was utilised where the initial key informant was kind enough to approach other suitable people to participate in the study. Gynaecological cancer key informants included a chief executive and past patient counsellor of a gynaecological support organisation and a gynaecological oncologist.

Colorectal cancer key informants were recruited either directly from the email or as a referral from the initial email receiver. Informants support experience collectively included the following roles: a leader of a stoma support group and an executive member of an Ostomy Association, a visiting team member, an assistant editor of the Ostomy Australia Journal and a counsellor for Queensland Cancer Fund. Both informant had had colorectal cancer and were fitted with a stoma.

It was identified during the interviews that colorectal cancer patients would have different needs depending on whether or not they were an ostomate. Hence key informants were recruited within both subgroups, that is colorectal cancer ostomate and colorectal cancer non-ostomate[*]..

Conducting and Analysing Interviews

All Interviews were semi-structured with guided questions (see appendix #). If the key informant was within 1 hour's drive from Brisbane, the interview was conducted face-to-face at a convenient location for the interviewee, otherwise interviews were conducted over the telephone. With permission, most interviews were recorded and transcribed into detailed notes and quotes. Detailed notes were taken from interviewees unwilling to be recorded, and then the interviewee reviewed the notes for accuracy. Data from the interview transcripts and notes were organised into the following construct: issues experienced, meeting needs, support service use, support service awareness, complementary therapies and lifestyle support use, social support, caregivers support and additional information. Within the 'issues experienced' construct, data were further categorised into specific issues, for example all quote pertaining to impotence were allocated under this subheading. Common themes under each construct and heading were piece together to inform the findings of this study. To maintain confidentiality of key informants' data, quotes were attributed to key informants using identification numbers.

Secondary Data Collection

Secondary sources of information have also been drawn on to inform the findings of this study. For example, in the course of the interviews, key informants have alerted the

---

[*] *Recruitment of three colorectal cancer non-ostomates is currently being sought through the Royal Brisbane Hospital.*

researcher to support group meeting notes, site-specific newsletters, journals, pamphlets, books and support website that provide important information about available supportive care and supportive care needs. These are incorporated into the results below in their relevant sections.

Results:

It is clear that there are many differences between the supportive care needs of prostate cancer, gynaecological cancer and colorectal cancer ostomates. While most cancer patients in the initial diagnosis and treatment stages generically experience shock and are confronted with issues of living and dying, (1), the main problems and concerns at the initial post treatment phase are diverse and may depend on the type and stage of cancer, the type of treatment, the patients' age, gender or their geographical location.

Prostate Cancer Patients' Supportive Care Needs

While all men deal with surviving prostate cancer differently, long-term treatment side effects, age and gender-specific issues seem to have a significant influence on prostate survivors' supportive care needs. These influences are often interrelated. For example, age may determine treatment type and therefore side effects experienced, or particular side effects such as impotence may challenge patients' masculinity.

The main problems and concerns for prostate cancer patients in the initial post treatment phase centre on impotence and incontinence, the side effects of treatment. Other long-term side effects from treatments can also include cramping, urinary retention, reduced muscle strength, weight gain, breast changes and impaired ability to concentrate (Lions Australia, 2003). The ramifications of these side effects filter into many of the varying categories of support needs.

Physical and Daily Living Needs

Incontinence affects one's ability to do what they would normally do in their daily life and hence affects a person's physical and daily living needs. *"After the operation you can't do what you would normally do in your daily life. For example, you can't get around 3 holes of golf because you have to wear a pad and the pad gets sopping and leaks. In public toilets men do not have sanitary bins to dispose of incontinence pads. (1)"*

Psychological Needs

This deficit in physical and daily living functions seems to have a strong effect on the patients' psychological response and needs. Some patients report feeling like a social outcast because of incontinence. *"As a result of the incontinence you feel like a social outcast as you have to confine yourself to very short periods out (2)."* In a few severe cases patients have even become suicidal. *"Loss of the ability to go about your normal life is where the distressing emotional state comes in because people choose to never leave the house anymore. Some patients have become suicidal (1)."* Incontinence also has a tangible effect on the supportive care needs of partners of prostate cancer patients. "*Missing out on the social side you feel at times a hermit. This puts extra strain on the female partner as it restricts their activities too (2)."*

Sexuality Needs

Impotence is even more so linked to the relationship needs of the patient and partner. As one key informant put it *"The marriage relationship and it's basis changes especially because of impotence. This can enhance the relationship because the couple is forced to talk about intimate things or it can go the other way. Changes take a while to adjust to. Marital relationships may become like flatmates (1)."* This process of adapting to change in the sexual relationship is reported to be a very difficult time, and requires much support in the sexual needs domain, as illustrated by the following quote. *"Impotence is one of the biggest hurdles for a man to lose that part of his being. This is why partners are invited along to the group meetings too. They are a vital part of the support, because it is something shared between the two. Partners need to speak openly with each other and maybe with close friends. This is part of quality of life (3)."*

Many devices can be tried to relieve impotence, however it is not guaranteed that any of these will work. Key informant (1) provided notes on his support group, which illustrate the frustration one of the patient's in his group had gone through. *"He was hoping that we might have some recent information to help his best friend. He had tried everything from injections to vacuum pumps to viagra and sex therapists but nothing helped. As Leo put it, in his own unique verbal style, he was lucky to be alive, but 'his friend had let him down'. All he could do now was 'window shop with his hands in his pockets' ". "Before Howard Harrod died from prostate cancer he wrote a paper explaining how difficult it was for him to live in a male body without potency and without desire. He spoke of the torment of the memory of desire, despite becoming much more aware of other forms of intimacy. Men considering their options on diagnosis should note that there is much more to erectile* *dysfunction than loss of potency. (Dornan et al., 2003)"* When recovery from impotence is not a likely prospect, it takes a very understanding partnership to work through this issue. *"Some patients are devastated due to the impotence, and their marriage is on the rocks. This means a lot to couples especially in the younger couples but also in the older couples. To overcome this it takes understanding from both partners that life is more important then sex (2)."*

Male Issues

"In Australian society, to be a man means certain things. You are supposed to be a beer drinker. You are supposed to like football and cricket. You are supposed to be ready to have sex whenever you can. If you can accept that you are impotent, and you don't want sex, then many of the problems associated with impotence disappear. This does not necessarily sound easy to do and for many men it is not. (Hopgood, 1996)" One reason why impotence is not easy to accept may be because in our society male sexuality is excessively genital in its focus. *"Male socialization had taught me to imagine the female body in a certain manner, to focus my erotic attention on particular body parts, to objectify and depersonalize these body parts, and to understand sexual pleasure as focused almost entirely on orgasm. These structures of the embodied imagination had shaped my experience of desire. The practices, language, and example of other males in my environment powerfully enforced them. I had been so deeply formed by that world that there was virtually no transcendence of it in my experience. Again, I was plunged into despair and, finally, into hatred of the structure of desire that was still alive in my memory and projected in my imagination.(Harrod, 2003)"*

In addition to the effect male socialisation reportedly has on individuals' acceptance of impotence, it may also have ramifications for the patterns of use of support services and networks. *"Males are bought up to feel they must look after themselves. (1)" "Men have a real barrier to the word support, they don't equate the word support with things like information, they think of it as the hand around the shoulder. (1)"* 1 estimates that only about 5% of prostate survivors would use cancer support services and attributes awareness, the male image of not needing help and the doctors not promoting support as reasons why service use maybe minimal. When considering these two effects of male socialisation we are presented with a distressing synergy. The Australian prostate survivor with permanent impotence evidently needs support to deal with this devastating issue, but the very construct of gender socialisation, which makes this issue so difficult to deal with, also prohibits the male to seek support.

Age issues

With different age groups, supportive care needs may be different. As illustrated above, younger people may find impotence the most difficult thing to cope with, whereas older prostate survivors may find incontinence the hardest side effect to deal with. "*Many patients have problems with incontinence and impotence. At the age of 60 + incontinence is the worst side effect. (2)"*

There are also different treatment options depending on age, and hence a different set of side effects may be correlated with different age groups. In the opinion of one key informant: "*60-70 year olds are probably the greatest affected, because they have surgery or radiation and then the incontinence and impotence affects their life. (3)".* Hence this age group may require the most support.

Gynaecological Cancer Patients Supportive Care Needs

"Gynaecological cancer confronts a woman with issues related to her health, survival, body image, identity, personal and cultural roles, and psychosexual functioning. Multiple losses and potential losses can be experienced as an overwhelming overall sense of loss. These can include: loss of fertility; loss of good health; loss of control, independence, identity and self-esteem; loss of sexuality and intimacy; separation from family and other support networks during treatment; loss of financial stability. A resurfacing of previous losses in the woman's life can compound this sense of loss. Long after the completion of treatment, women may report a continuing sense of vulnerability, fear and anxiety. (Gynaecological Cancer Society, 2001)"

Psychological and Sexuality Needs

After gynaecological cancer treatment, patients are reportedly faced with deep emotional feelings of turmoil and loss. These natural and normal feelings appear to occur for a number of reasons. Emotional issues may be due to the generic cancer experience of dealing with the fact that the patient has changed as a result of having cancer. "*You have to deal with the fact that you have changed because of the cancer and that you are a different person now. The grief of the experience takes a long time to come to terms with and people around you expect that once you have had treatment and 6 weeks recovery time you should be fine, but it takes a lot longer psychologically (4)."* Emotional issues may be more specifically related to the cancer site and treatment. It has been documented that *"surgery to the part of the body which is normally associated only with the most intimate and private areas of life – sexuality and womanhood – can evoke all kinds of emotions, from deep shame to fear and anger (Gynaecological Cancer Society, 2002e)."*

In addition to these feeling about surgery to a women's intimate region, the surgery itself can be the physical cause of psychological issues. *"A hysterectomy is a major operation for all women and has some very important emotional side-effects. Many younger women in particular often find it difficult to come to terms with the fact that they can no longer have children. They may also feel that in losing their uterus, they have lost a large part of their female identity. (Gynaecological Cancer Society, 2002d)" "If you require a bilateral salpingo-oophorectomy (removal of both ovaries and fallopian tubes) you will become menopausal. This may result in you feeling distressed about aging prematurely, however, premature aging does not occur. (Gynaecological Cancer Society, 2002d)" "If lymphoedema develops, as a result of the surgery, it may affect your self-esteem, and may well affect your needs and wants in relation to your sex life. (Gynaecological Cancer Society, 2002e)"*

Even more specifically there are particular emotional issues associated with different gynaecological cancer sites. "*Patients with cancer of the cervix deal with the issue of it possibly being sexually transmitted. That is, the wart virus is associated with cancer of the cervix and those women who are sexually inactive don't get cervical cancer. The stigma is a real problem for some people (5)." "Ovarian cancer patients see their disease as a death sentence and don't cope well (6)." "A vulvectomy for vulva cancer can permanently change the outward appearance of your body, a change many women find hard to accept. It may have an effect of how you feel about your sexuality and womanhood and may well affect your needs and wants in relation to your sex life (Gynaecological Cancer Society, 2002a)."* Any gynaecological cancer patients who experience changes to their physical appearance, be it the removal of the vulva or external scarring may require emotional support to deal with body image issues. "*Body image is an issue with patients who have external scarring. These women may find the cancer more confronting (4)."*

"*Psychological problems are the biggest concern (6)."* Psychological issues have major ramifications for both the psychological and sexuality support needs of patients, as emotional issues can manifest negatively upon the relationship. "*Relationships become very strained due to the inability of the male to not easily fix the woman's psychological problems and therefore around 60% of males adopt the "flight" response (6)."*

In addition to emotional issues impacting on relationships, the treatment gynaecological cancer patients receive can also result in many physical side effects, which affect sexuality needs in the survival phase of the cancer experience. After many treatment modalities, there are problems with sexual function, as can be seen in table 1. These sexual problems require a great deal of understanding and support from partners; unfortunately this support is often withdrawn, rather than provided. *"There are some problems with sexual function or dysfunction. Many marriages have come down to a working relationship and when you add the stress of cancer on top of it, it unmasks a whole lot of problems. In a significant number of cases relationships fall apart as it becomes the straw that breaks the camels' back (5)."* Again there are some site-specific differences that attribute to sexuality issues. "*Vulva cancer patients have a lot of sexual concerns as removal of the clitoris makes sex very painful (6)."*

Table 1: Possible Sexuality Issues Involved With Gynaecological Cancer Treatment (Gynaecological Cancer Society, 2002f)

Treatment	**Low Sexual Desire**	**Less Vaginal Moisture**	**Reduced Vaginal Size**	**Painful Intercourse**	**Trouble Reaching Orgasm**	**Infertility**
Chemotherapy	Sometimes	Often	Rarely	Often	Rarely	Often
Pelvic radiation therapy	Rarely	Often	Often	Often	Rarely	Always
Radical hysterectomy	Rarely	Often*	Often	Rarely	Rarely	Always
Radical cystectomy	Rarely	Often*	Always	Sometimes	Rarely	Always
Abdominoperineal (AP) resection	Sometimes	Often*	Sometimes	Sometimes	Rarely	Sometimes
Total pelvic exenteration with vaginal reconstruction	Sometimes	Always	Sometimes	Sometimes	Sometimes	Always
Radical vulvectomy	Rarely	Never	Sometimes	Often	Sometimes	Never
Conization of the cervix	Never	Never	Never	Rarely	Never	Rarely
Oophorectomy (removal of one tube and ovary)	Rarely	Never*	Never*	Rarely	Never	Rarely
Oophorectomy (removal of both tubes and ovaries)	Rarely	Often*	Never*	Rarely*	Rarely	Always
Anit-estrogen therapy for uterine cancer	Sometimes	Often	Sometimes	Sometimes	Rarely	Always

*Vaginal dryness and size changes should not occur if one ovary is left or if hormone replacement therapy is given.

Physical and Daily Living Needs

Gynaecological cancer patients also experience support needs in the physical and daily needs domain. *“Gynaecological cancer and its treatments can impact upon your ability to perform activities of daily living, with symptoms such as weakness, general fatigue, excessive stress levels, lymphoedema and nausea from chemotherapy and radiation therapy. (Gynaecological Cancer Society, 2002c)”* Although the area of the operation can heal within about six weeks (Gynaecological Cancer Society, 2002c), for some patients it takes a lot longer to recover. “*Gynae cancer patients take up to a year to physically recover from the radical surgery in which 99% have. Therefore they need a lot of physical help around the home (6).”* In particular, patients who develop lymphoedema (chronic swelling) as a result of the surgery take much longer to recover and in many cases patients never fully recover. The symptoms of lymphoedema including badly swollen legs, feet or abdomen may result in loss of mobility, discomfort and pain (Lymphoedema Association of Queensland, 2003a). Coping with everyday activities may become difficult for lymphoedema sufferers and affects the quality of life (Lymphoedema Association of Queensland, 2003a). “*The removal of lymph nodes can lead to lymphoedema. About 15% of Gynae cancer patients undergoing surgery are at risk of lymphoedema, in particular vulva, cervical and uterus cancers are at risk. The ramifications are that they have to really take care of their lower limbs from trauma including sunburn because it increases the workload on the lymphatic system (5).”* Another issue that women with lymphoedema go through is the frustration of ongoing consultation with clinicians, which may impact on their ability to psychologically move on. “*Some women develop lymphoedema as a result of the surgery. It is a frustration for these women to have to continually have to return to clinicians (4).* Women with lymphoedema also report extended issues relating to financial needs. “*Lymphoedema may interfere with work. Patients have to deal with not being back at work and additionally the financial constraints of this. Many women want to know when and if they can go back to work (4).”*

Financial Needs

Many gynaecological cancer patients express financial concerns. However, these concerns are generally focused around the diagnosis and treatment phase of the cancer experience (unless they have lymphoedema), when patients and their partners have to travel and stay in treatment centres that are not in their home region. “*Many patients raise financial needs. There is a patient transport scheme for financial assistance but many patients do not become aware of it until after treatment. It should be the responsibility of the referring doctor or hospital to tell patients about this scheme but this is not always* *happening. There are also limitations with this scheme. Patients who are a long way from Brisbane and have to come to Brisbane for treatment can utilise the patient transport scheme for financial assistance but it doesn't provide assistance for a support person which means some patients choose not to complete their treatment because it is cost prohibitive (5)."*

Ostomate Colorectal Cancer Survivors' Needs

Becoming an ostomate elicits many questions about diet, clothes, love and sex, pregnancy, family life, support for the significant other, work, travel, exercise and sport. While patients should be able to lead a fulfilling life, have a rewarding career, have children, be physically active, wear what they like (with a few exceptions), eat what they want (with a few exceptions), travel and lead active social lives, they will need to adjust to a few thing. In particular, they may need to: adjust to the loss of all or part of a vital organ. It is common to experience feelings of grief and sadness; adjust to the changed process of eliminating body waste; learn to manage the stoma; adjust to gradually regaining physical and emotional wellbeing, and; learn to feel secure in relationships – with their partner, family members, friends and general public. (Australian Council of Stoma Associations, 2002)

Psychological Needs

The shock period for colorectal cancer patients requiring a stoma continues from the shock of diagnosis right through to the after treatment phase when the patients are presented with the fact that they will have a pouch on their stomach for the rest of their life. *"Patients are totally in a maze just after the operation. It is a shock to have a pouch on your stomach that will be there for the rest of your life and you have got to learn to live with it. It's hard to come out of the operation and realise the only way you're going to get rid of your waste product is into a pouch and you physically have to go and change it. There is a lot of work you have to do on yourself. Quality of life has got to be the most important thing but you think you have lost that." (7) "After the operation, patients may experience mixed emotions – sometimes relief, sometimes apprehension and they may, at times, feel tearful and angry. There may be feelings of 'not being able to cope' or 'being out of control', which are all normal reactions. (Australian Council of Stoma Associations, 2002)"* All patients deal with the shock and emotional responses differently however, there may be some significant differences between the way men and women react to the stoma. It is hypothesised by one of the key informants that this may be due to society sex role conditioning. *"It is more a shock for the men than the women because there is an ego* *thing. Most men do not go through changing dirty nappies and doing all the dirty things. When all of a sudden they have to handle a pouch of faeces on their stomach it is not good for the ego." (7).*

In addition to the emotions experienced from the initial shock and psychological adjustment of having a stoma, the external bag confronts the ostomate with a body image change. "*If you are fitted with a stoma, there is a body image change because you have a bag on your stomach (8)."* Body image issues may extend past a personal concerns that their body has changed to an issue of fear to be in public. This fear to be in public may manifest from several of the following things. Firstly, the concern for feeling embarrassment when people ask if the person wears a bag when the topic of being a survivor of bowel cancer comes up. When one ostomate wrote a letter to the editor of the Ostomy Australia Journal about her concern for feeling embarrassment she found*, "in the answers I received it became very evident that there are lots of ostomates who have, and are currently feeling the way I did (Dale, 2002)"* Secondly some ostomates fear that their bag is noticeably protruding. However, today's lightweight appliances allow most ostomates to dress as they please without anyone knowing (Australian Council of Stoma Associations, 2002). "*Body image is a consideration. If you let the pouch fill up and fill up the pouch is noticeable out there. 90% of people do worry about how they look. Body image is part of your quality of life. (7)".* Thirdly, the stoma and bag may also play on a person's fears of odours. "*If they have had a stoma they may have fears of odours. Diet can be a problem; different food can have an adverse effect on you that didn't before hand. Every individual is different (8)."* Fourthly, there is the fear that their bag may come off, if a patient gets diarrhoea. *"It took me the best part of 12 months to sort out what worked best for me. I have had the occasional accident with my bag, two times in really inconvenient places (Witt, 2002)."* Fifthly there is the consideration of having to change the bag. "*In public situations men have to be prepared to change. Firstly they have to find a sit down toilet, not just urinals. If they are not wearing an open-ended pouch and need to change they will have to rap the pouch up in toilet paper and then put it in a plastic bag, which they brought with them, and then look for the closest bin, whereas women can dispose of the pouch in the sanitary bins in the toilets. (7)"*

Physical and Daily Living Needs

The third, fourth and fifth points above that may affect an ostomates' fear to be in public correspondingly have an impact on physical and daily living needs. Diarrhoea, odours and frequency of bag changes are mostly a result of diet. *"Medically, there is no reason why an ostomate should not continue to eat the sorts of foods previously enjoyed. However* *with some people, the stoma behaves more comfortably if some thought is given to how much you eat of certain foods and when you eat them (Flaxman, 2001)." "Diet is a real consideration for an ostomate, because you have a pouch and the pouch is not all that big and you can only hold so much. Anything that is likely to give you diarrhoea or constipation you don't eat, because who wants to empty a pouch 6-8 times a day. It is not bad for you but it is the last thing an ostomate wants, because the constant responsibility of emptying the pouch impinges on your quality of life. Some people regulate their diet so that they know how long it takes for particular foods to pass through their system and they therefore know how much waste will come through and which size pouch to wear. This allows them to minimise their pouch changes. Some people don't think about it, they let it go, if they have to empty it they just stop what they are doing and go and empty it. (7)." "You're not restricted you just have to be aware that you have a pouch on your stomach and that if you eat certain foods you're going to get diarrhoea and odour. Even though the filter in the pouches are very sophisticated, if the food, such as fish, gives you strong odour, then that is going to come through. If the diarrhoea come through with force the pouch is likely to come off. (7)" "If you want quality of life you have got to work towards it. You may have to give up a few things like coconut and nuts because they don't digest and gather up in the bowel and cause a blockage that is so painful you end up back in hospital. (7)" "We are all different and foods affect us differently. (7)"*

Along with managing diet, an ostomate also has the consideration of managing the stoma and it's appliances. "*You can do most things with the pouch. It's just commonsense, you shouldn't lift heavy things or water ski, but there are people that do it. (7)" "A stoma shouldn't stop you doing anything, however for some people it does. Some people find it difficult to manage (8)."* An ostomate must maintain the region around the stoma. "*There is also maintenance with a stoma: the cleaning of it and the cleaning of your skin (8)."* An ostomate must also consider the type of appliance to wear, depending on their daily activities. The use of an open-ended pouch is recommended, if the ostomate is travelling or is in a situation where they will need to use public amenities. "*If you travel often and have to use small cubicles then it is recommended that you use an open-ended pouch that you can let some faeces out, rather then having to do a complete change. (7)"* Correspondingly the ostomate must ensure he or she has the necessary supply of appropriate appliances.

Another consideration of ostomates is the type of clothing they wear. *"Minor modifications may need to be made to some clothes. Comfortable clothes to suit the ostomate's lifestyle are best. An ostomate also needs to avoid wearing anything tight over their stoma. (Australian Council of Stoma Associations, 2002)"* For some people the location of the stoma may present a problem with their clothing. *"In some ways the clothing challenge was the greatest hurdle in returning to my normal lifestyle. My stoma is located on my right side approximately 30mm below and 50mm to the right of my belly button. Male underwear and pants are totally unsuitable for my stoma. The waistband is generally located straight across my stoma. With male underpants I needed to have my bag lying outside my underpants. A simple, cheap and very comfortable solution to this has been buying female undies. Trousers and shorts presented a problem, primarily from the location of my stoma and secondarily if I wanted to disguise my bag bulge a bit. The majority of trousers and shorts either fell below my stoma and constricted my bag or, the waist was right over my stoma. Overalls are a solution to part of this problem. I also buy pants with a baggier fit and there is stacks of stuff around that is meant to be worn baggy, they look good and work really well with braces. (Witt, 2002)"*

Sexuality Needs

Most people with stomas can, and do, enjoy a healthy sex life. The Australian Council of Stoma Associations (2002) recommends you believe, and have faith in yourself, be positive, communicate openly with those close to you, keep your sense of humour and always practice good hygiene so that you can be clean and confident. *"While sexual difficulties can be due to surgery, they can also be linked to anxiety, fear of failure or concern about your partners' feelings (Australian Council of Stoma Associations, 2002)." "Usually the surgery doesn't affect sexual function and activity at all. However if they have a stoma, it can sometimes be a bit off putting to the patients and sometimes the partner. (8)" "Relationship needs change with an ostomy. You need a supportive partner or significant other. Most partners are very supportive. You wonder how you are going to cope with an embrace and with intercourse with a pouch on your stomach. The sexual thing is a great concern to an ostomate when it happens. It is especially hard for men because their egos wont let them talk about it. You have got to change your method of doing it other wise you could spill everything everywhere. You have to work together on it and change positions. The older people don't worry as much but, the younger peoples' major concerns are sexuality and can they have children. However, the young ones are not normally cancer patients they are the inflammatory bowel or Crohn's disease patients. (7)*

Financial Needs

Ostomates seem to have few financial concerns as a result of their stoma. "*There is not a huge additional cost that comes with being an ostomate. They join an association for* *around $30pa and then their supplies are free (under the governments' stoma appliance scheme), but there is postage cost of suppliers. For the older ostomates the Department of Veteran Affairs pays for the association membership. (7)"*

Meeting Queensland Cancer Survivors Supportive Care Needs

Survivors' Perspective of Supportive Care

When considering meeting supportive care needs of survivors, it is important to define the patients' perception of what supportive care includes. This, however, is not an easy task as *"supportive care is a professional terms and patients don't think of it in these terms unless they reach a crisis point and go looking for help. (1)".* Key informants agreed that supportive care would include, services, social support and complementary therapies and stated that services would be the main area of supportive care. They also collectively mentioned that exercise programs and eating a diet to support wellbeing would have psychological and physiological benefits. These could also be considered means of supportive care for cancer survivors.

