Peer Support for Women with Gynaecological Cancer

Zara Jay

D. Clin. Psy. Thesis (Volume1) 2006

University College London

UMI Number: U592934

UMI

Dissertation Publishing

ProQuest

CONTENTS

LIST OF TABLES

OVERVIEW

This thesis is presented in three parts. Part One is a literature review of the key issues faced by women with gynaecological cancer, the need for psychosocial interventions, and the effectiveness of psychosocial interventions in meeting this need. Part Two presents the empirical paper. This paper explores how a new peer support service for women with gynaecological cancer was experienced by both the peer helpers and the women they were supporting. In Part Three, the issues and challenges raised during the completion of the empirical study are discussed.

ACKNOWLEDGEMENTS

Part 1: Literature Review

What are the psychosocial needs of women with gynaecological cancer, and how can they best be met?

ABSTRACT

Gynaecological cancers are among the most common forms of cancer in women. Treatment can involve extensive surgery to the reproductive organs, radiotherapy and/or highly emetic chemotherapy. This review aims to provide an overview of the empirical literature on women's emotional responses to the diagnosis and treatment of gynaecological cancer, and the needs they may have. A discussion then follows of the wide range of psychosocial interventions that have been evaluated with cancer patients in general, and the small literature specific to women with gynaecological cancer. Finally, the methodological limitations of the current literature and directions for further research are discussed.

Key terms: gynaecological cancer, psychosocial needs, psychosocial interventions

What are the psychosocial needs of women with gynaecological cancer, and how can they best be met?

Facing a diagnosis of cancer can provoke an understandably wide range of emotions, as the individual attempts to adjust to a potentially life threatening illness. Managing the impact of the accompanying treatment can be an additional challenge. Gynaecological cancer, by its nature, involves the reproductive organs, and so may raise additional concerns about femininity, sexuality, fertility and body image. A proportion of women with this diagnosis experience psychosocial difficulties to a level requiring professional support. It is necessary to gain an understanding of the pertinent issues so that tailored support can be provided. In comparison with the wealth of research evaluating the effectiveness of psychosocial interventions with women with breast cancer, there is a relative dearth of literature exploring the effectiveness of interventions for women with gynaecological cancer.

This review aims to provide an overview of the key issues faced by women with gynaecological cancer, the need for psychosocial interventions, and the effectiveness of psychosocial interventions in meeting this need. The first section will focus on the psychosocial impact of being diagnosed with and treated for gynaecological cancer. The second section will focus on the evaluation of psychosocial interventions. This review will conclude by discussing the future directions of intervention studies for women with gynaecological cancer, particularly the need for more sensitive outcome measures and comparison studies.

The literature for this review was identified through a number of research databases including BMJ, PubMed, PsycINFO, and the Cochrane Library. Combinations of the following search terms were used: cancer, neoplasm, oncology, gyn*, psych*, therapy, interven*, support, peer, sex*, distress, rel*, image, anx*, dep*, PTSD, intrusion*, avoid*. In addition, reference lists of articles were searched to identify articles that had not been found through computer databases.

The psychosocial impact of gynaecological cancer

This section will first provide a brief overview of the prevalence, survival rates and treatment for gynaecological cancer. A review of research on its psychosocial impact will then follow, with particular reference to psychological distress, body image, sexual functioning and impact on relationships.

Prevalence and survival rates for gynaecological cancers

In England and Wales gynaecological cancers (including cancers of the ovary, endometrium, cervix and vulva) are among the most common forms of cancer in women, after breast, lung and bowel cancer (Department of Health, 1999). Ovarian cancer is the most prevalent with nearly 7000 cases diagnosed each year, followed by endometrial, cervical and then vulval cancer. Ovarian cancer is predominantly a disease of post-menopausal women, with 85% of women diagnosed aged over fifty. This contrasts with cervical cancer, which is the second commonest cancer in women aged under 35 (Office for National Statistics, 2002).

The survival rates for gynaecological cancers vary depending on the site, mainly because this affects how early in the cancer's development the individual becomes symptomatic. The poorest survival rates are for ovarian cancer; this is largely because diagnosis may be delayed until the disease has progressed, as the early stages are often marked by vague, non-specific symptoms. The pattern of ovarian cancer is often one of remission and recurrence, with those with progressive disease rarely surviving more than three years (Neijt, ten Bokkel Huinink & van der Burg, 1991). Two thirds of women with ovarian cancer die within five years (Cancer Research Campaign, 1997).

Survival rates are much better for women with endometrial cancer. The women become symptomatic earlier and so the cancers are more likely to be diagnosed at an early stage, at which point the five year survival rate is 85%. Vulval cancer also has a fairly high survival rate, with 60% surviving five years. (Office for National Statistics, 2002)

Treatment for gynaecological cancer

Treatment for gynaecological cancer often involves a combination of modalities including surgery, chemotherapy and/or radiotherapy. Aside from surgery, treatment is generally provided on an outpatient basis, often requiring women to maintain dual roles of being a patient but also a contributor to the running of their household (Ekman, Bergbom, Ekman, Berthold & Mahsneh, 2004).

For some, surgery may only involve removal of the tumour, but, to increase chances of cure, women often undergo more extensive surgery such as hysterectomies with

removal of pelvic lymph nodes, or for those whose tumours have spread further within the pelvis, pelvic exenteration, the removal of all potentially affected organs. These surgeries raise a number of psychosocial issues including loss of childbearing status, managing menopause, leg oedema associated with poor lymphatic drainage, adjusting to having a stoma, and body image challenges (Knapp & Berkowitz, 1986).

Women being treated for gynaecological cancer are more likely than other cancer patients to receive highly emetic chemotherapy drugs, which increase the likelihood of their suffering from the conditioned responses of anticipatory nausea and vomiting, in addition to the more common side effects of nausea, vomiting, fatigue, anorexia, alopecia, and peripheral neuropathy (Redd, 1989). Radiotherapy treatment, which may include internal radiotherapy (known as brachytherapy), is associated with a number of side effects including diarrhoea, fatigue, cystitis or fistulas (Karlsson & Andersen, 1986).

Psychological distress

Psychosocial difficulties have been found to be a major concern reported by women during diagnosis and treatment for gynaecological cancer. Studies have shown the most common concerns to be anxiety, depression and fear of dying (Steginga & Dunn, 1997), and a need for interventions to help women manage these emotional difficulties (Miller, Pittman & Strong, 2003). In the absence of intervention, these concerns may persist for up to 6 years post-treatment (Cull, Stewart & Altman, 1995) and are associated with a reduction in quality of life, medication compliance, longer hospital stays and higher mortality (Newport & Nemeroff, 1998).

Anxiety and depression have been researched more than any other potential response to the experience of gynaecological cancer. Designs have predominantly been cross-sectional or retrospective, with only a few longitudinal studies addressing these difficulties. The results from these two types of research will be presented separately with comments as to how these designs shape the conclusions that can be drawn. It is important to note that whilst research has generally been symptom based, anxiety and depression are not the only emotional responses to the experience. The findings of a small body of literature that has begun to explore the full range of emotions in response to gynaecological cancer will be discussed. As will be demonstrated, not all women diagnosed and treated for gynaecological cancer suffer from psychological distress and so the factors that may influence this will also be discussed.

Whilst many studies have included participants with any form of gynaecological cancer, individuals with ovarian cancer have frequently been studied separately. It is unclear why this is, but it may be because this group has been found to have an increased risk of psychological distress (Bodurka-Bevers, Basen-Engquist & Carmack, 2000).

Cross sectional studies of psychological distress

Cross sectional studies have generally found high levels of psychological distress, with approximately a third of women with gynaecological cancer suffering from clinical levels of anxiety or depression (Thompson & Shear, 1998) and 50-100% of women suffering from mild to moderate affective symptoms and stress responses (Cain et al, 1983; Norton et al., 2004).

Emotional responses to the diagnosis and treatment of gynaecological cancer are not restricted to anxiety and depression. However, very few studies have examined other possible emotional reactions. Those that have addressed this gap have found that women commonly experience a wide range of often rapidly changing emotions (Ekman et al., 2004) including anger, shame, fear, shock, denial, confusion, guilt, disappointment, chaos and emptiness (Ashing-Giwa et al., 2004; Andersen & Turnquist, 1989; Ekman et al., 2004). Intrusive thoughts, avoidance, adjustment difficulties, and PTSD are also commonly experienced, with rates as high as 65% (Palmer, Tucker, Warren & Adams, 1993; Thompson & Shear, 1998).