General Support Services

Good quality organisational support for cancer survivors exists in Queensland. The Queensland Cancer Fund was established 1961 and currently provides some general support services for cancer patients, such as the "Living with Cancer Programme". While this programme is targeted at patients in the diagnosis and treatment phase it has many useful resources for patients in the survival phase including educational sessions on stress management (relaxation tapes are provided), practical suggestions for communication and relationships, diet and cancer and cancer pain as well as access to other services and information about complementary therapies. (Queensland Cancer Fund, 2003) "*Queensland Cancer Fund is also running meditation and relaxation classes. However these classes are only in the big centres. (1)"* Queensland Cancer Fund has Cancer Support Volunteers who have themselves had a personal experience with cancer. Volunteers assist by giving people the opportunity to talk about their fears and concerns with an understanding person, and by connecting people to useful information and community services. (Queensland Cancer Fund, 2003) In addition to these support programs for cancer survivors the Queensland Cancer Fund reportedly provided services for those close to the survivor. "*There are other infrastructures in the community that can help patients. For example there is the respire care. It can be arranged through the Queensland Cancer Fund for someone to come in* *and give the family a couple of hours of rest, so they can just get out and get away from the situation they are dealing with day by day. There is assessment of needs where for example if someone is getting frailer they will come in and put a rail in the bathroom and toilet. (8)" "The Queensland Cancer Fund Brisbane office has a Patient Resource Centre for people in the community who have personal concerns about cancer. It offers a pertinent selection of reference books, journals, videos and tapes, and there are photocopying and internet facilities available free of charge. (Dornan et al., 2003)"* Queensland Cancer Fund in conjunction with Griffith University have also recently established the Cancer Support Centre in Brisbane which provides professional counselling by psychologists for cancer patients and their families coping with diagnosis, treatment or life after cancer (Pinchen et al., 2002).

The Sunshine Coast is also fortunate to have a locally established cancer centre, the Bloomhill Cancer Help Centre in Buderim. It was established 5 years ago and provides respite care, support groups, relaxation and music therapy (Sunshine Coast Daily, 2002).

In addition to these cancer support organisations there are community organisations across Queensland such as, Adult Health Services, Women's Health Centres, Karuna Hospice Services, Aboriginal Women's Health Resource Centre, Family Planning Queensland, Women's Health Queensland Wide, Women's Infolink, Men's Information and Support Association, and the Wesley Healthwise Centre, which aid in support people through a variety of issues, including those related to the cancer experience. "*Bond University is also running an exercise class for senior Australians, with instructors and physiotherapist for a very low fee. Veterans affairs are funding veterans going to these classes. (1)"*

Gynaecological Cancer Support Services

The Queensland Centre for Gynaecological Cancer was established in 1982 and is responsible to Queensland Health for the provision of gynaecological cancer services for the State of Queensland. It is the largest such service in Australia. It is centred on the Herston campus at the Royal Women's Hospital with subcentres at the Mater Hospital, South Brisbane, Gold Coast Hospital, Southport, John Flynn Hospital, Coolangatta and Kirwan Hospital, Townsville. The centre provides an inpatient and outpatient clinic based social work service. Patients and their families are seen in individual and group sessions for assessment, counselling and follow-up. Contact with patients varies in duration according to their treatment and emotional needs. The service is extended to meet the needs of palliative patients also. In addition a gynaecological oncology support group for patient and their carers is held monthly at the Royal Women's Hospital in Brisbane. This group provides both education and support networks for cancer patients, both on the hospital and community level. The centre also runs a physiotherapy service for both inpatient and outpatient care to the women who attend the Royal Women's hospital or District Health Service. A large part of this service involves lymphoedema management and prevention for women who have had lymph node dissection and/or radiation therapy. In the ward all patients are seen daily by physiotherapist. All patients are followed up at outpatient clinics, where possible, to monitor their condition. Women who develop lymphoedema are treated at physiotherapy departments. (Queensland Centre for Gynaecological Cancer, 1997)

In 1997 the Gynaecological Cancer Society of Queensland was established in response to the need for more comprehensive site-specific services for gynaecological cancer patients. The society has an "Information & Education Programme", which covers a broad range of issues related to gynaecological cancer. The Society offers emotional support and practical advice to patients, their carers and close family members, through its "Emotional Support Helpline", which is staffed by specially trained gynaecological cancer past-patients. The Gynaecological Cancer Society hosts an online electronic mail discussion group called **talk@gcsau.org** which provides general group support to people either suffering from gynaecological cancer or those who are involved in any way in providing them with care both physical, psychological and spiritual. The Gynaecological Cancer Society also has the ability to provide financial assistance to patients and their carers currently experiencing severe hardship and distress. (Gynaecological Cancer Society, 2000b)

While the Gynaecological Cancer Society does not provide site-specific cancer support groups, it does advocate (if appropriate) the use of the following support sessions which are regularly run by the various community organisations within Queensland: Meditation, Tuesdays in Touch (for women interested in improving self-esteem, learning life skills and expanding social horizons), Tai Chi, Women's Group, Monthly morning tea (for women to discuss information of groups, resources and other Queensland agencies) Older Women's Network, Relaxation and Meditation, Body Image and Motivation, Hormone Support Group, African Drumming, Lymphoedema Support Group, Cancer Care Support Group, Anxiety Support Group, Women over 50 - Keeping In Touch, Women Staying on Top (for women experiencing or recovering from depression), Cancer Friendship Group. (Gynaecological Cancer Society, 2002b)

Women who develop lymphoedema as a result of gynaecological cancer treatment can seek specific support through the Lymphoedema Association of Queensland. This association provides a telephone contact and support services, regular meetings with speakers on relevant topics and opportunities for informal exchange, and there are currently active support groups in Brisbane, Gold Coast, Toowoomba, Bundaberg, Mackay and Sunshine Coast. (Lymphoedema Association of Queensland, 2003b)

Meeting Gynaecological Cancer Survivors Needs

These organisations meet most of gynaecological cancer patients needs through the provision of a variety of services. *"Needs are generally well met in Queensland now. Before the Gynaecological Cancer Society was operating there was a real need to address the non-core needs, that is the psychosocial needs and daily living needs (6)".* However, reportedly there is one type of need that is not well addressed by the current available services. "*Needs relating to sexual relationships has not yet been addressed in Australia. The partner is potentially the best support mechanism a woman has and yet if the partner is not educated about how to provide effective support then they become the aggravation to the woman overcoming psychological and sexual problems. The Gynaecological Cancer Society will be addressing this for the first time in Australia with a nationwide partner support program that begins in March 2003 (6)."*

Also apparently non-existent in the gynaecological cancer support experience are site-specific patient-to-patient support groups. Key informant interviewees expressed the following pros and cons of establishing gynaecological cancer support groups. *"There are no specific support groups for gynaecological cancer patients. Other support groups such as the lymphedema support group talk about many issues that are breast cancer specific and hence are not relevant for gynaecological cancer patients. The Queensland Cancer Fund has discouraged the development of gynaecological support groups because they believe it would be to depressive for the women, as the patients within these groups are generally older and at the terminal stages of the disease. There would be benefit in coordinating small groups for gynaecological cancer patients who are at similar stages with the cancer and/or women with similar age groups. Some women need to come and talk about their grief and loss due to their cancer experience with others who have had similar experiences. Support groups would be particularly beneficial due to the fact that women are expected by society to have completely recovered 6 weeks post operative and cease talking about it at this time, when it actually takes a lot longer to move on and the women want to still talk about it (4)." "The Gynaecological Cancer Society discourages the* *formation of support groups. However, if women really want to run support groups they provide them with all the support they need, be it financial, informational etc, to run a group. In most experiences support groups for gynae cancer patients have fallen apart. It is hypothesised that this may be due to the dependent nature of women and the destructive nature of dependency.(6)"*

A difficulty of Queensland cancer service provision is the geography of the state. Gynaecological cancer survivors maybe disadvantaged if they live in rural and remote locations, compared with those in urban locations. Queensland Cancer Fund-offered programs such as "Living with cancer" are only available in Brisbane, Cairns, Southport, Tweed Heads, Beaudesert, Mount Tamborine and Townsville. Community organisations are also restricted to certain urban locations and their outreach is limited. However, Queensland support organisations have considered geographical limitations. *"In terms of information, rural patients are able to access the Gynaecological Cancer Society internet site right across the state. All public places with free internet access are listed with Gynaecological Cancer Society and the information handed out by specialists. The Gynaecological Cancer Society site is download friendly so that it is both accessible to broadband and phone line downloads (6)"* In addition information needs are address by the provision of support resources at an early stage of the cancer experience that may be referred to when needed. "*Information and health care needs are getting better addressed as specialist are now providing patients with information booklets to take away with them (6)".* The Gynaecological Cancer Society also provided geographical equity by offering an emotional support and practical advice through its Emotional Support Helpline.

Gynaecological Cancer Patients Awareness of Support Services

Gynaecologist and Gynae-oncologist are the main means of making patients aware of the available cancer support organisation and their services. "*Awareness of supportive care services generally comes from talking with or being provided information from your oncologist (4)."* In addition, the Queensland Cancer Fund Helpline has trained operators who direct patients to appropriate services based on their enquiry. While the Queensland Cancer Fund Helpline bridges the gap of services awareness for patients between treatment and community care organisations, it requires the patient to be aware of it in the first place. However, Queensland Cancer Fund has a high profile public status and it is expected that most people are aware of this organisation. For specific gynaecological cancer services, three pathways evidently lead to the Gynaecological Cancer Society. *"Gynaecologist and Gynae-oncologist throughout Queensland are all aware of the Gynaecological Cancer Society and they are referring close to all patients to the* *organisation. Queensland Cancer Fund also refers patients. The website comes up on all major search engines. Close to all patients with gynae cancers are aware of Gynaecological Cancer Society. The society keeps a low profile from the rest of the public (6).”*

Gynaecological Cancer Survivors Use of Complementary Therapy Support, Dietary Support and Exercise

The Gynaecological Cancer Society advocates that you create a health plan for yourself: *“If you have been diagnosed with cancer, it is helpful to make a health plan and decide how you are going to give yourself support. What foods are you going to avoid? What foods shall you eat more of? What supplements will you take, considering your tolerance to taking pills, the taste and your budget? What form of treatment support may you get such as acupuncture, Chiropractic or Shiatsu massage? What changes are necessary to reduce stress? What is your exercise plan to improve oxygenation of the body that may include yoga, walking or more golf or fun sport? (Gynaecological Cancer Society, 2000a)”* While the society urges patients to consider these support mechanisms at the diagnosis phase of cancer, it is important to consider support of wellbeing at all stages of the cancer experience.

“Alternative medicines for treatment are a real problem, however for wellbeing “what ever helps the individual, psychologically or physically is great. Many complementary therapies are available and can be a great help. (6)”

It is unknown the extent of complementary therapies Queensland gynaecological cancer survivors are using, both in terms of types of therapies and proportions of users. Key informants were aware of the existence of some therapies that support wellbeing. *“There are pamphlets about relaxation, meditation and nutrition (4).” “Music therapy is available on the Gynaecological Cancer Societywebsite, however if a patient needs calming down then usually they require professional psychological help. (6)”* However, knowledge of patients use is limited. *“A significant proportion of patients use complementary therapies but what proportion is unknown (5).” “The patients I have spoken with did not report use of any complementary therapies (4).”* The key informants had a number of suggestions for complementary therapies that might be of use for survivors. *“Massage or aromatherapy would benefit the patient. While they probably don’t do anything specific for the cancer, they would relieve stress. (5).” “If funding were available a relaxation service, hypnotherapist and clinical psychologist would be an asset to the centre (5).”*

Colorectal Cancer Ostomate Support Services

"Ostomates are very well informed and very well looked after" (7).

At a national level, the Australian Council of Stoma Associations represents the interests of all 22 regional Stoma Associations in Australia. It provides liaison with the Australian Government and appliance suppliers, coordinates support services for ostomates throughout Australia and publishes the national journal "Ostomy Australia" three times per year. The Ostomate Support Program coordinated by the Australian Council of Stoma Associations provides assistance to all Australian residents who have undergone stomal surgery and is a national program of the Pharmaceutical Benefits Scheme. The Commonwealth Government fully subsidises stoma medicines and appliances used by entitled ostomates. The Australian Council of Stoma Associations represents the stoma associations on matters affecting the operation of the Stoma Appliance Scheme. (Australian Council of Stoma Associations)

In Queensland there are six regional branches of the Ostomy Association including: Gold Coast Ostomy Association; North Queensland Ostomy Association; Queensland Colostomy Association; Queensland Stoma Association; Toowomba and South West Ostomy Association; Wide Bay Ostomy Association (Australian Council of Stoma Associations). Each branch association operates independently however, there is some collaboration to ensure there is best practice and similar service delivery across association. "*Two delegates from each association meet at a conference once a year, to ensure that things are done similarly across the associations and that they are done in the most effective way. However each association has their own introduction booklet. (7)"* The main function of the individual associations is to purchase and issue supplies to their members and are reimbursed by the Commonwealth Government (Australian Council of Stoma Associations). Another service the Ostomy Associations facilitate is 'support visitors'. *"Many new ostomates find that talking with a successfully rehabilitated ostomate, one who is confident and obviously physically and emotionally well, can be inspirational and can do wonders to aid recovery. An ostomate support visitor can be arranged through the stomal therapy nurse while the ostomate is in hospital, or through the ostomates local association when they are at home (Australian Council of Stoma Associations, 2002)."*

While there are six ostomy associations with an outreach across Queensland, the outreach of support groups in Queensland is not as comprehensive. This is largely due to the fact that they not necessarily affiliated with any organisation. *"Support groups work as* *on offshoot of the association. Some dedicated person runs them. There aren't groups everywhere.(7)" "There are not many other support groups in Queensland. Besides the Cairns Stoma Support Group there is one in Mackay, and the Gold Coast that I know of. Other organisations are generally just for supplies. (8)"* Reportedly there is also support groups in the Wide Bay and Nanango area (Bob, 2002). A young ostomy support group also exists in Brisbane for teens to forties (Australian Council of Stoma Associations, 2002).

Stomal therapy nurses also provide ostomates with support throughout all stages of the cancer experience. *"There are stomal therapy nurses who see the ostomate before and after the operation and they look after the postoperative care. They provide medical support for patients. Patients can contact the stomal therapy nurse at any time in the future after their operation. The stomal therapy nurse also informs the patients about the Ostomy Associations. (7)"*

Meeting Colorectal Cancer Ostomates Needs

The supportive care needs experienced by colorectal cancer ostomates appear to be well met overall. Certainly the Commonwealth government helps meet healthcare and financial support needs by fully subsidising stoma medicines and appliances. There was however, some reports of breakdown in the healthcare system. "*There is a little bit of a breakdown with meeting health system and information needs as stomal therapists sometime think the support group is encroaching on their ground, even though they are not. They should be working together. However there is a breakdown and not everybody is made aware of the support group (8)."*

Information needs well meet by the Ostomy Australia Journal. *"I think that it is great that we have an ostomy journal as an outlet for our concerns, concerns that in many cases only fellow ostomates can fully understand and offer answers and possible solutions to our problems (Dale, 2002)."* Information needs are also meet by booklets provided by the various Ostomy Associations and support group meetings, which are formed by volunteers when there is a need to pass on knowledge that only someone who has been through the situation will know.

Support groups are multifunctional when it come to meeting supportive care needs, as they can address not only informational needs but psychological and sexuality needs as well. For example: "*Cairns Stoma Support Group is a free support group that puts their hand out to patients whom have had a colostomy, ileostomy or urostomy, many of whom* *are colorectal cancer patients. The group is not affiliated with any organisations. It has a shifting population. It exists because people living with a stoma know what the pitfalls can be and they can pass on knowledge about maintenance and lots of other things that they have learned which make it easier with the living from day to day. The group provides information, practical, social and emotional support to patients and partners. (8)"* Information, psychological and sexuality needs are also addressed by the ostomate support visitors.

Support groups can further serve the purpose of bridging people's support needs, that is, the leader of the group can invite medical professionals and organisational spokespersons to come and talk to their group. Continuing with the Cairns Stoma Support Group example: "*The group meets 4 times a year, February, May, August, and November. They do have a lot of professionals come and speak with the group, but it is not in all sessions. They have had people from HAC, which is a home help service, blue nurses, people on body image, the ambulance, Queensland Cancer Fund come and talk to the group. Because Cairns is so isolated, they also organise some trade displays through the suppliers. They will come up and show all the new supplies and have a representative available to talk about them.(8)"* It must, however, be reiterated that not all regions of Queensland have active support groups. It is unknown whether this is because there is not a need for support groups everywhere, or whether there is not a willing volunteer support group facilitator in all regions. Though, in the opinion of one key informants "*Ostomates are generally not disadvantaged by location, as there is an appointed stomal therapy nurse in most regions. Only the ostomates that live a long way out don't get that extra care and involvement with support groups. However they can call someone over the phone. (7)"*

In addition to support group's ostomates can address sexuality needs by either reading the many publications on this topic, talking with their stomal therapy nurse, or organising counselling through the Queensland Cancer Fund. "*There are alot of publications about relationship needs and sexuality. The association provides some. The* stomal therapy nurse *would be the person that a lot of people would talk to because they are the first contact post-op. If they need counselling Queensland Cancer Fund can help them. But for the people who won't talk about it and shut off, you can't help them and their marriages break down. (7)*

It is believed that existing support services have the capacity to meet psychological needs, however there is a question of whether people are aware these proficient services exist. "*Psychological needs are being well met by the services that are out there, as long* *as people are aware of these services, there are so many people willing to put their hand out and help (8).”*

Colorectal Cancer Ostomate Awareness of Support Services

All ostomates are aware of their local ostomy association, because without joining an ostomy association, they cannot get necessary stoma supplies. “*The stoma therapy nurses inform all ostomates about the organisation during their stay at the hospital (Bob, 2002).” “Without joining the association you cannot get the supplies. Hence it is compulsory for ostomates to join an association to receive their supplies.(7)“*

As the home visiting team is a function of the ostomy associations, awareness about this service should be high in the survival phase. Information about this service is outlined in the association booklets that all ostomates should receive.

Support groups rely on the stoma therapy nurses to inform patients of their existence, however they also have other means of advertising their service. *“Our group relies on the stoma therapy nurses to tell the patients we exist, which doesn’t always happen. We also advertise in the local media, paper radio and television, when there is a meeting coming up. These methods of advertising are not getting to most people in the region. (8)”*

Colorectal Cancer Ostomates Use of Complementary Therapy Support, Dietary Support and Exercise

There are reports of some complementary therapy use among ostomates to support wellbeing. “*People are trying special diets. Relaxation and meditation are advised for supporting wellness. Queensland Cancer Fund and other centres provide this type of support. They must be accredited. People are also advised to exercise when they are well enough. Swimming and walking are great for building themselves up. (*8)” It is the belief of one key informant that: *“People who are interested in complementary therapies will use it. It is not a recommendation, because everyone is different. If this is part of the patients’ lifestyles they will seek it out. (7)”*

Support for Colorectal Cancer Ostomates’ Caregivers

Carers of ostomates have information and psychological support needs. There are a number of support mechanisms available to those people close to ostomates. *“Partners are encouraged to come along to the ostomy association meetings and most of them do.*

The partner needs to know what's going on. The partner needs to be educated. They need to know what to do if the ostomate has an accident, falls over and becomes distraught because the pouch has come off. (7)" "The people in the close perimeter of the patients are well supported by the support group, Queensland Cancer Fund and respire care. The support group provides a lot of emotional support to partners, who are more then welcome to come along to the meetings. However they have to get into the system before those services can be provided. They need to be aware of what's out there. (8)"

Prostate Cancer Support Services

Since 1996 prostate cancer patients have been serviced by a national body, the Prostate Cancer Foundation of Australia. The foundation's vision is defined as being a national organization acting to reduce the impact of prostate cancer on Australian men, their families and the community. It aims to represent the interests of all men diagnosed with prostate cancer through a nation-wide network of affiliated support groups, with a special emphasis on raising money for research into the disease. The foundation has a website, which provides prostate cancer patients with informational support in the form of written text, articles, news magazines, breaking news, an on-line book and video store and personal experiences. There are 46 prostate cancer support groups in Australia affiliated with the Prostate Cancer Foundation of Australia. Nine of these support groups are in Queensland including the: Brisbane Prostate Cancer Support Network; Bundaberg & District Prostate Support Group; Central Queensland Prostate Cancer Support Group; Far North Queensland Prostate Cancer Support Group; Gold Coast Prostate Cancer Support Group; Hervey Bay Prostate Cancer Support Group; Mackay Prostate Support Group; Sunshine Coast Prostate Cancer Support Group; Townsville/Thuringowa Prostate Cancer Awareness & Support Group. (Prostate Cancer Foundation of Australia, 2003)

The Queensland Cancer Fund also supports the Queensland prostate cancer support groups by providing them with volunteer speakers, free photocopying, mail-out of newsletters, some financial assistance and communication links. *"The Queensland Prostate Cancer News provides the communication links to the 9 groups in Queensland and another 2 groups in Northern Rivers and Darwin. This is well over 1000 members that we contact that way through the Brisbane Chapter of the Prostate Cancer Foundation of Australia. The Queensland Prostate Cancer News is a quarterly newsletter that that advocates on a state bases, the services delivered. It is published by the Queensland Cancer Fund for the Queensland Chapter of the Prostate Cancer Foundation of Australia. (9)"*

In addition to the existing face-to-face support groups, prostate cancer patients are reportable also utilising a number of online prostate cancer support groups. "*ACOR* (http://www.acor.org/) *have a mailing lists which are support groups online for people with cancer and one of them is prostate problems. You can subscribe, there are rules and they will kick you off if you start to break them. You are supposed to do your bit and contribute where you can. It is one of the best. It is more evidence based. Where as there are other mailing lists that omit material that are not proven. (9)"* An Australian online support group that is recommended by members of the Brisbane Prostate Cancer Support Network (Dornan et al., 2003) is YANA (http://www.yananow.net) which means 'You Are Not Alone'.

Lions Australia run a Lions Australia Prostate Cancer Website (http://www.prostatehealth.org.au) that gives step-by-step information on prostate cancer, list of support groups, educational resources and where you can go to get them, you can also ask questions online and there are links to other useful websites.

Andrology Australia is the Australian Centre of Excellence in Male Reproductive Health. It undertakes programs to improve knowledge and provide much needed education in specific areas of male reproductive health. They have a website (http://www.andrologyaustralia.org/default.asp) which reflects this focus, with quality information on the male body, prostate disease (including prostate cancer), testicular cancer, male infertility, testosterone therapy, impotence and other resources.

The Continence Foundation of Australia exists to serve the interests of incontinent people throughout Australia by improving access to and availability of services, providing information and advice and promoting education, support and research. The foundation has a website (http://www.contfound.org.au) that has information in the form of papers, magazines, journals, information sheets, books for sale, annual reports, bulletins and news items. They also have a helpline (1800 33 00 66) for advise on managing bowel or bladder problems.

To support prostate cancer survivors with treatment side effect, members of the Brisbane Prostate Cancer Support Network have also recommended (Dornan et al., 2003) visiting the Phoenix5 website (http://www.phoenix5.org). It provides help with social, emotional and sexual issues.

On a more local level, "*Bond University started a thing called "Water Works" for urinary incontinence at Palm Beach community hall. It involves the local community nurses, psychologists and physiotherapists, who operate a couple of days a week so that people with incontinence problems can go to. (1)"*

The delivery of medical care for prostate cancer survivors seems to be dependant on the region where patients live. *"There are now prostate cancer nurses in some regions in Australia, but there are none in the Gold Coast region. (1)" "Physiotherapist can offer some help for incontinence. (1)"* There are also incontinence nurses. *"The division of general practice are endeavouring at this stage to educate GP's in the aftercare of prostate cancer. There is only 1 urologist in Townsville who covers an area from Cairns to Mackey and out to Mt Isa and he is completely run off his feet. In 2003 GPs will undertake the aftercare from the urologist. This will improve aftercare services. (2)"*

Meeting Prostate Cancer Survivors' Needs

"Queensland support for prostate cancer is probably ahead of the rest of Australia.(3)" In Queensland there is a high level of inter-organisational prostate cancer support that delivers services that target a variety of supportive care needs. As discussed above, support groups are affiliated with the Prostate Cancer Foundation of Australia and the Queensland Cancer Fund. Some support groups collaborate with professionals "*The group has a speaker every month, whether it is an oncologist, urologist, GP, incontinence nurse, sex therapist, QCF speakers.(2)".* All support groups have access community resources and provided their members with details about where to access information. *"The support groups have contact with the Queensland Cancer Fund, the Blue Nurses and Saint Vincents. There is also Lions Australia and Andrology Australia websites that patients can look up themselves. The Queensland Chapter produced in Brisbane is an excellent source of information for the group.(3)"*

While the Queensland prostate cancer support experience maybe ahead of the rest of Australia, there is still evidence of un-met supportive care needs in regions of the state.

Un-met needs seem to exist for two reasons. Firstly, because not all regions across the state have access to support groups. "*We really need more groups around the place, for example we need one in Ipswich, we need one in Toowoomba and so on. Some would say we need more groups in Brisbane that are smaller. (9)"* Secondly, because all support groups are run differently and each group targets different needs, that is, some are run predominantly as an information exchange, some exist to provide emotional, spiritual and informational support and others are more social in focus. "*All the groups have their own character, smaller groups are much more interactive, the Caloundra area group have a more a party approach to their meetings, the Brisbane group is very formal, despite our informality. (9)"*

The region in which the support group exists can often dictate how the group is conducted and what needs are met or remain un-met. For example: "*Because Bundaberg is more isolated then Brisbane they rely on videos more then guest speakers. They have Queensland Cancer Fund speakers available to talk to them, but most of the speakers are women and are really not appropriate. There is a need for professional speakers to add to the knowledge base and provide a broader perspective. (3)" "Support groups like Brisbane that are large and have a microphone out the front of rows of chairs are very intimidating especially when you have just been diagnosed with cancer. You can't sit is a circle and talk it's just too big. This is a real problem, as you want to encourage everyone to have access to support services. (1)" "All the bigger groups have to get the outside speakers in, but they also have the access to these speakers because they are in the big centres. There is a value in each type and it will vary from time to time with what you need. (1)"* Some survivors are lucky enough to live in a region where it is not to far to travel to access two groups. For example "*The gold coast region could use some professional speaker although gold coast people will travel to Brisbane for this. (1)"*

"With prostate cancer being a men's issue it is very important that the services are tailored for men and their specific needs. (2)" "Impotence is one of the biggest hurdles for a man to loose that part of his being. This is why partners are invited along to the support group meetings too. They are a vital part of the support, because it is something shared between the two. Partners need to speak openly with each other and maybe with close friends. This is part of quality of life.(3)" "Men wont come and ask about impotence or incontinence but they will sit up straight and listen to everything a speaker has to say about it. (2)" Some support groups have adopted the following approach to deal with this issue: "*Discussion is one-to-one for intimate issues such as impotence and incontinence. People are matched up with someone who has been through the experience.(2)"* In the prostate cancer experience, there are also a number of online support groups and resources which

cater to men whom prefer to obtain information and support without interacting face-to-face with people, as well as men who do not have access to support groups or who want additional information. While online support resources have their advantages, it must also be recognised that social support is a very important component for some men. "*When patients have problems with impotence and incontinence they ask what sort of hope do we have in life, is it worth going on, what do we do? When patients get together and talk about their problems they can get through them. Social support from the partner and friends is one of the main means of support. (3)"*

Existing supportive care is reportedly doing a good job meeting the needs of those who access them. *"Psychological needs are being well addressed by Queensland Cancer Fund and the support group and the urologist and the GP's. 70-80% of information needs are being met, provide patients have knowledge of the support groups and the Queensland Cancer Fund. Support groups and Queensland Cancer Fund are the local source of information, in addition the Prostate Cancer Foundation of Australia and the lions website provide a lot of information. Awareness about this website is being passed on by the support groups leader. The other 20-30% of unmet needs is related to awareness. (2)"*

Prostate Cancer Survivors' Awareness of Support Services

While there is a lot of inter-organisational promotion of prostate cancer support services in the survivor context as discussed earlier, there seems to be a break down in some regions of Queensland of supportive care clinicians in the treatment phase promoting support services for survivors. In this scenario, inter-organisational promotion of support services will have no impact on survivors who are not aware of or involved in any support services. "*Only about 5% of prostate patients would use cancer support services. Awareness, the male image of not needing help and the doctors not promoting support as necessary are all reasons to why service use maybe minimal. Specialists don't communicate well about support services. The younger generation of specialist is better than the old. Most have a belief that they aren't any good. There is a need for a collaborative partnership between specialist and support services. (1)"* However, not all regions of Queensland and services experience this breakdown. *"A lot of people phone the group leader on recommendation of the local urologist. The local urologist is provided with leaflets about the group and their meetings and these are handed out to patients. This is the main method of getting in touch with patients. (3)"*

Many support groups use different methods of promoting their services and have different perceptions of the proportion of people who are aware of their services. For example: *"Awareness about the services is promoted via Queensland Cancer Fund, doctors and at the local community level. There have been a few articles in the papers, they also get referrals from secondary sources, such as the naturopath at Tweed mall. Carelink (similar to centerlink) is a government-funded service that puts out a book of community services in which the group is listed. The division of GPs (northern rivers) has a directory list of services in with the group is listed. Good awareness of the group has only occurred in the last 18 months to 2 years. This awareness mainly comes from the QCF helpline.(1)" "The group advertises under community services in the daily papers (advertiser and bulletin), radio stations and TV stations. Advertising is also by word of mouth and fliers in the Mater, general and the Wesley Hospital and the group is listed in the Yellow pages under men's health. Most patients are aware of it. (2)" "Patients are generally referred through the cancer fund or through professionals. Queensland Cancer Fund also promotes the group, through their newsletter. There would be a substantial proportion of people who would not be aware of the group. (9)"*

Reportedly awareness of where to seek supportive aids is also low. *"There is no advertisement around to tell men where to get incontinence aids. Amcal chemists carry the aids. ADL solutions carry incontinence, impotence and invalids. There is also a government subsidy scheme for pensioners for an incontinence subsidy. There needs to be advertising to raise awareness. (2)"*

Prostate Cancer Survivors' Use of Complementary Therapy Support, Dietary Support and Exercise

When discussing the use of complementary therapies for support of wellbeing it was reported that: *"There is a great interest in complementary therapies. (1)"* The Brisbane Prostate Cancer Support Network document an article in their November 2002 newsletter that indicated more than 70% of cancer patients surveyed had used alternative medicine treatments. Most of those patients said they used the treatments successfully to improve their sense of well-being. The study of 356 adult breast, colon and prostate cancer patients in 14 counties specifically asked about cancer patients' attitudes toward alternative treatments, which include vitamins, massage therapy, naturopathic doctors, meditation, spirituality and support groups. Dietary supplements were the most common form of alternative therapy, taken by 65% of patients.

Anecdotal evidence shows that Queensland prostate survivors are trying a variety of complementary therapies for support*. "Shark cartridge, selenium, hyaloideum and other naturopathic remedies are tried by a lot of people.(2)" "Some people find meditation helpful, they come away feeling good. (9)"* Another key informant reported using intravenous vitamin C for immunity, 714x (canfa) injections into lymph gland into the pancreas, meditation, yoga and chi gong. (1) In spite of this, there are many concerns with its validity. *"There are concerns that complementary therapies maybe use by the patient who needs to feel like they are in control. The problem is that some of the people are doing it for commercial reasons and others have a good experience themselves that they think they can apply to everyone; they become total believers and can put people at risk. (1)" "Naturopaths sell some very expensive brews. There is no evidence to support any of it. (9)"*

The Brisbane Prostate Cancer Support Network published information (Dornan et al., 2003) about ten modern natural solutions with evidence to support prostate cancer patients. These included: essential fatty acids – omega 6 (deep water fish, flaxseed/linseed oil); Indoles (derived from cabbage family); Lycopene (tomatoes, sun-dried tomatoes); Modified Citrus Pectin; Proanthocyandins (berries); Shark's Cartilage; Lignans (flaxseed/linseed oils); Vitamin C; Zinc; Vitamin D. These natural remedies are all related to reducing the risk of prostate cancer.

When considering complementary and lifestyles approaches to support cancer survivors wellbeing, key informants spoke of Ian Gawler and his approach to surviving cancer. "*Arguably Australia's most prominent cancer survivor, Dr Ian Gawler, says taking an active role in your own healing process with cancer has a significant impact on your chances of survival. Dr Gawler said a pilot study in March this year by Newcastle University's senior lecturer in psychology, John Shea, reported "a dramatic decrease in physical symptoms among patients who talked openly about their illness and learned relaxation techniques (Dornan et al., 2002a)".* It appears that some survivors and even support groups model their wellbeing support on the therapeutic and holistic lifestyle practices of Ian Gawler's teachings. For example "*Meetings are run in the format of firstly talk about how they are feeling and their problems and then some meditation is done, then there is an informal chat over coffee.(1)"*

Ian Gawler teaching can be experienced in depth at the Gawler Foundation in Victoria. The Gawler Foundation has been conducting a fully integrated, holistic, self-help program for people affected by cancer since 1981. The programs conducted include a strong emphasis upon meditation, nutrition, developing and sustaining a positive state of mind, and providing active support. Many techniques are used including several forms of group therapy, art therapy, pain management, and extensive exploration of existential questions surrounding life and death, meaning and purpose in life. Humour is a major component of all aspects of the program and individual counselling and massage is offered. (The Gawler Foundation)

Exercise is reportedly another important component in the support of prostate cancer survivors. Exercise is particularly helpful for those patients who have had hormone therapy and patients suffering from incontinence. *"There needs to be an exercise program that starts with basic stretching and works all the way through to weight bearing exercise to combat osteoporosis, which is a result of the hormone therapy and cardiovascular exercise for physical and mental wellbeing. There is nothing like this available in Australia for cancer patients' support.(1)" "Pelvic floor and sphincter exercises are advocated in the support group for incontinence.(2)" "As there are seven command centres that control bladder voidance and continence, it is essential that a specific intense system of exercises be undertaken to improve all reflex circuitry relating to this control. The pelvic floor exercise program aims to: gain control, strength, power, endurance and speed of muscle contraction of the pelvic floor muscles; dynamically and functionally retrain and integrate the pelvic floor muscles with the abdominal muscles; dynamically and functionally retrain components of the reflex circuitry mechanism involved with continence and; aerobically condition elements of the local vascular system supplying neural and other structures in the pelvic region. (Dornan et al., 2002b)"*

Support for Prostate Cancer Survivor's Caregiver

Those close to prostate cancer patients play a very important support role. "*Family and partner support probably overcomes most of the problems with prostate cancer. (3)"* However, not all wives know how to deal with the cancer experience and therefore in addition to being the supporter they also require support. *"Some partners don't cope well with the cancer experience. They don't understand that it takes a long time to deal with cancer, and patients don't just get on with life after the treatment. It is my observation that the wedge goes in more then it brings patients closer. And when it comes to prostate cancer you've got the sexual activity issue that is even more difficult to deal with, because the male image as the initiator is damaged. (1)*" Prostate cancer is as much the partner's problem as it is the patient's. There are several support services available to partners. But are these services adequate? *"The mater hospital has a working scheme with the support group. Two men and their wife's from the group have had Queensland Cancer Fund* *tuition so that they can come along to the hospital to talk to patients and their families before and after treatment. They will talk patient-to-patient, partner-to-partner or all together depending on what is needed. (2)" "Wives are encouraged to come along to the support group meetings, but there is need for support specifically for them and the widows. (1)"*

Discussion: Implications for Main Study.

Needs Assessment

With the increase of survival from cancer, assessment of quality of cancer patients' survival has become more important, and outcomes such as psychological sequelae and quality of life are now recognised as valuable indicators of cancer care. Supportive care needs assessment of cancer patients is a complementary approach to the biomedical assessment which traditionally includes tumour shrinkage, survival and length of remission. By obtaining a direct index of patients' perceived needs, needs assessment ensures that assumptions do not have to be made about patients' care requirements. On a broader scale, it also enables service providers to pinpoint gaps in existing services and to prioritise resource allocation to those aspects of care that needs improving. (Boyes et al., 2002)

Despite the clear potential of needs assessment, there has been a paucity of reliable and valid instruments. This led to a program of work culminating in the development of the Supportive Care Needs Survey (SCNS), a 59 item survey that incorporates the following domains (Bonevski et al., 2000):

- Psychological: needs related to emotions and coping.
- Health system and information: needs relating to the treatment centre and obtaining information about the disease, diagnosis, treatment and follow-up.
- Physical and daily living: needs related to coping with physical symptoms and side effects of treatment and performing usual physical tasks and activities.
- Patient care and support: needs related to health care providers showing sensitivity to physical and emotional needs, privacy and choice.
- Sexuality: needs related to sexual relationships.

However, the SCNS is a core survey for general cancer patients across all stages of the disease. The findings of this pilot study demonstrate that there are specific issues attributed to cancer site, and that these site-specific issues generate particular support needs. To assess these site-specific support needs in the main study's population-based questionnaire, consideration will be required to further develop the instruments for site-specific needs assessment.

Across cancer sites (prostate, gynaecological and colorectal ostomates), there seems to be high levels of supportive care needs in the psychological, physical and daily, and sexuality needs categories. However, because of the different treatment modalities, and therefore, the different side-effects, losses or equipment with which survivors have to deal, the site-specific issues within these supportive care categories are different across cancer sites.

The main supportive care needs of prostate cancer survivors are a direct result of the treatment side effects, that is, they mainly deal with the issues of impotence and incontinence. These issues have ramifications in the supportive care needs categories of: physical and daily living needs; psychological needs and; sexuality needs. Age and treatment type maybe predictive of supportive care needs, however these two predictors are probably correlated. Male socialisation seems to exacerbate the effect of the psychosexual issues.

The main issues for gynaecological cancer survivors centre on the emotional feelings of turmoil and loss. This loss resonates as a psychological and/or physical reaction to the gynaecological cancer experience. It can be directly related to the treatment, e.g. the loss of fertility, loss of sexual functioning or damage to body image. The loss can also resonate as an emotional response to the cancer experience e.g. loss of control, independence, identity or self-esteem. Supportive care needs of gynaecological cancer survivors are dominant in the psychological needs, sexuality needs and physical and daily needs categories. Those survivors who develop lymphoedema also report financial needs related to the condition’s interference with work.

Ostomate colorectal cancer survivors have to adjust to a new process of eliminating body waste. Within this adjustment they must learn to manage the stoma, regain physical and emotional wellbeing, and learn to feel secure in public and relationships. They appear to have mainly psychological, physical and daily living supportive care needs. While most people with a stoma can enjoy a healthy sex life, some sexuality supportive care needs do occur as ostomates need to accept their new body image, and they may also need to adapt to a new sexual techniques to ensure the pouch doesn’t spill.

There were negligible needs registered for survivors in the health system and information needs category and the patient care and support needs category. Health system and information needs maybe well met by the available services, which offer extensive information for survivors. However, it must be noted that this reported perspective comes from key informants who are providers and users of services and may not be representative of the broader population, that is, these key informants have acted as spokespersons for the patients with whom they come into contact. The patients who do not access these services, and therefore, would not come into contact with these key informants, may have a very different view as to whether their health system and information needs are being met. Patient care and support needs seem to be well met as the past patients provide a large proportion of the support to survivors, and it is reported that they are sensitive to physical and emotional needs as they have been through the experience themselves.

When considering the development of the main study's instruments, it is considered that the proposed tool of needs assessment, the Supportive Care Needs Survey (SCNS), will need to be further refined and developed to address site-specific issues of the cancer patients surveyed. It is recognised that a number of supplementary modules have been developed for use in conjunction with the SCNS to address issues related to specific cancer site, stage of disease and type of treatment. These modules include breast cancer, melanoma, prostate cancer, colostomy and access to health care and ancillary support services.

The prostate module is designed for men with prostate cancer varying in disease stage, treatment modality and time since diagnosis (Steginga et al., 2001) and therefore will require refining to target survivors in the initial post treatment phase. This module consists of 7 items assessing urinary function, bowel function and masculine self-image (Steginga et al., 2001). However this module doesn't include any specific questions about meeting the support needs of survivors dealing with impotence. As this was one of the main reported issues survivors deal with in this pilot study, questions will be developed to capture needs assessment related to this issue.

The colostomy module is designed for colon cancer patients who wear a colostomy bag. It contains 10 items assessing emotional adjustment, lifestyle changes, interpersonal relations and management of colostomy bag (Hancock et al.). This will be a useful tool for assessing ostomate colorectal cancer survivors' needs.

The access to service module is applicable for all cancer patients regardless of cancer site, disease stage, treatment modality or time since diagnosis. It consists of 16 items assessing access to transport facilities, financial assistance, information resources, counselling and support services, home help (cleaning, gardening, nursing) and hospital facilities (child minding food drink). (Bonevski et al., 2000) It is important for the main study to assess access to support services, as this will aid in determining which geographical locations in Queensland require improved support service provision. However, some items in this module such as transport and hospital facilities may not be relevant to the survivor perspective of this study. When designing the questionnaire, refinement and development of this module will have to occur to ensure site-specific and disease stage appropriate questions are included.

A proportion of the women treated for gynaecological cancer will develop lymphoedema and suffer badly swollen legs, feet or abdomen. In addition to causing them discomfort or pain, this may affect their ability to cope with everyday activities. These women will have specific support needs associated with their condition. Modules are currently underdevelopment for lymphoedema following breast cancer treatment and long-term survivors of cancer (Boyes et al., 2002). Anecdotal evidence (4) reports that the needs of gynaecological cancer survivors with lymphoedema are different from breast cancer survivors with lymphoedema. It will be important to develop a module that will assess the supportive care needs of this subgroup.

In addition to the type of cancer, the type of treatment, the patients' age, gender and their geographical location, were all factors that may predict survivors' needs. It will be important to acquire specific information about all of the above factors in the main study.

Supportive Care Awareness and Use

Implicit in the assessment of supportive care needs is the assumption that patients' needs are not being met because the support care does not exist. However, this may not be the case. Patients' lack of awareness and barriers to use of supportive care may be where the support system breaks down. In this pilot study, awareness of services was highlighted as one of the main barriers to use of supportive care. It will be important to measure awareness of services, general and site specific, in the main study.

Furthermore, it is an objective of this project to determine use of supportive care by Queensland prostate, gynaecological and colorectal cancer patients in the initial post treatment phase. The pilot study has helped to determine what supportive care includes from a patients' perspective and what support care exists. It is clear that the term 'supportive care' is a professional term that many patients do not comprehend. Patients may equate supportive care with support services, such as support groups or organisations like the Queensland Cancer Fund or Gynaecological Cancer Society. However, when key informants discussed support and care patients were utilising to support their wellbeing, services, social support, complementary therapies, exercise programs and diet were all mentioned. The quality of cancer patients' survival appears to depend on many types of supportive care. Services are identified as the main type, however to provide a holistic model of supportive care use, it will be important to include questions in the main study about use of all of the above identified means of support. It is recognised that extensive questioning about use of support services, social support, complementary therapies, exercise programs and diet is beyond the scope of a PhD project. Therefore the main questioning of supportive care use will centre on services with limited exploration of the others.

Summary

This has been an important pilot study of the needs faced by prostate, gynaecological and colorectal ostomate cancer survivors and how well existing services address these needs. By listening to key informants describe their own and/or others experiences of living with cancer, the researcher was able to discover needs of Queensland survivors that might otherwise be overlooked in the literature. It also allowed the researcher to gain a holistic picture of needs assessment, that is, how particular issues filter into the varying needs categories and what existing supportive care can be utilised to deal with survivors' issues.

References

Australian Council of Stoma Associations.*Australian Council of Stoma Associations*, 2003, from http://www.australianstoma.org.au/

Australian Council of Stoma Associations. (2002). *A Beginning ... not an End*: Custom Press.

Bob. (2002). Personal Communication with Bob from Toowoomba & South West Ostomy Association.

Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Offord, K. P., Koch, C., Wen, K. Y., et al. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Educ Couns, 49*(3), 233-242.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., & Boyes, A. (2000). Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer, 88*(1), 217-225.

Boyes, A., Girgis, A., & Zucca, A. (2002). *Assessing Cancer Patients' Needs. Workshop 1: Practical aspects of needs assessment in oncology*. Sydney.

BUPA. (2002). *Stoma Care*, 2003, from http://hcd2.bupa.co.uk/fact_sheets/Mosby_factsheets/Stoma_care.html

Clinical Oncological Society of Australia, The Cancer Council Australia, & National Cancer Control Initiative. (2003). *Optimising Cancer Care in Australia*. Carlton, Australia.

Dale, S. (2002). You Have a Right to your Feelings. *Ostomy Australia, 11*(2), 38.

Dornan, P., Broughton, S., & McHugh, B. (2002a). *Brisbane Prostate Cancer Support Network Newsletter October 2002*. Brisbane.

Dornan, P., Broughton, S., & McHugh, B. (2002b). *Brisbane Prostate Cancer Support Network Newsletter September 2002*. Brisbane.

Dornan, P., Broughton, S., & McHugh, B. (2003). *Brisbane Prostate Cancer Support Network Newsletter March 2003*. Brisbane: Brisbane Prostate Cancer Support Network.

Flaxman, P. (2001). *Gold Coast Ostomy Association*. Arundel: Gold Coast Ostomy Association.

Gynaecological Cancer Society. (2000a). *Create a health plan for yourself*, 2003, from http://www.gcsq.org.au/resources/createhealthplan

Gynaecological Cancer Society. (2000b). *Gynaecological Cancer Society*, 2003, from http://www.gcsau.org/

Gynaecological Cancer Society. (2001). *Cancer of the Cervix - Social Work*, 2003, from http://www.gcsau.org/qcgc/cervix/social_work.asp

Gynaecological Cancer Society. (2002a). *Cancer of the Vulva*, 2003, from http://www.gcsq.org.au/resources/lf_cancer_vulva_nov2002.pdf

Gynaecological Cancer Society. (2002b). *GyCan*, 2003, from http://www.gcsq.org.au/resources/gyncan_1.pdf

Gynaecological Cancer Society. (2002c). *Gynaecological Cancer Booklets*, 2003, from http://www.gcsq.org.au/resources/default.asp

Gynaecological Cancer Society. (2002d). *Gynaecological Surgery - Hysterectomy and Salpingo-Oophorectomy*, 2003, from http://www.gcsq.org.au/resources/sx_tahbso_nov2002.pdf

Gynaecological Cancer Society. (2002e). *Gynaecological Surgery - Pelvic Lymphadenectomy*, 2003, from http://www.gcsq.org.au/resources/sx_pelvic_lymphadenectomy_nov2002.pdf

Gynaecological Cancer Society. (2002f). *Gynaecological Surgery - Sexuality Issues*, 2003, from http://www.gcsq.org.au/resources/lf_gen_sexuality_nov2002.pdf

Hancock, L., Lattimore-Foot, G., Lawrence, J., & Welch, J. (Under editorial review). The perceived needs of people diagnosed with colon cancer.

Harrod, H. L. (2003). A piece of my mind. An essay on desire. *Jama, 289*(7), 813-814.

Hopgood, A. (1996). *Surviving Prostate Cancer, One Man's Journey*. Sydney: Random House Australia.

Li, C., Samsioe, G., & Iosif, C. (1999). Quality of life in long-term survivors of cervical cancer. *Maturitas, 32*(2), 95-102.

Lions Australia. (2003). *PHIP Information*, from http://www.prostatehealth.org.au/perl/repat?event_id=26

Little, M., Jordens, C., Paul, K., & Sayers, E. (2001). *Surviving Survival Life After Cancer*. Marrickville, Australia: Choice Books.

Lymphoedema Association of Queensland. (2003a). *About Lymphoedema*, 2003, from http://homepage.powerup.com.au/~lymphqld/about.htm

Lymphoedema Association of Queensland. (2003b). *Lymphoedema Association of Queensland*, 2003, from http://homepage.powerup.com.au/~lymphqld/

National Cancer Institute. (2002, 2002). *Transitional Care Planning*, 2002, from http://www.cancer.gov/cancer_information/doc_pdq.aspx?version=1&summaryid=208_05471#2.2

Pinchen, K., Inglis, A., & Scott, J. (2002). *Media Releases: Care and Support for Cancer Patients*, 2003, from http://www.qldcancer.com.au/Whats_New/Media_Releases/Careand.html

Prostate Cancer Foundation of Australia. (2003). *Information About The Foundation*, 2003, from http://www.prostate.org.au/info.htm

Queensland Cancer Fund. (2003). *Education and Support for People with Cancer*, 2003, from http://www.qldcancer.com.au/Cancer_Info_and_Services/PCS/Education.html

Queensland Centre for Gynaecological Cancer. (1997). *Queensland Centre for Gynaecological Cancer Annual Report 1997*. Brisbane: Queensland Centre for Gynaecological Cancer.

Sahay, T. B., Gray, R. E., & Fitch, M. (2000). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice, 8*(1), 38-44.

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer, 88*(1), 226-237.

Steginga, S. K., Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer (2000). *Psycho Oncology, 10*(1), 66-75.

Sunshine Coast Daily. (2002). *Caring Counsel Changes Lives*, 2003, from http://www.sunshinecoastdaily.com.au/data/full_stories/sept_2002/13_02/caring.html

The Gawler Foundation.*The Gawler Foundation*, 2003, from http://www.gawler.org/cancer.htm

Whelan, T. J., Mohide, E. A., Willan, A. R., Arnold, A., Tew, M., Sellick, S., et al. (1997). The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer, 80*(8), 1518-1524.

Witt, P. (2002). Bowel Cancer Decisions. *Ostomy Australia, 11*(3), 22-25.

QUT Queensland University of Technology Brisbane, Australia

Queensland Cancer Fund

Queensland Government
Queensland Health

Date

Dr [Name]
Clinic Name
Address

Dear Dr [Name],

The Experience of Gynaecological Cancer Survivors: Supportive Care Needs and Use

The Queensland University of Technology, sponsored by the Queensland Cancer Fund, is planning to undertake a population based cross-sectional study to firstly assess gynaecological cancer patients' supportive care needs, awareness, and use, and secondly assess implications of the multi-level influences on patient needs for the delivery of supportive care services in Queensland. The project is being conducted as part of a PhD program. This research will facilitate informed program development to cancer support services in Queensland.

I am writing to you to ask if we may approach a sample of your patient(s) who is/are registered with the Gynaecological Cancer Registry at the Queensland Centre for Gynaecological Cancer as being treated by you. This includes patients who are 3 months to 5 years post diagnosis with gynaecological cancer to seek their agreement to participate in this study. This may include both public and private patients. The study has received ethics approval from the Queensland University of Technology and all treating hospitals of patients on the Gynaecological Cancer Registry including, Royal Brisbane and Women's Hospital, the Mater Hospital, The Wesley Hospital, John Flynn, The Townsville Hospital and Brisbane Private.

Following your written approval for approaching patients, the Queensland Cancer Fund and Queensland University of Technology collaboration would propose to send your patient(s) a personal letter signed by you *(letter is enclosed for your signature)* inviting their participation in this study. If patients consent to join the study, they will be asked to complete a 20-page questionnaire. It is estimated that this will take approximately 50 minutes.

If you agree to your patient(s) being invited to participate in this study, I would be grateful if you would provide your signed agreement on the enclosed form, sign the letter to your patient(s) and return both in the reply paid envelope.

Some doctors have preferred to provide their electronic signature to the research team. Particularly because when the main component of this study begins, which involves approximately 2000 patients, they will be faced with up to 500 patient letters and consent forms to sign. If you would prefer to view a spreadsheet of the patients and then to get the research team to insert your electronic signature on the agreed patient letters and/or consent forms, then please sign the attached form regarding electronic signature and return it in the reply paid envelope. Please contact the study research assistant Jessica Howie on (07) 3864 8299 if you have any questions regarding this matter.

The contact letter is worded to cover the possibility that patients may have passed away, and the research team is applying checks to minimise the chance that letters are sent to deceased patients. However, before you give your consent for the researchers to invite your patients to participate in this study, and if you have not been in contact with the patient within the last 3 months, you may prefer to ensure that they have not passed away.

I would be pleased to discuss this request with you on (07) 3864 8299.

With thanks
Yours sincerely

Beesley

Mrs Vanessa Beesley
PhD student project co-ordinator

QUT Queensland University of Technology
Brisbane, Australia

Queensland Cancer Fund

Queensland Government
Queensland Health

STUDY OF GYNAECOLOGICAL CANCER PATIENTS' SUPPORTIVE CARE NEEDS & USE

Patient's name:
Our ref number:
Date of birth:
Date of diagnosis:
Address:

Tick one box only

☐ YES, I am happy for my patient to be approached to participate in the study of cancer patients' supportive care needs.
⇓
Please sign the attached letter to your patient and return it, with this form, to the study coordinator in the reply paid envelope.

☐ NO, I do not wish my patient to be approached.

Dr:
Address:

Telephone:

___________________________________ ______________
Doctor's signature ***Date***

If another doctor is now caring for your patient, we would be grateful if you would supply their name.

New doctor: ___________________________________
Address: ___________________________________
____

Please return this form and your signed letter if appropriate in the enclosed reply paid envelope.

Thank you

Queensland University of Technology
Brisbane, Australia

Queensland Cancer Fund

Queensland Government
Queensland Health

[Date]

[Title] [Name]
[Address]

Dear [Title] [Name],

The Queensland University of Technology, sponsored by the Queensland Cancer Fund, is undertaking a study to identify issues about gynaecological cancer patient needs and supportive care use. A comprehensive investigation into the supportive care needs of people with gynaecological cancer in Queensland has not been carried out. This study will be used to inform program development in cancer support services in Queensland.

Researchers at the Queensland Cancer Fund and the Queensland University of Technology would like to ask you about your experience with gynaecological cancer, your particular support needs, your methods of obtaining support and your reasons for and barriers to use of supportive care. If you were to take part in the study you would be asked to fill in a written questionnaire that would take about 50 minutes to complete.

All information obtained from you will be treated in the strictest confidence and will be used for medical research purposes only. Identifying information will only be available to a few researchers directly involved in the project. With your help we can learn how to improve supportive care services for gynaecological cancer patients and the quality of life for people affected by the disease.

Please find enclosed an information sheet that explains a little more about the study. If you are willing to take part would you please complete the enclosed consent form and questionnaire and return both to the study coordinator in the reply paid envelope. A duplicate consent form is also enclosed for you to sign and keep as a copy for yourself.

Would you be willing to take part in this state-wide research project?
- ☐ Yes, I am willing to take part in this research
- ☐ No, I do not wish to take part

If you feel that you have received this survey in error, please tick a box below:
- ☐ I have never been diagnosed with gynaecological cancer
- ☐ The person to whom this letter is addressed is deceased
- ☐ Other reason for receiving this survey in error (please specify)________________________________

No matter which box you've ticked, please return this letter, the consent form and the questionnaire in the enclosed postage paid envelope.

If you have any questions about the study, please call the study's research assistant, Ms Jessica Howie on (07)38648299.

Thank you for considering this request.

Yours sincerely

Dr [Dr Name]

GYNAECOLOGICAL CANCER PATIENTS’ SUPPORTIVE CARE NEEDS STUDY INFORMATION SHEET

Our research study

Our project aims to inform cancer support service delivery in Queensland, particularly with respect to gynaecological cancer patients’ needs. The project is being conducted as part of a PhD research program. The research team comprises members from Queensland University of Technology and the Queensland Cancer Fund.

The purpose of our research

Five-year cancer survival rates in Australia indicate that more and more people are living with gynaecological cancer and for longer periods of time. This research project will evaluate whether existing supportive care is meeting the needs of patients with gynaecological cancer. Results of the study will be used to inform Queensland cancer support service delivery.

What you will be asked to do if you choose to be involved in our study

If you choose to participate in this project you will be asked to complete a - questionnaire of about 25 pages in length. It includes questions about your experience with gynaecological cancer, your particular support needs, your methods of obtaining support and your reasons for, and barriers to use of, supportive care. It is estimated that this will take approximately 50 minutes**.**

Possible risks

The risks of participating in this study are quite minimal. You may choose not to answer questions that you do not wish to. There is a small risk that you may experience distress from answering questions about your cancer experience. If this occurs and you agree, we shall refer you to an appropriate counselling service.

Benefits that may result from our research

There may be no direct benefit to you by your participation in this research. However, some people find that sharing their cancer experience with others has great emotional and social benefits. By participating in our study you may also become more aware about supportive care options that are available to you. On a grander scale, the opinions and experience of our participants will help shape the future of cancer support services in Queensland. With improved cancer supportive care we may increase the survival rate of cancer patients and enhance patients’ quality of life.

Any questions or concerns

Questions related to this project or how to fill out the questionnaire are welcome at any time. Please direct them to the research assistant, Ms Jessica Howie on 07 3864 8299, or the PhD student investigator, Mrs Vanessa Beesley on 07 3864 5677. You may prefer to direct your call to the investigator’s supervisor, Dr Diana Battistutta on 07 3864 3525 at the Queensland University of Technology. The study has a gynaecological oncologist contact, Associate Professor Andreas Obermair. For any medical questions please contact Associate Professor Obermair on 07 3636 5485 at the Royal Brisbane and Women’s Hospital.

This study has been reviewed and approved by all of the following research ethics committees. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study, or your rights as a participant, or should you wish to make an independent complaint, you may contact the secretary of any of the ethics committees listed below.

Committee	Secretary	Telephone
Queensland University of Technology’s Human Research Ethics Committee	Ms Wendy Heffernan	07 3864 2340
Royal Brisbane and Women’s Hospital and Health Service District Human Research Ethics Committee	Ms Jennifer Lonton	07 3636 5490
Mater Hospital Human Research Ethics Committee	MS Odette Petersen	07 3840 1585
The Wesley Hospital Multidisciplinary Ethics Committee	Dr D V Killer	07 3232 7926
John Flynn Human Research Ethics Committee	Ms Bev Borgas	07 5598 9008
The Townsville Hospital Institutional Ethics Committee	Ms Nerida Bishop	07 4796 1003
Brisbane Private Human Research Ethics Committee.	Dr Nic Loudon	07 3834 6555

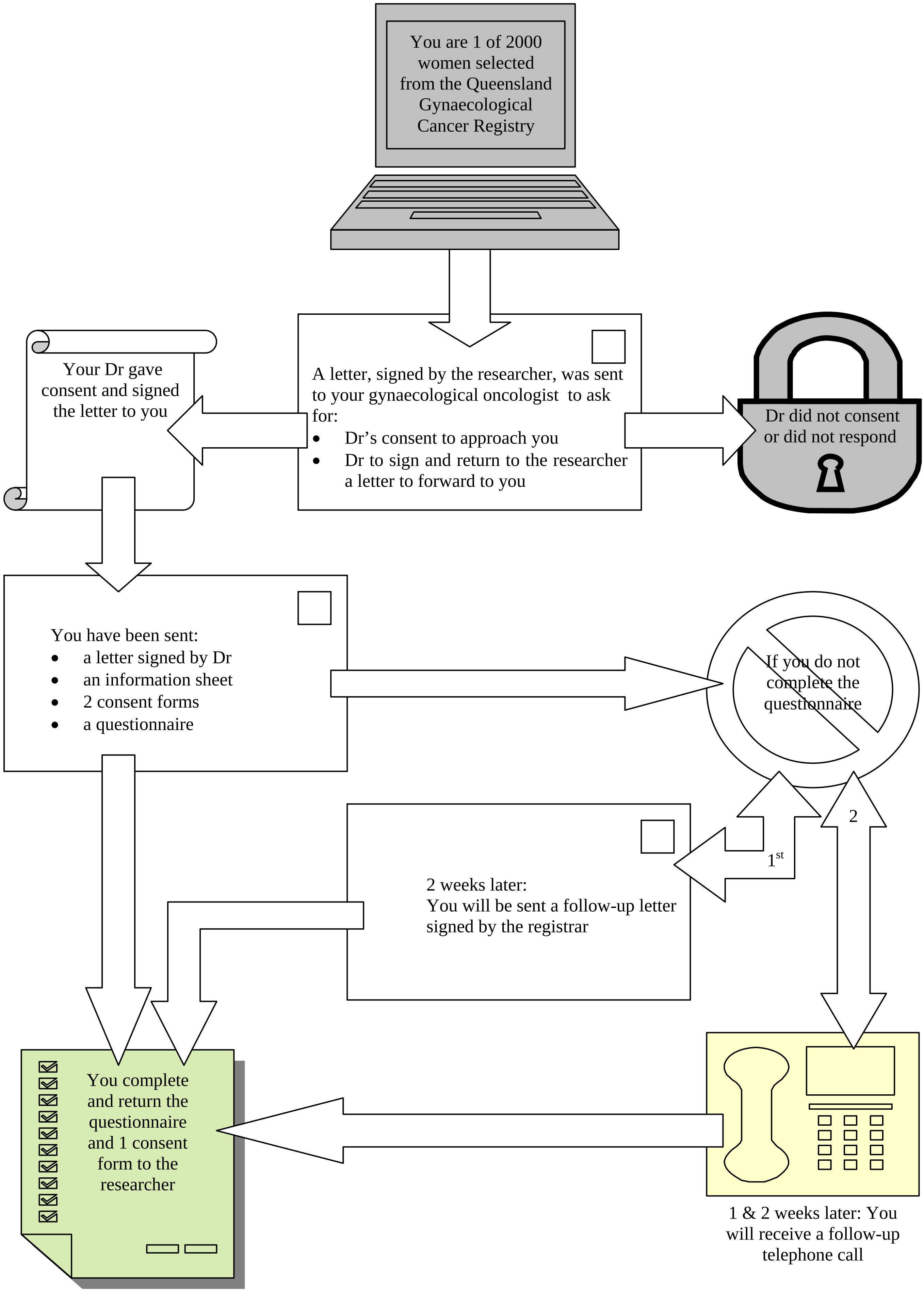
About your freedom to consent

Your participation in this project is entirely voluntary. You are free to withdraw consent before or during the study without comment or penalty. Under no circumstances will you be prejudiced as a result of your actions; your participation or withdrawal of consent will not affect your medical treatment, will not influence your present or future involvement with the Queensland University of Technology, your relationship with the Queensland Cancer Fund, or your relationship with your doctor.

Confidentiality of your data

Medical information about your cancer and its treatment will only be available to the researchers, yourself, and your physician. Your medical information and the information you supply in the questionnaire will be stored in a data file in a way in which you cannot be identified.. When the results of the study are published we will summarise information in such a way that you will remain anonymous.

About the consenting procedures



You are 1 of 2000 women selected from the Queensland Gynaecological Cancer Registry

A letter, signed by the researcher, was sent to your gynaecological oncologist to ask for:

- Dr's consent to approach you
- Dr to sign and return to the researcher a letter to forward to you

Dr did not consent or did not respond

Your Dr gave consent and signed the letter to you

You have been sent:

- a letter signed by Dr
- an information sheet
- 2 consent forms
- a questionnaire

If you do not complete the questionnaire

2 weeks later:
You will be sent a follow-up letter signed by the registrar

1 & 2 weeks later: You will receive a follow-up telephone call

You complete and return the questionnaire and 1 consent form to the researcher

CONSENT FORM
(COPY FOR YOU TO KEEP)

PhD Student Investigator: *Mrs Vanessa Beesley, Centre for Health Research – Public Health, Ph 07 3864 5677*
Research Assistant: *Ms Jessica Howie, Centre for Health Research – Public Health, Ph 07 3864 8299*
Investigator's Supervisor: *Dr Diana Battistutta, Centre for Health Research – Public Health, Ph 07 3864 3525*
RBWH contact: *Associate Professor Andreas Obermair, Royal Brisbane and Women's Hospital, Ph 07 3636 5485*

Project: *The Experience of Gynaecological Cancer Survivors: Supportive Care Needs and Use.*

You have been invited to participate in a questionnaire for the above PhD research project. The questionnaire is designed to identify issues about gynaecological cancer patient needs and supportive care use. The questionnaire will be approximately 25 pages long and is estimated to take about 50 minutes to complete. Information about your experiences will help us identify patient needs, help-seeking pathways, reasons for use and barriers to use of supportive care. This information will be used to inform program development in cancer support services in Queensland. If you participate, you will not be obliged to respond to all questions.

Consent

By signing this form below you indicate that you:

1. acknowledge that the nature of this research and your involvement in the project has been explained to you in the information sheet;

2. understand that confidentiality will be maintained and no identifying information will be released in papers or reports that will result from this project;

3. understand that your participation in the study is voluntary and you may withdraw from this study at any time, without comment or penalty;

4. understand that by consenting to participate, you are also giving researchers involved in this project permission to access medical information about your cancer and its treatment. This private personal information will be stored in a de-identifiable data file to maintain your anonymity;

5. understand that participation in this project does not involve any risks to you in terms of physical health and wellbeing, pain, discomfort, reduced employability or criminal or civil liabilities;

6. understand that there is a small risk that discussing your experiences with cancer supportive care may cause emotional distress - in this event, you are free to decide to end the questionnaire and we may provide contact details of counselling or support services if required or requested; and

7. understand that you are able to request a copy of the study results. If requested this will be provided to you by mail when they are available.

You are welcome to contact the research assistant, chief investigator, investigator's supervisor, or RBWH contact regarding any questions or concerns you may have about this project. Should you have any concerns relating to the ethical conduct of this research, please feel free to contact the Queensland University of Technology's Ethics Committee Secretariat on 07 3864 2340 or any of the hospital research ethics committees listed on the information sheet.

Patient Name .... **Signature**...…….......... **Date**....../........./.........

Witness Name .... **Signature**...…….......... **Date**....../........./.........

QUT Queensland University of Technology
Brisbane, Australia

Queensland Cancer Fund

Queensland Government
Queensland Health

CONSENT FORM
(TO BE RETURNED WITH THE QUESTIONNAIRE)

PhD Student Investigator: *Mrs Vanessa Beesley, Centre for Health Research – Public Health, Ph 07 3864 5677*
Research Assistant: *Ms Jessica Howie, Centre for Health Research – Public Health, Ph 07 3864 8299*
Investigator's Supervisor: *Dr Diana Battistutta, Centre for Health Research – Public Health, Ph 07 3864 3525*
RBWH contact: *Associate Professor Andreas Obermair, Royal Brisbane and Women's Hospital, Ph 07 3636 5485*

Project: *The Experience of Gynaecological Cancer Survivors: Supportive Care Needs and Use.*

You have been invited to participate in a questionnaire for the above PhD research project. The questionnaire is designed to identify issues about gynaecological cancer patient needs and supportive care use. The questionnaire will be approximately 25 pages long and is estimated to take about 50 minutes to complete. Information about your experiences will help us identify patient needs, help-seeking pathways, reasons for use and barriers to use of supportive care. This information will be used to inform program development in cancer support services in Queensland. If you participate, you will not be obliged to respond to all questions.

Consent

By signing this form below you indicate that you:

1. acknowledge that the nature of this research and your involvement in the project has been explained to you in the information sheet;

2. understand that confidentiality will be maintained and no identifying information will be released in papers or reports that will result from this project;

3. understand that your participation in the study is voluntary and you may withdraw from this study at any time, without comment or penalty;

4. understand that by consenting to participate, you are also giving researchers involved in this project permission to access medical information about your cancer and its treatment. This private personal information will be stored in a de-identifiable data file to maintain your anonymity;

5. understand that participation in this project does not involve any risks to you in terms of physical health and wellbeing, pain, discomfort, reduced employability or criminal or civil liabilities;

6. understand that there is a small risk that discussing your experiences with cancer supportive care may cause emotional distress - in this event, you are free to decide to end the questionnaire and we may provide contact details of counselling or support services if required or requested; and

7. understand that you are able to request a copy of the study results. If requested this will be provided to you by mail when they are available.

You are welcome to contact the research assistant, chief investigator, investigator's supervisor, or RBWH contact regarding any questions or concerns you may have about this project. Should you have any concerns relating to the ethical conduct of this research, please feel free to contact the Queensland University of Technology's Ethics Committee Secretariat on 07 3864 2340 or any of the hospital research ethics committees listed on the information sheet.

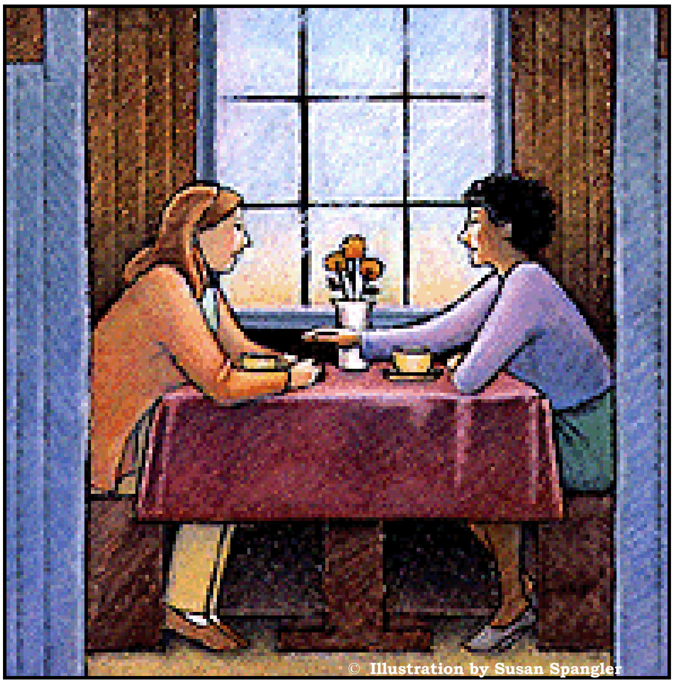
Patient Name .... **Signature**..............................……….......... **Date**....../......../........

Witness Name .... **Signature**..............................……….......... **Date**....../......../........

Queensland University of Technology

Queensland Cancer Fund

GYNAECOLOGICAL CANCER SUPPORTIVE CARE QUESTIONNAIRE



© Illustration by Susan Spangler

Thank you for participating in this study. Our purpose is to better understand the supportive care needs of women diagnosed with gynaecological cancer in Queensland. This questionnaire is for women recently diagnosed and up to 5 years post diagnosis. The experience can result in many needs over time. We are most interested in how you are feeling right now, so most of the questions ask about how you have been feeling in the last month.

There are no right or wrong answers to the following questions. We are particularly interested in your experience.

Some questions may seem personal, but it is important that you try to answer each question. Your answers will help us to better address the needs of the 2000 Queensland women completing this survey.

Your answers will be handled with the strictest confidence, and there is no way that your medical team or the Queensland Cancer Fund will be able to identify you via your answers on this survey.

We appreciate your time and commitment to this study. The questionnaire involves 11 sections and will take about 50 minutes to complete. If you find the size of the questionnaire too much to do all at once, you may wish to complete a few sections at a time.

It would be most helpful if you could complete and return this survey in the enclosed postage paid envelope within 7 days of receiving it.

SECTION 1: YOUR MEDICAL HISTORY

In the first section, we would like to ask you some questions about your gynaecological cancer and any other conditions that have affected you. If you have had more than one type of cancer, please answer the questions below in relation to your primary gynaecological cancer(s). This information will help us to understand how the type of treatment and other conditions you have had might affect your support needs.

1 With what type of primary cancer were you diagnosed? *(Please tick all that apply)*

1 ☐ Cervical
2 ☐ Uterine (also called endometrial or womb)
3 ☐ Ovarian
4 ☐ Vulval
5 ☐ Vaginal
6 ☐ Peritoneal
7 ☐ Fallopian tube
8 ☐ Other (please specify)________________________________
9 ☐ Don't know

2 With what stage of gynaecological cancer were you diagnosed? *(Please tick one)*

1 ☐ Stage 1
2 ☐ Stage 2
3 ☐ Stage 3
4 ☐ Stage 4
5 ☐ Don't Know
6 ☐ No Stage

3 When were you first told of your gynaecological cancer? *(Please tick one)*

1 ☐ Within the last 3 months
2 ☐ 4-6 months ago
3 ☐ 7-12 months ago
4 ☐ More than 1 and up to 2 years ago
5 ☐ More than 2 and up to 3 years ago
6 ☐ More than 3 and up to 5 years ago
7 ☐ More than 5 years ago
8 ☐ Can't remember

4 Have you ever received any of the following treatments for gynaecological cancer? *(Please tick all that apply)*

1☐ Chemotherapy
2☐ Pelvic radiation therapy
3☐ Radical hysterectomy
4☐ Removal of ovaries
5☐ Bowel resection
6☐ Total pelvic exenteration with vaginal reconstruction
7☐ Radical vulvectomy
8☐ Conization of the cervix
9☐ Oophorectomy (removal of one tube and ovary)
10☐ Oophorectomy (removal of both tubes and ovaries)
11☐ Progesterone therapy for uterine cancer
12☐ Lymph node(s) removed
13☐ Other *(please specify)* ________________________
14☐ Have not had any treatment

5 As a result of your treatment, were you fitted with a stoma (an artificial opening on the abdominal wall to bypass parts of the normal intestine)? *(Please tick one)*

1☐ No ***[go to question 6]***
2☐ Yes I was fitted with a colostomy (opening from large bowel)
3☐ Yes I was fitted with a ileostomy (opening from small bowel)
4☐ Yes I was fitted with a urostomy (opening from urinary tract)

If yes, is/was the stoma temporarily or permanently fitted? *(Please tick one)*
  1☐ Temporary stoma which I currently still have
  2☐ Temporary stoma which I no longer have
  3☐ Permanent stoma

6 When was the last time you were admitted to hospital to receive treatment for your gynaecological cancer? *(Please tick one)*

1☐ Within the last month ***[go to question 7]***
2☐ 1-2 months ago ***[go to question 8]***
3☐ 3-6 months ago ***[go to question 8]***
4☐ 7-12 months ago ***[go to question 8]***
5☐ More than 1 and up to 2 years ago ***[go to question 8]***
6☐ More than 2 years ago ***[go to question 8]***
7☐ Never ***[go to question 8*]**
8☐ Can't remember ***[go to question 8]***

7 In the last month have you received any of the following treatments for gynaecological cancer? *(Please tick all that apply)*

1☐ Chemotherapy
2☐ Hormone Therapy
3☐ Radiation Therapy
4☐ Other *(please specify)* ______________________

8 Which of the following treatment centres were you treated at? *(Please tick all that apply)*

1☐ Royal Brisbane and Women's Hospital, Herston
2☐ The Wesley Hospital, Auchenflower
3☐ Mater Hospital, South Brisbane
4☐ Gold Coast Hospital, Southport
5☐ John Flynn Hospital, Coolangatta
6☐ Kirwan Hospital, Townsville
7☐ Other (*please specify)* ______________________

9 Has your health care provider indicated to you that the gynaecological cancer is in a state of remission (that is, the signs and symptoms of cancer have completely or partially disappeared)? *(Please tick one)*

$_1$☐ Yes
$_2$☐ No
$_3$☐ Don't Know

10 Since completing treatment for cancer, have you had an illness or been involved in a serious accident requiring hospitalisation?

$_1$☐ No
$_2$☐ Yes ***(tick all that apply)***...
  $_1$☐ Disease recurrence
  $_2$☐ A different type of cancer ***(list)***__________________________________
  $_3$☐ Other illness or surgery ***(list)***____________________________________
  $_4$☐ Accident ***(specify)***____
  $_5$☐ Psychiatric reasons ***(specify)***___________________________________

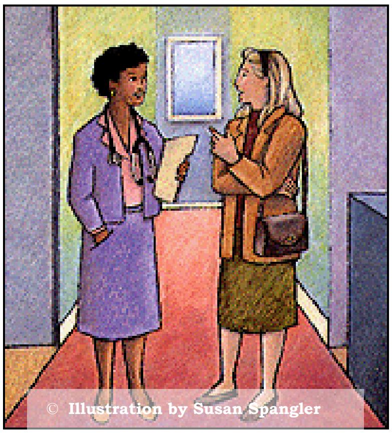
11 Do you have, or have you ever been diagnosed with any of the following physical or emotional illnesses?

$_1$☐ No
$_2$☐ Yes ***(tick all that apply)*** ..
  $_1$☐ Kidney disease or problem
  $_2$☐ Heart disease
  $_3$☐ Diabetes
  $_4$☐ Hypertension/ high blood pressure or stroke
  $_5$☐ Serious respiratory disease or problem
  $_6$☐ High cholesterol
  $_7$☐ Hearing loss
  $_8$☐ HIV/ AIDS related illness
  $_9$☐ Arthritis
  $_{10}$☐ Depression
  $_{11}$☐ Anxiety / panic attacks
  $_{12}$☐ Eating disorders
  $_{13}$☐ Fatigue
  $_{14}$☐ Other ***(specify)***____

12 Since you were treated for gynaecological cancer, have you experienced any of the following conditions? *(Please tick all that apply)*

I have experienced the following <u>since being treated</u> for gynaecological cancer
  $_1$☐ Depression
  $_2$☐ Anxiety / panic attacks
  $_3$☐ Eating disorders
  $_4$☐ Fatigue
  $_5$☐ None of the above

<u>In the past month</u> I have experienced the following:
  $_1$☐ Depression
  $_2$☐ Anxiety / panic attacks
  $_3$☐ Eating disorders
  $_4$☐ Fatigue
  $_5$☐ None of the above



SECTION 2: PROBLEMS WITH YOUR LOWER LIMBS

1. **Since being treated for gynaecological cancer have you noticed any of the following symptoms in your lower limbs? *(Please tick all that apply)***

1☐ Swelling of part or all of the leg(s) or groin
2☐ Visible lumps in the leg(s)
3☐ Puffiness and reddened areas in the leg(s)
4☐ Pain in the leg(s)
5☐ Leg(s) feeling heavy
6☐ Flesh feeling thick and hard in the leg(s)
7☐ Heat in the leg(s)
8☐ Tenderness in the leg(s)
9☐ Pins and needles in the leg(s)
10☐ Skin feeling tight in the leg(s)
11☐ Decreased range of movement in the leg(s)
12☐ Stiffness of the leg(s)
13☐ Other *(please specify)* ____________________
14☐ None of the above ***[go to section 3 "Your Support Needs"]***

If you have not experienced any of the above symptoms skip this section and go to Section 3 "Your Support Needs" on page 7. If you have, proceed with question 2.

2. **Have you ever been diagnosed by a medical practitioner or other health professional with lymphoedema of the lower limbs (swelling of the lower limbs)?*(Please tick one)***

1☐ Yes
2☐ No

If yes, approximately when were you diagnosed? /
Month Year

The symptoms listed in question 1 are sometimes indicative of lymphoedema (swelling of the lower limbs). If you have any of the symptoms or have been diagnosed with lower limb lymphoedema please continue completing this section of the questionnaire.

3. **Approximately when did the lymphoedema symptoms begin?**

/
Month Year

4. **On average in the last month, how severe have the symptoms been for you? *(please tick one)***

1☐ I have had no symptoms in the last month
2☐ Mild
3☐ Moderate
4☐ Severe

5. **If you have ever experienced lower limb swelling, in which of the following areas have you experienced the swelling? (Please tick all that apply)**

1☐ I have not experienced any lower limb swelling
2☐ Left Leg
3☐ Right Leg
4☐ Groin

6. **Which of the following triggers preceded the appearance or worsened the lymphoedema symptoms? *(please tick all that apply)***

$_{1}$☐ Cellulitis
$_{2}$☐ A fall
$_{3}$☐ Ascitic tap
$_{4}$☐ Sunburn
$_{5}$☐ Injection to affected limb
$_{6}$☐ Insect bite
$_{7}$☐ Being on feet all day
$_{8}$☐ Long-distance travel
$_{9}$☐ Air travel
$_{10}$☐ Driving a car
$_{11}$☐ Sitting close to a radiator
$_{12}$☐ Hot weather
$_{13}$☐ Being in a hot spa
$_{14}$☐ Other (please specify)____
$_{15}$☐ Don’t know
$_{16}$☐ None of the above

7. On average, what level of difficulty do the lymphoedema symptoms give you with performing your daily tasks? *(Please tick one)*

$_{1}$☐ No difficulty
$_{2}$☐ Mild difficulty
$_{3}$☐ Moderate difficulty
$_{4}$☐ Severe difficulty
$_{5}$☐ unable

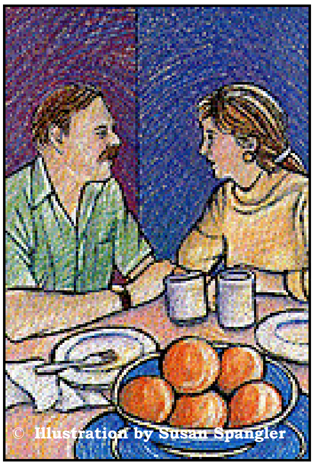
8. **When did you become aware of the potential risk of developing lower limb lymphoedema? *(please tick one)***

$_{1}$☐ I was informed before my operation for cancer
$_{2}$☐ I was informed after my operation for cancer but before I developed the symptoms
$_{3}$☐ I was informed after I developed the symptoms of lower limb lymphoedema
$_{4}$☐ I can not remember
$_{5}$☐ I was not informed

9. Please complete the following table about lymphoedema treatments you have used and their effectiveness.

Treatment Type	**Place a ✓ tick next to the treatments you have used**	**On a scale of 0 - 4 rate how effectively the treatments you used controlled or reduced your lymphoedema symptoms Where 0=Not effective & 4=Very effective Circle a number for each treatment you used**
		Not effective Very effective
Compression garment eg. stockings		0 1 2 3 4
Lymphatic massage		0 1 2 3 4
Lymphatic exercise		0 1 2 3 4
Bandaging		0 1 2 3 4
Diuretics		0 1 2 3 4
Care of limb instructions		0 1 2 3 4
Bike shorts		0 1 2 3 4
Anti-inflammatory drugs, analgesics		0 1 2 3 4
Paddling in water		0 1 2 3 4
Other (please specify)		0 1 2 3 4

SECTION 3: YOUR SUPPORT NEEDS


© Illustration by Susan Spangler

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

NO NEED	**1**	**Not applicable** – This was not a problem for me as a result of having cancer.
	2	**Satisfied** - I did need help with this, but my need for help was satisfied at the time.
SOME NEED	**3**	**Low need** - This item caused me little concern or discomfort. I had little need for additional help.
	4	**Moderate need** – This item caused me some concern or discomfort. I had some need for additional help.
	5	**High need** - This item caused me a lot of concern or discomfort. I had a strong need for additional help.

<u>For example</u>

In the <u>last month</u>, what was your level of need for help with:	**No need**		**Some need**		
	Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1. Being informed about things you can do to help yourself to get well	1	2	3	[✓ 4]	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now please complete the next few pages about your needs.

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied	Low need	Moderate need	High need
1.	Pain	1	2	3	4	5
2.	Lack of energy/tiredness	1	2	3	4	5
3.	Feeling unwell a lot of the time	1	2	3	4	5
4.	Work around the home	1	2	3	4	5
5.	Not being able to do the things you used to do	1	2	3	4	5
6.	Anxiety	1	2	3	4	5
7.	Feeling down or depressed	1	2	3	4	5
8.	Feelings of sadness	1	2	3	4	5
9.	Fears about the cancer spreading	1	2	3	4	5
10.	Worry that the results of treatment are beyond your control	1	2	3	4	5
11.	Uncertainty about the future	1	2	3	4	5
12.	Learning to feel in control of your situation	1	2	3	4	5
13.	Keeping a positive outlook	1	2	3	4	5
14.	Feelings about death and dying	1	2	3	4	5
15.	Changes in sexual feelings	1	2	3	4	5
16.	Changes in your sexual relationships	1	2	3	4	5
17.	Concerns about the worries of those close to you	1	2	3	4	5
18.	More choice about which cancer specialists you see	1	2	3	4	5
19.	More choice about which hospital you attend	1	2	3	4	5
20.	Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21.	Hospital staff attending promptly to your physical needs	1	2	3	4	5
22.	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5

In the <u>last month</u>, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied	Low need	Moderate need	High need
23.	Being given written information about the important aspects of your care	1	2	3	4	5
24.	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25.	Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26.	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27.	Being informed about your test results as soon as feasible	1	2	3	4	5
28.	Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29.	Being informed about things you can do to help yourself to get well	1	2	3	4	5
30.	Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31.	To be given information about sexual relationships	1	2	3	4	5
32.	Being treated like a person not just another case	1	2	3	4	5
33.	Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34.	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

35. What was your level of need for easy access to the following services and resources in the last month?

NO NEED	1	**Not applicable** or never interested in having access to this service or resource
	2	**Fully satisfied** with access to this service or resource
SOME NEED	3	**Low need** - Had a low desire for better access to this service
	4	**Moderate need** - Had a moderate desire for better access
	5	**High need** - Had a strong desire for better access

In the last month, what was your level of need for access to:		**No need**		**Some need**		
		Not applicable	**Fully Satisfied**	**Low need**	**Moderate need**	**High need**
a.	Counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for you or your family/partner	1	2	3	4	5
b.	Brochures about services and benefits for patients with cancer	1	2	3	4	5
c.	Library of books and videos about cancer and related issues	1	2	3	4	5
d.	Relaxation classes	1	2	3	4	5
e.	Drop-in counselling and support service	1	2	3	4	5
f.	24-hour telephone support and cancer advisory service	1	2	3	4	5
g.	Home nursing service	1	2	3	4	5
h.	Home cleaning service	1	2	3	4	5
i.	Home gardening service	1	2	3	4	5
j.	Respite care	1	2	3	4	5
k.	Monetary allowance for travel, treatment and equipment expenses	1	2	3	4	5

The questions on this page are related to lower limb lymphoedema. If you did not experience any of the lymphoedema symptoms listed in section 2 question 1, please <u>go to the next page</u>. If you did experience symptoms of lower limb lymphoedema <u>please complete this page</u>.

In the last month, what was your level of need for help with:		**No need**		**Some need**		
		Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1.	To be given more help in managing the symptoms of lymphoedema.	1	2	3	4	5
2.	To have help in initially coping with the emotional shock of having lymphoedema.	1	2	3	4	5
3.	To be more informed about the causes, preventions and treatment of lymphoedema	1	2	3	4	5
4.	To be given written information about ways to manage symptoms of lymphoedema.	1	2	3	4	5
5.	Managing the symptoms of lymphoedema in the workplace.	1	2	3	4	5
6.	Doing your daily activities around the home	1	2	3	4	5
7.	Coping with changes in your self-image as a result of having lymphoedema.	1	2	3	4	5
8.	Dealing with your partner's reaction to your legs.	1	2	3	4	5
9.	Finding a support group which addresses your particular lymphoedema needs	1	2	3	4	5
10.	Pain or discomfort in the legs or groin	1	2	3	4	5
11.	The cost of having lymphoedema	1	2	3	4	5

SECTION 4: YOUR USE OF COMMUNITY SUPPORT SERVICES

Please complete the following table about your awareness and use of support services and support organisations. If you answer yes in the first column then complete the rest of the line. If you answer no in the first column then skip to the next line.

	**Circle yes or no next to the support services or organisations:**				**Rate on 0 - 4 scale Where 0=Not at all satisfied 4=Completely satisfied**
	You were aware existed If you answer no in this column then skip to the next line.	**You were referred to by a health care provider**	**You have ever utilised for support with your cancer experience**	**You have utilised in the past month for support with your cancer experience**	**How satisfied you were overall with the support services or organisations you utilised** Circle NA if you did not use the service
Types of Support Services:					
Cancer information and support telephone lines	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Community-based cancer support groups	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Workshops/programs for coping with cancer	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Internet based cancer support groups	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Information booklets on cancer from support organisations	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Information on cancer available on the internet	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Face-to-face counselling services for cancer patients	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Physiotherapy service for cancer patients	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Financial assistance for cancer patients	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Respite care for cancer patients	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Community health nurse for cancer patients	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Support Services Offered by the Organisations Below:					
Centre for Gynaecological Cancer at Royal Brisbane & Women's Hospital	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Gynaecological Cancer Society	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Lymphoedema Association of Queensland	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Ostomy/Stoma Association	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Queensland Cancer Fund	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Cancer Support Centre at Griffith University	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Bloomhill Cancer Help Centres in Buderim	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
Other Community Support Services or Organisations Not Mentioned Above:					
(specify)	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA
(specify)	Yes No	Yes No	Yes No	Yes No	0 1 2 3 4 NA

SECTION 5: YOUR COMPLEMENTARY THERAPY SUPPORT

Complementary therapies and alternative therapists appear to be widely used by cancer patients in many parts of the world. This section will assess therapy use and how effective it is in improving health and wellbeing.

IF YOU HAVE NEVER USED ANY COMPLEMENTARY THERAPIES OR ALTERNATIVE THERAPISTS FOR COPING WITH CANCER OR REDUCING THE RISK OF CANCER SPREADING OR RETURNING, TICK THIS BOX ☐ AND GO TO THE NEXT SECTION "YOUR LIFESTYLE SUPPORT"

Otherwise please complete the following table about the complementary therapies and alternative therapists you have utilised in relation to your gynaecological cancer.

© Australian Daisy Study Group

For all the complementary therapies and alternative therapists you have ever utilised to cope with cancer or reduce the risk of it spreading or returning, please rate how much the therapy improved your health and wellbeing on the 0 - 4 scale where:

0=No improvement &
4=Great improvement

Circle NA if you have not used the therapy

Alternative medicine providers						
Acupuncturist	0	1	2	3	4	NA
Massage therapist	0	1	2	3	4	NA
Naturopath	0	1	2	3	4	NA
Spiritual healer / therapeutic touch	0	1	2	3	4	NA
Other (specify below)						
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
Diet and Nutrition						
Anticancer diet (specify below)						
*	0	1	2	3	4	NA
Herbal remedy (specify below)						
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
Vitamins or minerals (specify below)						
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
Other supplements eg garlic, shark cartilage (specify)						
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA
Mind-body techniques						
Meditation	0	1	2	3	4	NA
Yoga	0	1	2	3	4	NA
Tai chi	0	1	2	3	4	NA
Music therapy	0	1	2	3	4	NA
Imagery/visualization	0	1	2	3	4	NA
Other (specify below)						
*	0	1	2	3	4	NA
*	0	1	2	3	4	NA

SECTION 6: YOUR LIFESTYLE SUPPORT

1. **On average in the last month, how many serves of vegetables have you eaten each day, where a ‘serve’ is ½ cup cooked vegetables or 1 cup of salad vegetables? This includes fresh, dried, frozen, and tinned. Please include tomatoes.**

☐☐ Serves

2. **On average in the last month, how many serves of fruit have you eaten each day, where a ‘serve’ is 1 medium piece or 2 small pieces of fruit or a cup of diced pieces? This includes fresh, dried, frozen, and tinned. Please do not include tomatoes or fruit juices.**

☐☐ Serves

3. **Are you eating the same amount of fruit and vegetables now, as you were just prior to your cancer diagnosis? *(Please tick one)***

1 ☐ Yes – same
2 ☐ No –eating more
3 ☐ No – eating less
4 ☐ I don’t eat fruit or vegetables

4. **In the last week, how many times have you walked continuously, for at least 10 minutes, for recreation or exercise or to get to or from places?**

☐☐ Times

5. **What do you estimate was the total time that you spent walking in this way in the last week?**

☐☐ Minutes or ☐☐ Hours per week

6. **In the last week, how many times did you do any vigorous gardening or heavy work around the yard, which made you breathe harder or puff and pant?**

☐☐ Times

7. **What do you estimate was the total time that you spent doing vigorous gardening or heavy work around the yard in the last week?**

☐☐ Minutes or ☐☐ Hours per week

8. **In the last week, how many times did you do any vigorous physical activity, which made you breathe harder or puff and pant? (e.g. jogging, cycling, aerobics, competitive tennis, etc.) Do not include household chores or gardening or yardwork.**

☐☐ Times

9. **What do you estimate was the total time that you spent doing this vigorous physical activity in the last week?**

☐☐ Minutes or ☐☐ Hours per week

10. In the last week, how many times did you do any other more moderate physical activity that you haven't already mentioned? (e.g. gentle swimming, social tennis, golf, etc.)

☐☐ Times

11. What do you estimate was the total time that you spent doing these moderate activities in the last week?

☐☐ Minutes or ☐☐ Hours per week

12. On average, which of the following statements best describes your current level of physical activity compared to what it was just prior to your cancer diagnosis? *(Please tick one)*

$_1$☐ I was more active before the cancer diagnosis than I am now
$_2$☐ I was less active before the cancer diagnosis than I am now
$_3$☐ My activity levels were very similar to now

13. How tall are you?

☐☐☐ Cms OR ☐ Ft ☐☐ Inches

14. How much do you weigh now?

☐☐☐ Kgs OR ☐☐ Stones ☐☐ Lbs

15. How would you describe your cigarette smoking status?

$_1$☐ I am currently a cigarette smoker
$_2$☐ I have never been a cigarette smoker ***[go to question 17]***
$_3$☐ I have been a cigarette smoker in the past and quit.

If you have quit how long ago was it? ______________________________

16. Do you smoke the same amount of cigarettes now, as you were smoking just prior to your cancer diagnosis? *(Please tick one)*

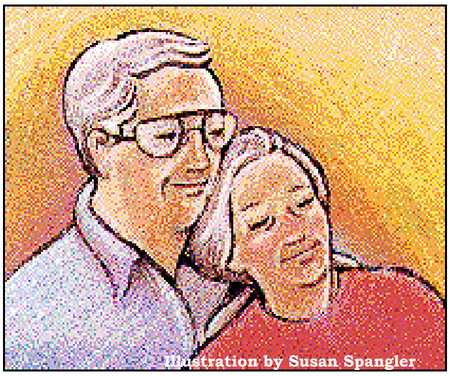
$_1$☐ Yes – same
$_2$☐ No – smoke more
$_3$☐ No – smoke less

17. Which of the following best describes your alcohol drinking now? *(Please tick one)*

$_1$☐ I am a life-long NON-drinker ***[skip question 18 and go to the next section]***
$_2$☐ I currently drink alcohol less than once a month
$_3$☐ I currently drink alcohol at least once a month, but not weekly
$_4$☐ I currently drink alcohol on 1 or 2 days a week
$_5$☐ I currently drink alcohol on 3 or 4 days a week
$_6$☐ I currently drink alcohol on 5 or 6 days a week
$_7$☐ I currently drink alcohol every day
$_8$☐ I used to drink alcohol but have stopped

18. Do you drink the same amount of alcohol now, as you did just prior to your cancer diagnosis? *(Please tick one)*
$_1$☐ Yes – same
$_2$☐ No – drink more
$_3$☐ No – drink less

SECTION 7: YOUR SUPPORT FROM OTHERS



Below is a list of some things that other people do for us, or give us, that may be helpful or supportive. Please circle the number that is closest to your situation.

Here is an example:

	Much Less Than I would Like			**As Much As I Would Like**	
I get enough vacation time	1	2	3	4	5

If you answered "4", that means that you get almost as much vacation time as you would like, but not quite as much as you would like. Please answer each item as best you can.

	Much Less Than I would Like			**As Much As I Would Like**	
1) I have people who care what happens to me.	1	2	3	4	5
2) I get love and affection.	1	2	3	4	5
3) I get chances to talk to someone about problems at work or with my housework.	1	2	3	4	5
4) I get chances to talk to someone I trust about my personal and family problems.	1	2	3	4	5
5) I get chances to talk about money matters.	1	2	3	4	5
6) I get invitations to go out and do things with other people.	1	2	3	4	5
7) I get useful advice about important things in life.	1	2	3	4	5
8) I get help when I'm sick in bed.	1	2	3	4	5

SECTION 8: YOUR QUALITY OF LIFE

Section 8 is a standard questionnaire used widely in research. You will note the word "illness" mentioned many times. We realise that some women completing this questionnaire are long past the diagnosis and treatment phase of their gynaecological cancer and that they are no longer ill. In this case please view the word "illness" in reference to your cancer diagnosis. Please answer the questions in reference to your well-being during the past week.

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	<u>PHYSICAL WELL-BEING</u>	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
GP 1	I have a lack of energy	0	1	2	3	4
GP 2	I have nausea	0	1	2	3	4
GP 3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP 4	I have pain	0	1	2	3	4
GP 5	I am bothered by side effects of treatment	0	1	2	3	4
GP 6	I feel ill	0	1	2	3	4
GP 7	I am forced to spend time in bed	0	1	2	3	4

	<u>SOCIAL/FAMILY WELL-BEING</u>	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
GS 1	I feel close to my friends	0	1	2	3	4
GS 2	I get emotional support from my family	0	1	2	3	4
GS 3	I get support from my friends	0	1	2	3	4
GS 4	My family has accepted my illness	0	1	2	3	4
GS 5	I am satisfied with family communication about my illness	0	1	2	3	4
GS 6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	***Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer*** *it, please check this box* ☐ *and go to the next section.*					
GS 7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

		Not at all	A little bit	Some what	Quite a bit	Very much
	EMOTIONAL WELL-BEING					
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4
	FUNCTIONAL WELL-BEING					
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4
	SPIRITUAL WELL-BEING					
SP1	I feel peaceful	0	1	2	3	4
SP2	I have a reason for living	0	1	2	3	4
SP3	My life has been productive	0	1	2	3	4
SP4	I have trouble feeling peace of mind	0	1	2	3	4
SP5	I feel a sense of purpose in my life	0	1	2	3	4
SP6	I am able to reach down deep into myself for comfort	0	1	2	3	4
SP7	I feel a sense of harmony within myself	0	1	2	3	4
SP8	My life lacks meaning and purpose	0	1	2	3	4
SP9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
SP10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
SP11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
SP12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4

The following questions are specific to the type of cancer you have been diagnosed with. The following questions are sensitive and personal. Please remember that your responses will remain *strictly* confidential and you can refuse to answer any question if you choose. **If you have been diagnosed with more than one primary gynaecological cancer please complete all sections that relate to the cancers you have been diagnosed with.**

Complete this page if you have been diagnosed with CANCER OF THE CERVIX
Go to page 20 if you have been diagnosed with OVARIAN CANCER
Go to page 21 if you have been diagnosed with ENDOMETRIAL CANCER
Go to page 22 if you have been diagnosed with VULVA CANCER
Go to page 23 if you have not been diagnosed with any of the above types of cancer

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FOR PATIENTS WITH CANCER OF THE CERVIX	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**Very much**
CX1	I am bothered by discharge or bleeding from my vagina	0	1	2	3	4
CX2	I am bothered by odour coming from my vagina	0	1	2	3	4
CX3	I am afraid to have sex	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
CX4	My vagina feels too narrow or short	0	1	2	3	4
BMT7	I have concerns about my ability to have children	0	1	2	3	4
CX5	I am afraid the treatment may harm my body	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
CX6	I am bothered by constipation	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
BL1	I have trouble controlling my urine	0	1	2	3	4
BL3	It burns when I urinate	0	1	2	3	4
CX7	I have discomfort when I urinate	0	1	2	3	4
HN1	I am able to eat the foods that I like	0	1	2	3	4

NOW PLEASE GO TO SECTION 9 ON PAGE 23, EXCEPT IF YOU HAVE BEEN DIAGNOSED WITH ANOTHER TYPE OF GYNAECOLOGICAL CANCER, IN WHICH CASE PROCEED TO THE PAGE BELOW WHICH ASKS ABOUT YOUR OTHER CANCER DIAGNOSIS.

ONLY COMPLETE THIS PAGE IF YOU WERE DIAGNOSIED WITH OVARIAN CANCER

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FOR PATIENTS WITH OVARIAN CANCER	Not at all	A little bit	Some What	Quite a bit	Very much
O1	I have swelling in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels..	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
B5	I am bothered by hair loss...	0	1	2	3	4
C6	I have a good appetite...	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
BMT5	I am able to get around by myself	0	1	2	3	4
B9	I am able to feel like a woman..	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
BMT7	I have concerns about my ability to have children	0	1	2	3	4

NOW PLEASE GO TO SECTION 9 ON PAGE 23, EXCEPT IF YOU HAVE BEEN DIAGNOSED WITH ANOTHER TYPE OF GYNAECOLOGICAL CANCER, IN WHICH CASE PROCEED TO THE PAGE BELOW WHICH ASKS ABOUT YOUR OTHER CANCER DIAGNOSIS.

ONLY COMPLETE THIS PAGE IF YOU WERE DIAGNOSIED WITH ENDOMETRIAL CANCER

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FOR PATIENTS WITH ENDOMETRIAL CANCER	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**Very much**
O1	I have swelling in my stomach area	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
Hep 8	I have discomfort or pain in my stomach area	0	1	2	3	4
ES6	I have vaginal bleeding or spotting	0	1	2	3	4
ES4	I have vaginal discharge	0	1	2	3	4
Hep 1	I am unhappy about a change in my appearance	0	1	2	3	4
ES1	I have hot flushes	0	1	2	3	4
ES2	I have cold sweats	0	1	2	3	4
ES3	I have night sweats	0	1	2	3	4
HI7	I feel fatigued	0	1	2	3	4
ES8	I have pain or discomfort with intercourse	0	1	2	3	4
En1	I have trouble digesting food	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
Cx6	I am bothered by constipation	0	1	2	3	4
Bl2	I urinate more frequently than usual	0	1	2	3	4
En2	I have discomfort or pain in my pelvic area	0	1	2	3	4

NOW PLEASE GO TO SECTION 9 ON PAGE 23, EXCEPT IF YOU HAVE BEEN DIAGNOSED WITH ANOTHER TYPE OF GYNAECOLOGICAL CANCER, IN WHICH CASE PROCEED TO THE PAGE BELOW WHICH ASKS ABOUT YOUR OTHER CANCER DIAGNOSIS.

ONLY COMPLETE THIS PAGE IF YOU WERE DIAGNOSIED WITH VULVA CANCER

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FOR PATIENTS WITH VULVA CANCER	Not at all	A little bit	Some what	Quite a bit	Very much
V1	I am bothered by discharge or bleeding from my vulva ...	0	1	2	3	4
V2	I am bothered by odour coming from my vulva	0	1	2	3	4
V3	I am afraid to have sex...	0	1	2	3	4
V4	I am bothered by swelling/fluid in my legs.......................	0	1	2	3	4
V5	My vagina feels too narrow or short	0	1	2	3	4
V6	I am bothered by discomfort in my groin	0	1	2	3	4
V7	I am afraid the treatment may harm my body	0	1	2	3	4
V8	I am interested in sex	0	1	2	3	4
V9	I like the appearance of my body	0	1	2	3	4
V10	I am bothered by constipation	0	1	2	3	4
V11	I have a good appetite..	0	1	2	3	4
V12	I have trouble controlling my urine	0	1	2	3	4
V13	I am bothered by itching/burning in my vulva area...........	0	1	2	3	4
V14	I have discomfort when I urinate	0	1	2	3	4
V15	I am able to eat the foods that I like	0	1	2	3	4
V16	I have discomfort when I am sitting	0	1	2	3	4
V17	I am bothered by pain in my legs.....................................	0	1	2	3	4
V18	I have trouble bending	0	1	2	3	4
V19	I need more information about my medical condition	0	1	2	3	4

NOW PLEASE GO TO SECTION 9 ON PAGE 23, EXCEPT IF YOU HAVE BEEN DIAGNOSED WITH ANOTHER TYPE OF GYNAECOLOGICAL CANCER, IN WHICH CASE PROCEED TO THE PAGE BELOW WHICH ASKS ABOUT YOUR OTHER CANCER DIAGNOSIS.

SECTION 9: YOUR GYNAECOLOGICAL HISTORY

The next questions ask about your gynaecological history, including menopause symptoms and any gynaecological problems that may affect your sex life. We recognise that the following questions are sensitive and personal. Please remember that your responses will remain ***strictly*** confidential and you can refuse to answer any question if you choose.

1. Did your menstrual periods completely stop: *(Please tick one)*

1☐ Before gynaecological cancer treatment ***[go to the next question]***
2☐ As a result of cancer treatment ***[go to the next question]***
3☐ My menstrual period has not completely stopped ***[go to question 7]***

2. At what age did your menstrual periods completely stop?

☐☐ Years

3. Have you had a hysterectomy, an operation to remove your uterus or womb? *(Please tick one)*

1☐ Yes
2☐ No

4. Have you had both ovaries removed? *(Please tick one)*

1☐ Yes
2☐ No

5. Please circle one (1) number per line to indicate the answer which best describes your reproductive feelings and experiences.

	<u>Reproductive feelings</u>	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**Very much**
1	In general, how much distress has going through menopause caused you overall?....	0	1	2	3	4
2	In general, how much of a problem has menopause been for you?..........................	0	1	2	3	4

6. Have you ever used hormone replacement therapy (HRT)? *(Please tick one)*

1☐ Yes
2☐ No

7. In the past 3 months have you taken any female hormones, including hormone replacement therapy (HRT) or birth control pills? *(Please tick one)*

1☐ Yes – hormone replacement therapy (HRT)
2☐ Yes - birth control pills
3☐ No


Illustration by Susan Spangler

We recognise that the following questions are sensitive and personal. Please remember that your responses will remain ***strictly*** confidential and you can refuse to answer any question if you choose.

8. Do you currently engage in sexual activity?

1☐ Yes – ***[go to question 9]***
2☐ No - please tick your reason why not: ***[then skip to the next page]***
- ☐ I do not have a partner at the moment.
- ☐ I am not interested in sex.
- ☐ My partner is not interested in sex.
- ☐ My gynaecological cancer has made sexual relations difficult or uncomfortable.
- ☐ I have another physical problem which makes sexual relations difficult or uncomfortable.
- ☐ My partner has a physical problem which makes sexual relations difficult or uncomfortable.
- ☐ Other (please specify) ______________________________

9. Please circle one (1) number per line to indicate the answer which best describes your sexual feelings and experiences *during the past month*.

		Not at all	**A little bit**	**Some what**	**Quite a bit**	**Very much**
1	Was 'having sex' an important part of your life this month?	0	1	2	3	4
2	Did you enjoy sexual activity this month?	0	1	2	3	4
3	In general, were you too tired to have sex this month?............	0	1	2	3	4
4	Did you desire to have sex with your partner(s) this month?	0	1	2	3	4
5	During sexual relations, how frequently did you notice dryness of your vagina this month?	0	1	2	3	4
6	Did you feel pain or discomfort during penetration this month?............	0	1	2	3	4
7	In general, did you feel satisfied after sexual activity this month?	0	1	2	3	4
8	Were you satisfied with the frequency of sexual activity this month?	0	1	2	3	4
		Not at all	**1-2 times**	**3-4 times**	**5 or more times**	
9	How often did you engage in sexual activity this month?............	0	1	2	3	
		Less than usual	**About the same**	**Some what more**	**Much more**	
10	How did the frequency of sexual activity this month compare with what is usual for you?	0	1	2	3	

SECTION 10: GENERAL INFORMATION

1. **Today's date:** / /20

2. **Your Date of Birth:** / /19

3. **Your Residential Postcode:**

4. **Are you of Aboriginal or Torres Strait Islander origin?** ***(Please tick one)***

1☐ No
2☐ Aboriginal
3☐ Torres Strait Islander

5. **In which country were you born?** ***(Please tick one)***

1☐ Australia
2☐ United Kingdom
3☐ New Zealand
4☐ Italy
5☐ Vietnam
6☐ China
7☐ Greece
8☐ Germany
9☐ Other (specify)________________________________

6. **What is the HIGHEST level of education you have COMPLETED?** ***(Please tick one)***

1☐ A university or college degree (*this includes registered nurses)*
2☐ A trade or technical certificate or diploma (*this includes ENROLLED nurses)*
3☐ Senior high school (*Grade 12, age 17-18 in QLD)*
4☐ Junior high school (*Grade 10, age 15-16 in QLD)*
5☐ Primary school *(Grade 7, age 12-13 in QLD)*
6☐ Did not complete primary school or have no formal schooling

7. **Which of the following best describes your main current employment status?** ***(Please tick one)***

1☐ In full time paid work
2☐ In part time or casual paid work
3☐ Work without pay (eg in a family business)
4☐ Home duties only – no paid work
5☐ Full time student
6☐ Part time student
7☐ Unemployed
8☐ Unpaid voluntary work
9☐ Retired
10☐ Unable to work because of illness or disability

8. What is your relationship status? *(Please tick one)*

$_1$☐ Single
$_2$☐ Defacto/Living together
$_3$☐ Married
$_4$☐ Separated
$_5$☐ Divorced
$_6$☐ Widowed

9. How many children aged 0-17 live in your household?

Enter number ☐☐

10. How many adults aged 18 years and older live in your household (including yourself)?

Enter number ☐☐

11. What is your current gross/annual household income (that is, before tax)? *(Please tick one)*

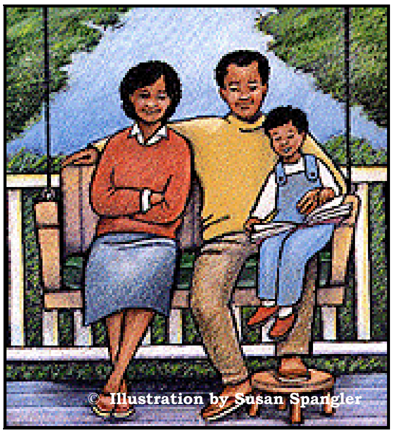
$_1$☐ < $20,000
$_2$☐ $20,000 – less than $40,000
$_3$☐ $40,000 – less than $60,000
$_4$☐ $60,000 – less than $80,000
$_5$☐ $80,000 – less than $100,000
$_6$☐ $100, 000 +
$_7$☐ Do not wish to answer
$_8$☐ Don't know

12. How many people are dependent on this income?

Enter number ☐☐

13. Do you have private health insurance? *(Please tick one)*

$_1$☐ No (Medicare only)
$_2$☐ Yes – Private hospital insurance only
$_3$☐ Yes – Private hospital insurance and private health insurance for ancillary services (eg. dental)
$_4$☐ Yes – Only private health insurance for ancillary services (eg. dental, physiotherapy)
$_5$☐ Don't know



© Illustration by Susan Spangler

SECTION 11: SURVIVORSHIP CONCERNS

The next questions are for you to answer freely in your own words. Answers to these questions may be used to help develop programs to increase the quality of life of other women diagnosed with cancer in the future. If there is not enough space please include further comments on a separate sheet of paper.

What was the most significant challenge or problem for you during or shortly following your initial gynaecological cancer treatment?

____
____
____
____

What, if any, is the most significant challenge or problem for you now related to having had gynaecological cancer?

____
____
____
____

What would have been helpful for you during the diagnosis and treatment period?

____
____
____
____

What support service would be helpful for you now?

____
____
____
____

What do you think health care professionals should know about gynaecological cancer survivorship?

____
____
____
____

Please describe any other services that would be helpful for you or your family for support with your cancer experience.

____
____
____
____

YOU HAVE REACHED THE END OF THIS QUESTIONNAIRE.
PLEASE CHECK THAT YOU HAVE COMPLETED ALL THE QUESTIONS THAT APPLY TO YOU.

THANK YOU FOR SO GENEROUSLY GIVING YOUR TIME TO PARTICIPATE IN THIS PROJECT.

PLEASE RETURN THIS QUESTIONNAIRE AND SIGNED CONSENT FORM IN THE ENCLOSED REPLY PAID ENVELOPE DURING THE NEXT WEEK.

Front and back of seed packets for study participants

Gynaecological Supportive Care

Striving to improve support for the future

©Australian Daisy Study Group

Plant these everlasting
daisy seeds today and
brighten your tomorrow

QUT Queensland University of Technology
Brisbane, Australia

Queensland Cancer Fund

Planting Directions

- Sow seeds in late Autumn in full sun
- Dampen soil before sowing
- Grows best in sandy soil
- Don’t water until seeds germinate
- Once established, water every 2 weeks.
- Once 10-15cm in hight, use a native liquid fertiliser every 3 weeks
- Expect flowers from late winter

QUT Queensland University of Technology Brisbane, Australia
Queensland Cancer Fund
Queensland Government Queensland Health

GYNAECOLOGICAL CANCER PATIENTS’ SUPPORTIVE CARE NEEDS STUDY

[Date]

[Title] [Name]
[Address]

Dear [Title] [Name],

Recently you would have received a questionnaire package regarding your experiences of supportive care needs associated with gynaecological cancer. According to our records your questionnaire has not yet been received by our research team. It would be greatly appreciated if you could please post your completed surveys and signed consent form in the reply paid envelope at your soonest convenience. If you have returned the questionnaire and consent form recently, please disregard this reminder letter.

If you feel that you have received this survey in error, please tick a box below and return this letter to us in the reply paid envelope supplied in the first package:

- ☐ I have never been diagnosed with gynaecological cancer
- ☐ The person to whom this letter is addressed is deceased
- ☐ Other reason for receiving this survey in error (please specify) ________________________________

If you do not wish to complete the survey please tick the box below and return this letter to us in the reply paid envelope supplied in the first package.

- ☐ No, I do not wish to take part

Your information is important to our research and may influence the types of services and their availability to other cancer sufferers in the future. Please also keep in mind that all information you provide will be kept strictly confidential.

Should you require a new questionnaire, or have any questions regarding the questionnaire please feel free to call Jessica Howie (Research Assistant) on (07) 3864 8299.

Thank you for your assistance with our research.

Yours sincerely

Professor Alex J Crandon
Director of the Queensland Centre for Gynaecological Cancer

Patient follow-up calls

If Answers:

Hello, this is ____________ from the Queensland Gynaecological Cancer Study. May I please speak to ____?

Hello ____, we recently sent you out some information about a gynaecological cancer study that we are doing. I'm just calling today to see whether you did receive that information, and to see if you are intending to complete the questionnaire that was enclosed.

If Yes:

That's great. Your responses will help shape the future of cancer support services in Queensland. Do you think you will have time in the next few days to complete the questionnaire and consent form and pop it in the post.

Note: if too busy say study deadline is in 2 weeks and it is ok if you send it in before then.

Do you have any other questions about our study?

Thank you for generously giving your time to our study ________. Goodbye.

If not received:

I'll just tell you a little about the study so you can decide if you want to be sent the survey and information package.

We are a team of researchers comprising members from Queensland University of Technology, the Queensland Cancer Fund and your gynaecological oncologist __________. We are conducting a survey of 1800 Queensland women who have been diagnosed with gynaecological cancer to evaluate whether existing support services are meeting the needs of gynaecological cancer survivors. The survey includes questions about your experience with gynaecological cancer, your particular support needs and your methods of obtaining support. The survey takes about 50 minutes to complete. The survey is for women recently diagnosed and up to 5 years post diagnosis.

Do you think you would be willing to fill-out one of these surveys?

What address can we send that to Mrs ________________?

Do you have any other questions about our study?

You should receive the survey in the mail in the next few days. Thank you for generously taking the time to talk to me today______. Goodbye.

If No:

That is OK because it is your choice. However, it is really important for us to know why people have chosen not to complete our questionnaire. Was there a particular reason why you don't want to fill it out?

Code as:
Deceased
Never diagnosed
Moved out of QLD
Too sick to participate
Refused

Note: If they don't think it is relevant to them, then convince them that we are interested in all women's perspectives whether they have any needs for help or not and whether they are 3 months or 5 years post diagnosis. If they have other health conditions then we can take this into account with questions 10 and 11 in section 1 which ask about other physical or emotional illnesses.

Do you have any other questions about our study?

Thank you for generously taking the time to talk to me today______. Goodbye.

If no number, wrong number, disconnected or no answer after 3 attempts (1 of these attempts must be after office hours), code as unsuccessful contact.

If answering machine is reached:
1st time don't leave a message and attempt to contact again after office hours.
2nd time leave the following message:

Hello, this is a message for ___________. My name is _______________ from the Queensland Gynaecological Cancer Study. I'm am just calling today to see if you received the information package and cancer survey your gynaecological oncologist sent out to you last month and if so, were you planning to complete the questionnaire. My number is 07.3864.8299. Please give me a call if you do not wish to be followed up to complete this survey. Otherwise if you could please pop the completed questionnaire and consent form into the reply paid envelope and post it in the next few days that would be greatly appreciated. Thank you kindly __________.

GYNAECOLOGICAL CANCER PATIENTS' SUPPORTIVE CARE NEEDS STUDY

16th November 2004

[NAME]
[ADDRESS]

Dear [NAME],

Within the last 3 months you received a questionnaire package regarding your experiences of supportive care needs associated with gynaecological cancer. When our project officer spoke to you on the telephone recently, you kindly expressed an interest in completing the questionnaire. As we have not yet received your questionnaire, I wanted to ask you one final time if you would take part in this project by completing the questionnaire and orange consent form. If you could return these to us in the next few days in the reply paid envelope that was supplied with the questionnaire, we would be grateful. All information you provide will be treated in the **strictest confidence.** If you have replied in the last few days, please disregard this reminder letter.

To be confident of our results, it is important that we hear from everyone we contact. With your help, we can learn more about the support needs of women diagnosed with gynaecological cancer and tailor service delivery to meet these needs. However, if you feel you do not wish to complete the survey please tick the box below and return this letter to us in the reply paid envelope or send it to the Project Manager directly at the address below.

☐ No, I do not wish to take part

Send in reply paid envelope or to:
Mrs Vanessa Beesley
Queensland University of Technology
Centre for Health Research – Public Health
Victoria Park Road
Kelvin Grove 4059

If you are still interested in being involved in the study but have misplaced your questionnaire, please contact the Project Manager Mrs Vanessa Beesley on 07 3864 5677 and we will send you another copy of the questionnaire.

Yours sincerely

Professor Alex J Crandon
Director of the Queensland Centre for Gynaecological Cancer

QUT Queensland University of Technology Brisbane, Australia
Queensland Cancer Fund
Queensland Government Queensland Health

GYNAECOLOGICAL CANCER PATIENTS' SUPPORTIVE CARE NEEDS STUDY

17th November 2004

[NAME]
[ADDRESS]

Dear [NAME],

Within the last 3 months you would have received a questionnaire package regarding your experiences of supportive care needs associated with gynaecological cancer. As we have not yet received your reply, I wanted to ask you again if you would take part in this study by completing this questionnaire. For your convenience, I have enclosed another copy of the questionnaire with this letter. All information you provide will be treated in the **strictest confidence.** If you have replied in the last few days, please disregard this reminder letter.

To be confident of our results, it is important that we hear from everyone we contact. With your help, we can learn more about the support needs of women diagnosed with gynaecological cancer and tailor service delivery to meet these needs.

We would be grateful if you would read the enclosed information sheet, complete the enclosed orange consent form and questionnaire, and return it to us in the reply paid envelope in the next few days.

However, if you feel that you have received this survey in error or do not wish to complete the survey please tick the appropriate box below and return this letter to us in the reply paid envelope supplied.

☐ I have never been diagnosed with gynaecological cancer
☐ The person to whom this letter is addressed is deceased
☐ Other reason for receiving this survey in error (please specify) ______________________________
☐ No, I do not wish to take part

If you have any questions or wish to inform the Project Manager by phone about your reason for not completing the survey please call Mrs Vanessa Beesley on 07 3864 5677.

Yours sincerely

Professor Alex J Crandon
Director of the Queensland Centre for Gynaecological Cancer

Queensland University of Technology
Brisbane, Australia

Queensland Cancer Fund

Queensland Government
Queensland Health

2nd of August, 2005

[Name]
[Address]

Dear [Name],

We would like to thank you for participating in the Gynaecological Cancer Survivors' Supportive Care Needs Study. We are pleased to be able to share some of the results from this research with you. You were one of over 800 Queensland women to fill out the questionnaire. This response is marvellous support for our study. As a result, we now have information that will be used to inform cancer support service delivery in Queensland to assist the physical and emotional recovery of women diagnosed with gynaecological cancer.

We found that nearly a half (44%) of all women reported using at least one community support service or organisation. The most commonly used services were: cancer information booklets (29%), internet information on cancer (20%) and telephone information and support lines (15%). The most commonly used support organisation was the Queensland Cancer Fund (17%). Use of these services was higher for those of you who had had ovarian or cervical cancer than other types of gynaecological cancer.

About a quarter (28%) of all women reported using complementary therapies or alternative therapists for coping with cancer or reducing the risk of the cancer spreading or returning. Again, those of you who had had ovarian cancer used these therapies more often (35%) than women with other types of gynaecological cancer. The group with the lowest use of these therapies was women who had had uterine cancer; their use was at 22%. The most common complementary therapy supports used were meditation, naturopathy and massage.

Many of you made healthy lifestyle changes after being diagnosed with gynaecological cancer. About one quarter (23%) of women improved their eating habits by increasing their fruit and vegetable intake, and about half (44%) increased their physical activity levels. The recommended daily intake of fruit and vegetables for Australians is 2 serves per day of fruit and 5 serves per day of vegetables. The National Physical Activity Guidelines recommend 30 minutes of at least moderate-intensity physical activity on most days of the week. These physical activity and eating guidelines are also important for cancer survivors, for improving quality of life and for reducing the risk of cancer recurrence as well as the risk of other chronic conditions such as diabetes and heart disease. Many women surveyed are not meeting these guidelines. One-third did not meet the fruit recommendations. More than 80% do not meet the vegetable recommendations and over a half do not meet the physical activity guidelines.

Women reported unmet needs across a number of areas. Five issues that concerned the group the most were "fear about the cancer spreading" (32%), "uncertainty about the future" (28%), "lack of energy/tiredness" (28%), "concerns about the worries of those close to you" (27%) and "not being able to do things you used to do" (25%).

The results from this survey tell us that, while women with gynaecological cancer in Queensland are doing quite well overall, there is still room for improvement in a few key areas. In particular, at least a third of women need some additional support in coping with the uncertainties of cancer survivorship. In addition, a large number of women could use support for healthy living – that is getting more physical activity and eating a healthy diet.

This study was made possible by support from the Queensland Cancer Fund and the Queensland Gynaecological Cancer Registry. However, the study's success was due to women like yourself who have been willing to share your experiences about support care needs. Thank you for helping us achieve our research goals. We will be sharing these results with the relevant Queensland cancer support agencies in the near future where they will translate into benefits for women diagnosed with gynaecological cancer in the future. We could not have done it without you!

All the very best for the future from the Research Team

Cancer survivors need more support

Researcher Vanessa Beesley believes women need more support after battling cancer.

Public health

WOMEN recovering from gynaecological cancer are making an effort to live a healthier lifestyle but many need added support to help improve their diet and physical activity levels and to deal with the uncertainties of survivorship, a major study has revealed.

The joint QUT-Queensland Cancer Fund survey of more than 800 Queensland women diagnosed with a gynaecological cancer found most coped well with their condition.

However, a large number of survivors could use more support to improve their quality of life and address concerns about the risk of cancer recurrence.

They also required more information about the debilitating lower limb swelling condition lymphoedema, a complication which can arise as a result of treatment.

The survey of 802 gynaecological patients three months to five years post-diagnosis was conducted by Vanessa Beesley from QUT's Institute of Health and Biomedical Innovation who is exploring the supportive care needs of survivors for her PhD thesis.

Of the 700 Queensland women diagnosed each year with a gynaecological cancer, uterine, ovarian and cervical cancers were the most common and Mrs Beesley said it was vital support services met the specific needs of these survivors.

The survey revealed half the survivors accessed a support service or organisation and that young women in particular were more in need of assistance than older women.

"The top category of needs reported was psychological but others included physical and daily living needs, sexuality needs, care needs and information needs," Mrs Beesley said.

"Each age group has specific needs which we have to meet. For example, a younger woman may not be able to have children as a result of treatment and thus may require help to deal with the situation but an older woman may not need that kind of support.

"On the other hand, older women tend to have higher rates of co-morbidities and may require support such as respite care more often than a younger person."

Mrs Beesley said women who develop lymphoedema are another group that have very specific needs.

"While there has been extensive research into lymphoedema development in the upper limbs following breast cancer treatment, there needed to be more research into how it affected the lives of gynaecological cancer survivors."

About 10 per cent of all gynaecological cancer survivors are diagnosed with lymphoedema but many more remain unaware of the condition. The survey found that another 15 per cent were symptomatic of undiagnosed lower limb swelling.

"It does not develop straight away and women can go undiagnosed and these patients are hard to reach."

The survey also looked at lifestyle behaviours as a means of support and revealed a third of survivors don't meet fruit recommendations, more than 80 per cent don't meet vegetable recommendations and half don't meet the physical activity guidelines.

Australian guidelines for adults recommend two serves of fruit and five serves of vegetables a day and 30 minutes of moderate-intensity physical activity on most days.

Complementary therapies are another form of supportive care that women are turning to. The survey found that more than one in four women reported using complementary therapies, particularly meditation, naturopathy and massage to help cope or reduce the risk of the cancer spreading or returning.

- Heath Kelly

PLEASE READ THIS BEFORE COMPLETING THE QUESTIONNAIRE
PLEASE MAKE COMMENTS IN THE MARGINS WHILE FILLING OUT THE QUESTIONNAIRE

Pilot Questionnaire Check List

1. How long did it take you to complete the questionnaire? __________ minutes

2. Did you complete it all in one go or over 2 or more sessions?
   - ☐ All in one go
   - ☐ Over 2 or more sessions

3. How did you find the length of the questionnaire?
   - ☐ Too long
   - ☐ Long but bearable
   - ☐ Fine
   - ☐ Too Short

4. How did you find the font size?
   - ☐ Readable
   - ☐ Difficult to read at times (please specify which questions in the margins of the questionnaire)

5. Did you find the tick boxes (eg ☐) impractically close or too small?
   - ☐ Yes
   - ☐ No

6. Did you find any of the language in the questionnaire to technical?
   - ☐ Yes (please specify which words in the margins of the questionnaire)
   - ☐ No

7. How did you find the instructions? *e.g please go to the next page, please tick one*
   - ☐ Understandable/unambiguous
   - ☐ Some were hard to understand (please specify which instructions in the margins of the questionnaire)

8. Did you find any of the questions difficult to understand?
   - ☐ Yes (please specify which questions in the margins of the questionnaire)
   - ☐ No

9. Did you find the questionnaire repetitive?
   - ☐ Yes (please specify which questions in the margins of the questionnaire)
   - ☐ No

10. Did you find any of the questions offensive or too sensitive?
    - ☐ Yes (please specify which questions in the margins of the questionnaire)
    - ☐ No

11. Section 4 “Your Use of Community Support Services” and Section 5 “Your Complementary Therapy Support” were particularly detailed. How did you find these sections to complete? ________________
    ____
    ____
    ____
    ____

12. Do you have any other comments about the questionnaire?____________________________
    ____
    ____
    ____
    ____
    ____

Full results of the consistency checks

A number of consistency checks were conducted within section 2 of the questionnaire “problems with your lower limbs”. If respondents ticked any lower limb symptoms and said ‘yes’ to ‘none of the above symptoms’, their response ‘none of the above’ was removed. This applied to 1 respondent. If respondents did not indicate that they experienced any symptoms but failed to tick that they had ‘none of the above symptoms’, this was coded for them. This applied to 74 respondents (9%). Where respondents indicated they had no lymphoedema symptoms and that they had not been diagnosed with lymphoedema, the latter response was deleted as they were meant to skip this question. This applied to 61 respondents (8%). Respondents who indicated that they had no lymphoedema symptoms were not supposed to complete any further questions in section two. Those who did were considered on a case-by-case basis. In total 41 respondents (5%) had their responses for these questions removed.

For those women who indicated that they had lymphoedema symptoms in section 2, question 1, a check was done to ensure they completed the lymphoedema needs questions in section 3. 124 of the 376 (33%) respondents who had lymphoedema symptoms did not complete any of the lymphoedema needs questions. However, only 3 of the 81 (4%) respondents with a self-reported lymphoedema diagnosis did not complete the lymphoedema needs section. Fifty seven respondents who did not have lymphoedema answered the lymphoedema needs section and therefore their responses were removed.

In section 4 participants were asked if they were aware of existing support services or organisations and if they were, they were asked to complete further questions about the services. A number of checks were performed across this section of the questionnaire. If respondents indicated that they used the service in the past month but also indicated that they had never used the service, the later response was altered to indicate that they had used the service. This applied to 8 respondents (1%). If respondents indicated that they used a service yet said that they were not aware of the service, the later response was altered to indicate that they were aware of the service. This applied to 13 respondents (1%). If respondents indicated that they were referred to a service, yet said that they were unaware of the service, the later response was altered to indicate that they were aware of the service. This applied to 13 respondents (2%). If respondents recorded ‘NA’ as a service satisfaction rating, their response to whether they had ever used the service was changed to ‘no’ if they had recorded ‘yes’. This applied to 37 respondents (5%). By far the largest number of inconsistent responses for the services section involved people rating the services yet stating that they were unaware of them. In this instance responses were altered to show that respondents who rated the services were aware of them. This applied to 61 respondents (8%).

All skip patterns were also checked to ensure that they were followed correctly and recoded if not. In particular, in section 5, a check was done to ensure that participants have either indicated they have not used any complementary therapies or therapist or have filled out this section. In instances where respondents indicated that they had never used any alternative therapies but went on to rate them, their response as to whether they had ever used natural therapies was altered from a ‘no’ to a ‘yes’. This applied to 37 respondents (5%).

Skip patterns were also checked for section 9. In question 1, if participants indicate their menstrual period has not stopped they should not have data for questions 2 – 6. Six respondents (1%) indicated that they had stopped menstruating at question 1 but went on to complete questions 2-6. These respondents were assessed on a case by case basis. It was determined that three of the women were likely pre-menopausal and their responses to section 9 questions 2-6 were removed. The remaining three women were determined to be menopausal thus their response to question 1 was removed and a missing data code (99) was inserted.

In question 8 of the gynaecological history section those respondents who indicated they did engage in sexual activity should not have nominated any of the reasons why they do not participate in sexual activity Q8 (A-G). Ten respondents (1%) were identified as being inconsistent in this way. If a respondent indicated in questions 9-18 that they did engage in sexual activity then their response to question 8 was altered to ‘1’ to indicate that they did have sex and their responses to question 8 (A-G) were removed.

A substantial number of respondents answered the questions regarding sexual activity (section 9, questions 9-18) when their response to question 8 indicated that they were not sexually active and therefore should have skipped these questions. All responses given by non-sexually active respondents were removed. The question which received the most responses from non-sexually active respondents was the first subsequent question (question 9) with 188 (23%) persons responding when they should have skipped questions 9-18.

Skip pattern checks were also preformed within section 6 “your lifestyle support”. Six respondents (1%) completed a smoking question that they should have skipped and their data were coded to missing. Nine respondents (1%) completed a drinking question that they should have skipped and their data were coded to missing.

Table: Independent variables defined

Variable	Definition	Measurement
Age	Categorical ordinal	Ranked categories of 10 year age groups
Marital status	Categorical	Marital categories
Education levels	Categorical ordinal	Ranked categories of highest level of education completed
Employment status	Categorical	Work appointment categories
Household income	Categorical ordinal	Ranked categories of annual household income
Country of origin	Categorical dichotomous	Born in Australia or not
Children living at home	Categorical dichotomous	Yes or no
Type of cancer	Categorical	Cancer site
Survival phase	Categorical ordinal	Ranked categories of time since diagnosis
Cancer stage	Categorical ordinal	Ranked categories of figo staging
Treatment centre	Categorical	Hospitals
Health insurance	Categorical dichotomous	Private or public
Surgery	Categorical ordinal	Ranked categories of invasiveness of surgery
Chemotherapy	Categorical dichotomous	Yes or no
Radio therapy	Categorical ordinal	Ranked categories of extensiveness of radium
Hormone therapy	Categorical dichotomous	Yes or no
Lymph nodes removed	Categorical dichotomous	Yes or no
Last admission for treatment	Categorical ordinal	Ranked categories of time since treatment
Remission status	Categorical dichotomous	Yes or no
Disease presence	Categorical dichotomous	Absent or present
Lymphedema status	Categorical	Lymphoedema diagnosis or symptomatic or not
Stoma status	Categorical dichotomous	Fitted with stoma or not
Hospitalised since completing treatment for gynaecological cancer	Categorical dichotomous	Yes or no
Ever diagnosed with a physical or emotional illness	Categorical dichotomous	Yes or no
Menopausal status	Categorical	Menopausal categories
HRT in the past 3 months	Categorical dichotomous	Yes or no
Sexual activity status	Categorical dichotomous	Yes or no
Psychological needs	Categorical dichotomous	No need or some need
Sexuality needs	Categorical dichotomous	No need or some need
Physical/ daily living needs	Categorical dichotomous	No need or some need
Patient care/ support needs	Categorical dichotomous	No need or some need
Health system/ information needs	Categorical dichotomous	No need or some need
Physical wellbeing	Continuous	Score between 0-28 (worst to best)
Social wellbeing	Continuous	Score between 0-28 (worst to best)
Emotional wellbeing	Continuous	Score between 0-24 (worst to best)
Functional wellbeing	Continuous	Score between 0-28 (worst to best)
Spiritual wellbeing	Continuous	Score between 0-48 (worst to best)
Alcohol consumption	Categorical ordinal	Ranked categories of how often alcohol is consumed
Smoking	Categorical dichotomous	Yes or no
Physical activity	Categorical ordinal	Sedentary, insufficient sufficient
Vegetable intake	Categorical dichotomous	Inadequate, adequate
Fruit intake	Categorical dichotomous	Inadequate, adequate
BMI (Kgs/m^2)	Categorical ordinal	Ranked categories of weight classification
Social support	Continuous	Score between 8-40 (inadequate to adequate)
Use of 1 or more community support services or organisations	Categorical dichotomous	Yes or no
Use of complementary therapy support	Categorical dichotomous	Yes or no
Awareness of 1 or more support services or organisation	Categorical dichotomous	Yes or no
Provider referral to 1 or more support services or organisations	Categorical dichotomous	Yes or no
Geographic location	Categorical	14 Queensland zones
Accessibility/Remoteness Index of Australia (ARIA)	Categorical ordinal	Ranked accessibility to a wide range of goods and services and opportunity for social interaction
Rural, Remote and Metropolitan Area Classification (RRMA)	Categorical	Capital city, other metropolitan centre, rural, remote
Socio-Economic Indexes of Areas (SEIFA)	Categorical ordinal	Ranked categories of level of social and economic wellbeing in a region

TABLE 1 EFFECT MODIFICATION BY TYPE OF CANCER OF BIVARIATE ASSOCIATIONS BETWEEN PSYCHOLOGICAL NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some psychological support need stratified by gynaecological cancer type				
	All sites pooled	Cervical	Uterine	Ovarian	Other
Total participants	**49.6 (368)**	48.7 (93)	44.7 (96)	52.0 (115)	55.7 (64)
Age (years)					
18-39	**61.0 (47)**	60.4 (32)	*83.3 (5)*	*60.0 (9)*	*33.3 (1)*
40-49	**60.8 (79)**	49.1 (26)	76.2 (16)	62.2 (23)	*73.7 (14)*
50-59	**47.8 (97)**	45.5 (20)	39.7 (27)	53.4 (31)	56.3 (18)
60-69	**43.5 (87)**	44.0 (11)	42.3 (30)	47.8 (32)	40.0 (12)
70+	**43.9 (58)**	*26.7 (4)*	34.1(15)	47.5 (19)	62.1 (18)
	a + c	b + c	a + c	b	Not linear
Chemotherapy					
Yes	**55.7 (157)**	66.7 (42)	*50.0 (7)*	51.9 (84)	55.8 (24)
No	**45.9 (211)**	39.8 (51)	44.3 (89)	52.5 (31)	55.6 (40)
	a	a	not considered	NS	NS
Remission					
Yes	**46.1 (253)**	46.9 (75)	45.2 (76)	42.8 (62)	52.6 (40)
No/don't know	**59.6 (115)**	58.1 (18)	42.6 (20)	69.7 (53)	61.5 (24)
	a	b	NS	a	b
Use of at least 1 support service or organisation					
Yes	**54.4 (209)**	57.1 (64)	55.4 (46)	51.9 (67)	53.3 (32)
No	**44.8 (130)**	37.9 (25)	36.8 (39)	56.3 (45)	55.3 (21)
	a	a	a	NS	NS
Referral to at least 1 support service or organisation					
Yes	**51.8 (176)**	52.5 (53)	53.4 (39)	51.7 (60)	48.0 (24)
No	**48.8 (163)**	46.8 (36)	39.7 (46)	55.9 (52)	60.4 (29)
	NS	NS	b	NS	b
Geographical locations collapsed					
South East QLD	**49.0 (255)**	47.6 (68)	44.4 (60)	52.5 (85)	52.5 (42)
Central/ South West	**47.9 (57)**	45.8 (11)	43.5 (20)	44.8 (13)	65.0 (13)
Northern Zone	**54.4 (56)**	58.3 (14)	47.1 (16)	56.7 (17)	*60.0 (9)*
	NS	Different pattern	NS	Different pattern	Different pattern

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by cancer type

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 2 EFFECT MODIFICATION BY TYPE OF CANCER OF BIVARIATE ASSOCIATIONS BETWEEN SEXUALITY NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some sexuality support need stratified by gynaecological cancer type				
	All sites pooled	Cervical	Uterine	Ovarian	Other
Total participants	**25.3 (183)**	33.0 (62)	20.1 (43)	22.2 (48)	28.3 (30)
Surgery					
None	**33.3 (4)**	*16.7 (1)*	*0.0 (0)*	*100.0 (1)*	*50.0 (2)*
Vaginal or laparoscopic	**21.7 (23)**	21.9 (7)	13.8 (4)	*0.0 (0)*	27.3 (12)
Open abdominal	**25.8 (138)**	36.4 (52)	20.8 (37)	22.2 (39)	26.3 (10)
Open bowel resection	**25.9 (15)**	*66.7 (2)*	*25.0 (1)*	22.2 (8)	*26.7 (4)*
	NS	b	NS	NS	NS
Chemotherapy					
Yes	**27.1 (74)**	43.3 (26)	*15.4 (2)*	21.3 (34)	30.0 (12)
No	**24.2 (109)**	28.1 (36)	20.4 (41)	25.0 (14)	27.3 (18)
	NS	a	not considered	NS	NS
Radiotherapy					
No radium	**23.1 (125)**	28.4 (29)	20.0 (29)	22.3 (47)	23.8 (20)
Internal brachytherapy	**22.2 (8)**	*0.0 (0)*	21.2 (7)	*50.0 (1)*	*0.0 (0)*
External radium beam Therapy ± brachytherapy	**34.2 (50)**	38.8 (33)	19.4 (7)	*0.0 (0)*	45.5 (10)
	a	b	NS	not considered	b
Remission					
Yes	**24.6 (133)**	32.7 (51)	21.3 (36)	18.9 (27)	26.4 (19)
No/don't know	**27.2 (50)**	34.4 (11)	15.6 (7)	28.8 (21)	32.4 (11)
	NS	NS	NS	b	NS
Disease presence					
Disease absent	**24.8 (153)**	32.7 (55)	19.0 (36)	21.7 (38)	27.9 (24)
Disease present	**28.2 (29)**	35.0 (7)	29.2 (7)	24.4 (10)	*27.8 (5)*
	NS	NS	b	NS	not considered
Use of at least 1 support service or organisation					
Yes	**28.7 (110)**	39.6 (44)	22.6 (19)	22.1 (29)	31.6 (18)
No	**21.2 (59)**	23.4 (15)	17.1 (15)	24.3 (18)	22.9 (8)
	NS	a	NS	NS	b
Awareness of at least 1 support service or organisation (excluding QCF, the project sponsor)					
Yes	**27.7 (159)**	36.1 (57)	22.3 (35)	23.0 (41)	31.7 (26)
No	**11.6 (10)**	*11.8 (2)*	6.3 (2)	22.2 (6)	*0 (0)*
	a	not considered	a	NS	not considered
Geographical locations collapsed					
South East QLD	**25.5 (131)**	31.0 (44)	20.3 (28)	22.6 (36)	30.7 (23)
Central/ South West	**25.0 (28)**	34.8 (8)	20.5 (9)	17.9 (5)	*35.3 (6)*
Northern Zone	**24.5 (24)**	43.5 (10)	18.8 (6)	24.1 (7)	*7.1 (1)*
	NS	b	NS	NS	not considered

---

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by cancer type

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 3 EFFECT MODIFICATION BY TYPE OF CANCER OF BIVARIATE ASSOCIATIONS BETWEEN PHYSICAL/ DAILY LIVING NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some physical / daily living support need stratified by gynaecological cancer type				
	All sites pooled	Cervical	Uterine	Ovarian	Other
Total participants	**38.2 (286)**	41.7 (78)	35.0 (78)	36.0 (80)	42.7 (50)
Age (years)					
18-39	**46.7 (35)**	47.1 (24)	*66.7 (4)*	*46.7 (7)*	*0.0 (0)*
40-49	**37.7 (49)**	40.4 (21)	57.1 (12)	21.1 (8)	*42.1 (8)*
50-59	**33.8 (69)**	47.7 (21)	22.1 (15)	34.5 (20)	39.4 (13)
60-69	**34.2 (69)**	33.3 (8)	29.6 (21)	39.1 (27)	35.5 (11)
70+	**46.4 (64)**	*26.7 (4)*	46.2 (24)	44.7 (17)	56.7 (17)
	a	Different pattern	Different pattern	Different pattern	Different pattern
Chemotherapy					
Yes	**42.7 (120)**	59.7 (37)	*42.9 (6)*	36.4 (59)	41.9 (18)
No	**35.5 (166)**	32.8 (41)	34.4 (72)	35.0 (21)	43.2 (32)
	NS	a	not considered	NS	NS
Remission					
Yes	**35.3 (198)**	41.4 (65)	35.2 (63)	27.4 (40)	38.0 (30)
No/don't know	**46.8 (88)**	43.3 (13)	34.1 (15)	52.6 (40)	52.6 (20)
	a	NS	NS	a	b
Menopausal status					
Pre/ peri menopausal	**25.0 (8)**	*28.6 (4)*	*0.0 (0)*	*28.6 (2)*	*20.0 (2)*
Post menopause	**35.1 (147)**	46.0 (29)	28.2 (40)	33.8 (47)	41.3 (31)
Iatrogenic menopause	**40. 9 (92)**	43.1 (44)	41.8 (23)	35.8 (19)	*40.0 (6)*
	a	NS	a	NS	not considered
Use of at least 1 support service or organisation					
Yes	**39.1 (152)**	45.9 (50)	38.8 (33)	34.3 (46)	37.7 (23)
No	**35.9 (103)**	39.1 (25)	26.9 (29)	40.8 (31)	46.2 (18)
	NS	NS	b	NS	b
Referral to at least 1 support service or organisation					
Yes	**40.4 (138)**	42.9 (42)	41.9 (31)	37.8 (45)	39.2 (20)
No	**35.0 (117)**	44.0 (33)	26.1 (31)	35.2 (32)	42.9 (21)
	NS	NS	a	NS	NS
Geographical locations collapsed					
South East QLD	**37.4 (196)**	42.4 (59)	30.5 (43)	35.8 (58)	43.9 (36)
Central/ South West	**36.8 (46)**	33.3 (8)	37.5 (18)	34.4 (11)	42.9 (9)
Northern Zone	**44.0 (44)**	45.8 (11)	50.0 (17)	39.3 (11)	*35.7 (5)*
	NS	Different pattern	Different pattern	NS	NS

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

< *20 cases across the needs categories within this stratification, therefore over sensitive and not discussed*

Different pattern: a change in direction or size of the effect across subgroups when stratified by cancer type

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 4 EFFECT MODIFICATION BY TYPE OF CANCER OF BIVARIATE ASSOCIATIONS BETWEEN HEALTH SYSTEM / INFORMATION NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some health system / information support need stratified by gynaecological cancer type				
	All sites pooled	Cervical	Uterine	Ovarian	Other
Total participants	**33.2 (245)**	34.0 (65)	28.0 (61)	35.7 (79)	37.0 (40)
Age (years)					
18-39	**48.1 (37)**	45.3 (24)	*83.3 (5)*	*40.0 (6)*	*66.7 (2)*
40-49	**47.0 (62)**	38.9 (21)	60.0 (12)	51.3 (20)	*47.4 (9)*
50-59	**31.3 (63)**	27.3 (12)	25.8 (17)	37.9 (22)	37.5 (12)
60-69	**24.6 (50)**	24.0 (6)	20.3 (15)	30.9 (21)	23.3 (7)
70+	**26.4 (33)**	*14.3 (2)*	25.0 (12)	24.3 (9)	36.4 (8)
	a + c	b + c	Not linear	b + c	Not linear
Chemotherapy					
Yes	**40.9 (113)**	46.9 (30)	*58.3 (7)*	36.9 (59)	42.5 (17)
No	**28.6 (132)**	27.6 (35)	26.2 (54)	32.8 (20)	33.8 (23)
	a	a	not considered	NS	b
Remission					
Yes	**29.7 (163)**	32.1 (51)	26.7 (46)	27.8 (40)	35.6 (26)
No/don't know	**43.2 (82)**	43.8 (14)	32.6 (15)	50.6 (39)	40.0 (14)
	a	b	NS	a	NS
Use of at least 1 support service or organisation					
Yes	**37.6 (146)**	41.6 (47)	34.9 (29)	38.3 (51)	32.2 (19)
No	**27.4 (78)**	23.1 (15)	21.3 (23)	32.9 (25)	41.7 (15)
	a	a	a	NS	b
Referral to at least 1 support service or organisation					
Yes	**37.1 (126)**	41.2 (42)	36.6 (26)	37.3 (44)	28.6 (14)
No	**29.4 (98)**	26.3 (20)	21.7 (26)	35.2 (32)	43.5 (20)
	NS	b	a	NS	b
Geographical locations collapsed					
South East QLD	**32.8 (169)**	31.5 (45)	25.5 (35)	37.9 (61)	37.3 (28)
Central/ South West	**33.3 (41)**	33.3 (8)	34.7 (17)	32.3 (10)	~~31.6 (6)~~
Northern Zone	**35.4 (35)**	50.0 (12)	28.1 (9)	27.6 (8)	~~42.9 (6)~~
	NS	Different pattern	Different pattern	Different pattern	not considered

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by cancer type

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 5 EFFECT MODIFICATION BY SURVIVAL PHASE POST-DIAGNOSIS OF BIVARIATE ASSOCIATIONS BETWEEN PSYCHOLOGICAL NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some psychological support need stratified by survival phase			
	All phases pooled	3-12 months post-diagnosis	1-3 years post-diagnosis	3-5 years post-diagnosis
Total participants	**49.6 (368)**	49.2 (87)	54.8 (167)	43.8 (114)
Age (years)				
18-39	**61.0 (47)**	*46.7 (7)*	76.2 (32)	40.0 (8)
40-49	**60.8 (79)**	75.0 (21)	53.7 (29)	60.4 (29)
50-59	**47.8 (97)**	45.8 (27)	54.2 (39)	43.1 (31)
60-69	**43.5 (87)**	43.2 (16)	45.3 (39)	41.6 (32)
70+	**43.9 (58)** **a + c**	42.1 (16) Different pattern	54.9 (28) Different pattern	32.6 (14) Different pattern
Type of gynaecological Cancer				
Cervical	**48.7 (93)**	41.7 (15)	58.1 (50)	40.6 (28)
Uterine	**44.7 (96)**	43.1 (31)	48.8 (40)	41.0 (25)
Ovarian	**52.0 (115)**	54.5 (24)	56.3 (49)	46.7 (42)
Other	**55.7 (64)** **b**	68.0 (17) Different pattern	56.0 (28) Different pattern	47.5 (19) Different pattern
Surgery				
None	**46.2 (6)**	*100.0 (2)*	*42.9 (3)*	*25.0 (4)*
Vaginal or laparoscopic	**40.4 (44)**	31.8 (14)	47.4 (18)	44.4 (12)
Open abdominal	**49.2 (265)**	50.9 (59)	54.8 (120)	42.2 (86)
Open bowel resection	**65.6 (42)** **a**	*90.9 (10)* Different pattern	58.8 (20) Different pattern	*63.2 (12)* Different pattern
Chemotherapy				
Yes	**55.7 (157)**	53.3 (32)	63.4 (78)	47.5 (47)
No	**45.9 (211)** **a**	47.0 (55) NS	48.9 (89) a	41.6 (67) NS
Radiotherapy				
No radium	**47.8 (265)**	49.2 (59)	51.5 (118)	42.9 (88)
Internal brachytherapy	**34.3 (12)**	*35.7 (5)*	*40.0 (4)*	*27.3 (3)*
External radium beam Therapy ± brachytherapy	**59.5 (91)** **a**	53.5 (23) NS	68.2 (45) a	52.3 (23) b
Lymphoedema status				
No lower limb swelling	**45.5 (259)**	47.6 (70)	50.7 (116)	37.8 (73)
Lower limb swelling but not diagnosed	**59.6 (59)**	*47.4 (9)*	67.4 (31)	55.9 (19)
Diagnosed lymphoedema	**67.6 (50)** **a**	*72.7 (8)* not considered	66.7 (20) Different pattern	66.7 (22) Different pattern
Menopausal status				
Pre/ peri menopausal	**26.7 (8)**	*25.0 (1)*	*28.6 (4)*	*25.0 (3)*
Post menopause	**45.2 (188)**	46.9 (53)	50.3 (83)	37.7 (52)
Iatrogenic menopause	**58.1 (132)** **a**	55.3 (26) b	62.9 (61) b	54.2 (45) a

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by survival phase

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 6 EFFECT MODIFICATION BY SURVIVAL PHASE POST-DIAGNOSIS OF BIVARIATE ASSOCIATIONS BETWEEN SEXUALITY NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some sexuality support need stratified by survival phase			
	All phases pooled	3-12 months post-diagnosis	1-3 years post-diagnosis	3-5 years post-diagnosis
Total participants	**25.3 (183)**	25.7 (44)	28.1 (83)	21.7 (56)
Type of gynaecological Cancer				
Cervical	**33.0 (62)**	20.0 (7)	43.5 (37)	26.5 (18)
Uterine	**20.1 (43)**	22.9 (16)	18.5 (15)	19.0 (12)
Ovarian	**22.2 (48)**	26.2 (11)	26.7 (23)	15.9 (14)
Other	**28.3 (30)**	41.7 (10)	18.6 (8)	30.8 (12)
	a	Different pattern	Different pattern	Different pattern
Radiotherapy				
No radium	**23.1 (125)**	26.7 (31)	24.1 (54)	19.8 (40)
Internal brachytherapy	**22.2 (8)**	*21.4 (3)*	*36.4 (4)*	*9.1 (1)*
External radium beam Therapy ± brachytherapy	**34.2 (50)**	24.4 (10)	41.7 (25)	33.3 (15)
	a	NS	a	b
Lymphoedema status				
No lower limb swelling	**23.0 (127)**	25.0 (36)	24.9 (54)	19.4 (37)
Lower limb swelling but not diagnosed	**25.5 (25)**	*17.6 (3)*	36.2 (17)	14.7 (5)
Diagnosed lymphoedema	**41.9 (31)**	*50.0 (5)*	38.7 (12)	42.4 (14)
	a	not considered	Different pattern	Different pattern

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by survival phase

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 7 EFFECT MODIFICATION BY SURVIVAL PHASE POST-DIAGNOSIS OF BIVARIATE ASSOCIATIONS BETWEEN PHYSICAL/ DAILY LIVING NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some physical/ daily living support need stratified by survival phase			
	All phases pooled	3-12 months post-diagnosis	1-3 years post-diagnosis	3-5 years post-diagnosis
Total participants	**38.2 (286)**	44.4 (80)	41.5 (130)	29.7 (76)
Age (years)				
18-39	**46.7 (35)**	*53.3 (8)*	45.0 (18)	45.0 (9)
40-49	**37.7 (49)**	50.0 (14)	33.3 (19)	35.6 (16)
50-59	**33.8 (69)**	37.9 (22)	43.8 (32)	20.5 (15)
60-69	**34.2 (69)**	28.2 (11)	39.3 (35)	31.1 (23)
70+	**46.4 (64)**	62.5 (25)	48.1 (26)	29.5 (13)
	a	Different pattern	Different pattern	Different pattern
Type of gynaecological Cancer				
Cervical	**41.7 (78)**	44.4 (16)	47.1 (40)	33.3 (22)
Uterine	**35.0 (78)**	39.7 (29)	40.4 (36)	21.3 (13)
Ovarian	**36.0 (80)**	44.4 (20)	38.6 (34)	29.2 (26)
Other	**42.7 (50)**	57.7 (15)	39.2 (20)	37.5 (15)
	NS	Different pattern	Different pattern	Different pattern
Surgery				
None	**46.2 (6)**	*50.0 (1)*	*57.1 (4)*	*25.0 (1)*
Vaginal or laparoscopic	**30.6 (33)**	31.1 (14)	32.4 (12)	26.9 (7)
Open abdominal	**38.0 (208)**	47.9 (56)	40.0 (92)	29.9 (60)
Open bowel resection	**49.2 (31)**	*58.3 (7)*	53.1 (17)	*36.8 (7)*
	b	Different pattern	Different pattern	Different pattern
Chemotherapy				
Yes	**42.7 (120)**	43.3 (26)	48.8 (60)	34.7 (34)
No	**35.5 (166)**	45.0 (54)	36.8 (70)	26.6 (42)
	NS	NS	a	b
Radiotherapy				
No radium	**33.5 (187)**	41.5 (51)	34.2 (80)	27.9 (56)
Internal brachytherapy	**43.2 (16)**	*50.0 (7)*	*58.3 (7)*	*18.2 (2)*
External radium beam Therapy ± brachytherapy	**53.9 (83)**	51.2 (22)	64.2 (43)	40.9 (18)
	a	b	a	b
Lymphoedema status				
No lower limb swelling	**34.0 (193)**	39.9 (59)	39.6 (91)	22.6 (43)
Lower limb swelling but not diagnosed	**50.0 (52)**	52.4 (11)	52.9 (27)	43.8 (14)
Diagnosed lymphoedema	**53.2 (41)**	*90.9 (10)*	37.5 (12)	55.9 (19)
	a	Different pattern	Different pattern	Different pattern
Menopausal status				
Pre/ peri menopausal	**25.0 (8)**	*25.0 (1)*	*25.0 (4)*	*25.0 (3)*
Post menopause	**35.1 (147)**	39.5 (45)	40.1 (67)	25.4 (35)
Iatrogenic menopause	**40. 9(92)**	51.1 (24)	42.3 (41)	33.3 (27)
	a	b	NS	NS

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by survival phase

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

TABLE 8 EFFECT MODIFICATION BY SURVIVAL PHASE POST-DIAGNOSIS OF BIVARIATE ASSOCIATIONS BETWEEN HEALTH SYSTEM/ INFORMATION NEEDS AND INDEPENDENT VARIABLES OF INTEREST, FOR QUEENSLAND GYNAECOLOGICAL CANCER SURVIVORS 3 MONTHS TO 5 YEARS POST-DIAGNOSIS, IN 2004.

	% (n) who reported some health system/ information support need stratified by survival phase			
	All phases pooled	3-12 months post-diagnosis	1-3 years post-diagnosis	3-5 years post-diagnosis
Total participants	**33.2 (245)**	33.1 (59)	36.6 (111)	29.2 (75)
Age (years)				
18-39	**48.1 (37)**	*33.3 (5)*	54.8 (23)	45.0 (9)
40-49	**47.0 (62)**	60.7 (17)	43.9 (25)	42.6 (20)
50-59	**31.3 (63)**	27.3 (15)	40.5 (30)	25.0 (18)
60-69	**24.6 (50)**	24.4 (10)	24.1 (21)	25.3 (19)
70+	**26.4 (33)**	30.8 (12)	27.9 (12)	20.9 (9)
	a + c	Different pattern	Different pattern	Different pattern
Type of gynaecological Cancer				
Cervical	**34.0 (65)**	25.7 (9)	43.7 (38)	26.1 (18)
Uterine	**28.0 (61)**	29.7 (22)	28.0 (23)	25.8 (16)
Ovarian	**35.7 (79)**	39.1 (18)	34.1 (30)	35.6 (31)
Other	**37.0 (40)**	43.5 (10)	43.5 (20)	25.6 (10)
	b	Different pattern	Different pattern	Different pattern
Chemotherapy				
Yes	**40.9 (113)**	44.8 (26)	45.5 (56)	32.6 (31)
No	**28.6 (132)**	27.5 (33)	30.6 (55)	27.2 (44)
	a	a	a	NS
Radiotherapy				
No radium	**31.2 (172)**	31.7 (38)	33.0 (76)	28.7 (58)
Internal brachytherapy	**27.0 (10)**	*23.1 (3)*	*25.0 (3)*	*33.3 (4)*
External radium beam Therapy ± brachytherapy	**42.3 (63)**	40.0 (18)	52.5 (32)	30.2 (13)
	a	b	a	NS
Lymphoedema status				
No lower limb swelling	**31.6 (178)**	30.6 (45)	37.3 (84)	25.5 (49)
Lower limb swelling but not diagnosed	**37.4 (37)**	30.0 (6)	39.6 (19)	38.7 (12)
Diagnosed lymphoedema	**40.0 (30)**	*72.7 (8)*	26.7 (8)	41.2 (14)
	b	Different pattern	Different pattern	Different pattern

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

< 20 cases across the needs categories within this stratification, therefore over sensitive and not discussed

Different pattern: a change in direction or size of the effect across subgroups when stratified by survival phase

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 1: Associations between demographic characteristics and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation
Total participants	56.2 (400)
Age (years)	
18-39	76.3 (58)
40-49	70.5 (91)
50-59	58.2 (113)
60-69	48.5 (98)
70+	36.0 (40)
	a + c
Children living at home	
No	59.0 (266)
Yes	68.5% (89)
	a
Marital status	
Single	64.5 (40)
Defacto/married	58.0 (272)
Seperated/divorced	59.5 (47)
Widowed	41.1 (39)
	a
Employment type	
Paid full- time	67.9 (89)
Paid part time or casual	60.8 (76)
Home duties	50.9 (59)
Retired	50.0 (104)
Unable to work because of Illness	51.6 (33)
Other	62.1% (36)
	a
Education level	
University/college degree	65.6 (84)
Trade/ technical certificate	68.8 (66)
Senior high school	53.8 (56)
Junior high school	54.9 (150)
Primary or no schooling	41.7 (35)
	a
Household income	
<$20 000	54.5 (103)
$20 000 - <$40 000	58.2 (82)
$40 000 - <$60 000	67.0 (61)
$60 000 - <$80 000	70.2 (40)
$80 000+	62.8 (49)
Do not wish to answer	41.7 (65)
	a
Country of origin	
Australia	57.4 (318)
Other	53.1 (76)
	NS

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 2: Associations between diagnosis and treatment variables and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation
Total participants	56.2 (400)
Surgery	
None	58.3 (7)
Vaginal or laparoscopic	52.4 (54)
Open abdominal	55.1 (287)
Open bowel resection	76.7 (46)[a]
Chemotherapy	
Yes	63.1 (171)
No	51.9 (229)[a]
Radio therapy	
No radium	56.5 (300)
Internal brachytherapy	38.9 (14)
External radium beam	59.3 (86)[b]
Hormone therapy	
Yes	73.5 (25)
No	55.3 (375)[a]
Stage	
Early stage	53.4 (267)
Late stage	64.4 (116)[a]
Type of gynaecological Cancer	
Cervical	62.4 (113)
Uterine	42.7 (88)
Ovarian	61.8 (136)
Other	60.0 (63)[a]
Survival phase post-diagnosis	
3-12 months	57.3 (98)
1-3 years	59.9 (178)
3-5 years	50.8 (124)[b]
Treatment centre	
Treatment hospital A	55.8 (116)
Treatment hospital B	53.4 (78)
Treatment hospital C	50.9 (59)
Other treatment hospitals	58.2 (57)
Multi-treatment centres	66.2 (86)[a]
Last administration of treatment	
Within the last month	62.5 (15)
1-12 months ago	61.6 (125)
1-2 years ago	61.9 (91)
>2 years ago	51.6 (143)[a]
Lymph nodes removed	
No	54.5 (214)
Yes	58.3 (186)[NS]
Insurance	
Medicare only	54.5 (180)
Private insurance	59.8 (217)[NS]

---

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 3: Associations between physiological conditions and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation
Total participants	56.2 (400)
Remission	
Yes	58.3 (307)
No/don't know	50.3 (93) [b]
Sexually active	
Yes	62.1 (187)
No	53.1 (195) [a]
Menopausal status	
Pre/ peri menopausal	68.8 (22)
Post menopause	52.0 (210)
Iatrogenic menopause	68.9 (151) [a]
HRT in the 3 past months	
Yes	64.1 (82)
No	55.0 (310) [b]
Stoma	
No	54.8 (371)
Yes	82.9 (29) [a]
Disease presence	
Disease absent	55.0 (333)
Disease present	62.5 (65) [NS]
Lymphoedema status	
No lower limb swelling	54.3 (294)
Undiagnosed lower limb swelling	62.9 (61)
Diagnosed lymphoedema	60.8 (45) [NS]
Hospitalisation since completing treatment for gynaecological cancer	
No	55.5 (295)
Yes	59.5 (103) [NS]
Ever diagnosed with a physical or emotional illness	
No	60.4 (148)
Yes	53.7 (246) [NS]

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 4: Associations between unmet supportive care needs and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation
Total participants	56.2 (400)
Unmet psychological needs	
No	52.2 (175)
Yes	61.7 (209) [a]
Unmet sexuality needs	
No	55.5 (273)
Yes	65.1 (110) [a]
Unmet health system/ information needs	
No	53.9 (242)
Yes	65.2 (146) [a]
Unmet patient care/ support needs	
No	56.6 (304)
Yes	64.9 (87) [b]
Unmet physical/ daily living needs	
No	56.3 (237)
Yes	59.6 (152) [NS]

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 5: Associations between quality of life and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	N, Median (min, max) wellbeing scores stratified by women who reported using and not using support services or organisations									
	Physical wellbeing		Social/ family wellbeing		Emotional wellbeing		Functional wellbeing		Spiritual wellbeing	
	N	Median (min, max)	N	Median (min, max)	N	Median (min, max)	N	Median (min, max)	N	Median (min, max)
All sites pooled										
Users of support services or organisations	397	25.0 (2-28)	398	24.0 (0-28)	395	20.0 (1-24)	396	23.0 (0-28)	391	36.0 (4-48)
Non-users of support service or organisations	297	26.0 (0-28) [c]	300	24.5 (0-28) [NS]	291	20.0 (3-24) [NS]	296	23.7 (0-28) [NS]	287	36.0 (8-48) [NS]

[a] Statistically and clinically significant

[b] Clinically significant only (defined as a differences of at least 2 between all groups except spiritual which was a difference of 4 between due to larger range)

[c] Statistically but not clinically different

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 6: Associations between health behaviours variables and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation (All sites pooled)
Total participants	56.2 (400)
Physical activity	
Sedentary	49.4 (81)
Insufficient activity	54.5 (158)
Sufficient activity for health	62.4 (161)
	a + c
Alcohol consumption	
None	48.8 (100)
< weekly	61.6 (146)
1-4 days / week	64.7 (108)
5-7 days / week	50.0 (44)
	a
Body Mass Index	
Underweight	52.0 (13)
Normal weight	59.2 (142)
Overweight	52.6 (92)
Obese	60.5 (115)
	NS
Smoker	
Yes	53.7 (44)
No	56.7 (350)
	NS
Vegetable intake	
Inadequate serves	55.7 (303)
Adequate serves (5 per day)	60.2 (65)
	NS
Fruit intake	
Inadequate serves	54.9 (130)
Adequate serves (2 per day)	57.9 (252)
	NS

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[c] Clinically and statistically linear

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables

Table 7: Association between social support and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	Social support scores stratified by women who reported using and not using support serviced or organisations		
	N	Median	Min - Max
All sites pooled [NS]			
Users of support services or organisations	378	36	8-40
Non-users of support service or organisations	265	38	8-40

[a] Statistically and clinically significant

[b] Clinically significant only (defined as a differences of at least 2.5 between groups)

[NS] Non-significant statistically and clinically

Table 8: Association between complementary therapy support and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation
Total participants	56.2 (400)
Complementary therapy support	
Yes	68.8 (150)
No	50.6 (250)
	[a]

[a] Statistically and clinically significant

Table 9: Associations between community factors and community support service or organisation use for 712 Queensland gynaecological cancer survivors 3 months to 5 years post-diagnosis, in 2004. Bivariate analysis.

	% (n) who used at least 1 support service or organisation (all sites pooled)
Total participants	56.2 (400)
Geographical location	
Gold Coast	46.1 (35)
Logan-Beaudesert	56.1 (32)
Bayside	55.6 (20)
QEII Hospital & District	53.1 (43)
Prince Charles Hospital & District	53.1 (60)
Redcliffe-Caboolture	56.5 (26)
Sunshine Coast	60.7 (34)
West Moreton	53.7 (22)
Darling Downs/South West	62.5 (20)
Wide Bay-Burnett	48.9 (22)
Fitzroy/Central West	71.4 (25)
Mackay	44.4 (8)
Northern/North West	75.6 (31)
Far North	62.9 (22)
	[b]
Geographical locations collapsed	
South east QLD	53.8 (272)
Central & south west	59.8 (67)
Northern zone	64.9 (61)
	[b]
Accessibility / remoteness index of Australia	
Highly Accessible	54.8 (284)
Accessible	62.8 (59)
Moderately Accessible	56.0 (42)
Remote to very remote	60.0 (15)
	[b]
Rural Remote and Metropolitan Area Classification	
Capital City	54.3 (183)
Other Metropolitan Centre	52.6 (50)
Rural and Remote Zone	61.0 (136)
	[b]
Socio-economic status for areas	
High SES	54.5 (61)
Moderately high SES	53.2 (82)
Moderate SES	57.9 (77)
Moderately low SES	56.8 (125)
Low SES	59.1 (55)
	[NS]

[a] Statistically and clinically significant

[b] Clinically significant only (based on group comparisons and defined as differences of at least 8% between groups)

[NS] Non-significant statistically and clinically

Note: Missing data varied from variable to variable and hence total sample was slightly different between variables