Comparing women with gynaecological cancer to the general population

Gynaecological cancer patients have been found to have higher levels of distress than women in the general population. In a study comparing women with gynaecological cancer with a female community sample and with women diagnosed with depression and no physical illness, cancer patients reported more depressive symptoms than the normative group but less than the clinically depressed group (Cain et al, 1983). It should be noted, however, that some cancer patients reported symptoms of equivalent severity as the clinically depressed sample: women with ovarian cancer, poorly differentiated tumours and/or those receiving triple agent chemotherapy had more severe depressive symptoms. Women with gynaecological cancer have also been found to have higher levels of anxiety than general population norms and higher levels of distress than disease free cancer sufferers (Cull et al., 1993).

Comparing women with gynaecological cancer with other cancer patients

Studies comparing levels of distress of gynaecological cancer patients with other cancer patients have found mixed results. In one study, gynaecological cancer patients had significantly higher levels of depressive symptoms than benign breast biopsy patients and breast mastectomy patients. Whilst the scores for the breast groups remained low throughout the study, the number of depressive symptoms in the gynaecological cancer group increased over the 20month follow up (Krause & Krause, 1981). However, in a study comparing levels of distress across several cancer groups (using the Brief Symptom Inventory), gynaecological cancer patients were found to have similar levels of distress to breast cancer patients, with 29.6% and 32.8% respectively reporting clinically significant levels of distress. The highest levels of distress were found in lung cancer sufferers with 43.4% reporting clinical levels of distress (Zabora, Brintzenhofeszoc, Curbow, Hooker & Piantadosi, 2001). The high levels of distress for lung cancer suffers were thought to be related to issues of self blame and also poor prognosis. It is unclear why the two studies had such different findings; it may be due to the measures used or variation in the populations studied.

Longitudinal studies of psychological distress

While cross sectional studies can only provide information about the level of distress at a particular time point, longitudinal studies provide the opportunity to monitor the duration of distress, and also whether distress fluctuates generally over time or whether it is triggered at particular points along the cancer trajectory.

Duration of distress

Only a few studies, using a longitudinal design, have examined the duration of psychological distress reported by women with gynaecological cancer. These studies present a mixed picture. Chan et al. (2001) found that 81% of women with gynaecological cancer had the same level of anxiety 18 months post-treatment as they did pre-treatment, despite being disease free. Anderson, Anderson and deProsse (1989) found women with benign gynaecological tumours and women with gynaecological cancer to have significant anxiety at initial assessment , and the cancer group to have depressed mood. However, from the fourth month to the twelfth month follow-up scores for anxiety and depression were comparable for both groups with healthy women. It has been proposed that differences in findings between these two studies may be due to whether the issue of staging of the cancer had been considered, with women suffering from more advanced staged cancer having longer-standing elevated scores on depression measures (Thompson & Shear, 1998).

Points in the cancer trajectory that can provoke distress

Studies examining why distress in women with gynaecological cancer can be long-lasting have found that there are points along the process, other than diagnosis and treatment, that may provoke these responses. In studying women with ovarian cancer, Hipkins, Whitworth, Tarrier and Jayson (2004) found a significant increase in anxiety three months after chemotherapy treatment had been completed. They proposed that this was due to the women reacting to the sudden reduction in support and medical attention from staff, and the absence of external safety checks, leading them to experience increased intrusive thoughts and high vigilance of bodily sensations as signals of cancer recurrence. It has also been repeatedly found that

attendance at follow-up appointments is associated with increased anxiety as women fear being informed of evidence of recurrence (Howell, Fitch & Deane, 2003a, Saegrov & Halding, 2004).

Additionally, being informed that the cancer has recurred or progressed are points in the trajectory that provoke increased levels of distress, and are often experienced as overwhelming and devastating (Howell, Fitch & Deane, 2003a; Guidozzi, 1993). Women who were told that their ovarian cancer had progressed reported higher anxiety levels than they did at the time of diagnosis (Guidozzi, 1993). Recurrence is associated with the loss of hope of a cure, distrust in medical treatment, a sense of helplessness and lack of control, all of which negatively impact on mood (Kullmer et al., 1999).

Women struggle with fears of cancer reoccurrence or spread and fears of dying, even during cancer remission (Howell, Fitch & Deane, 2003a; Cull et al., 1993, Pistrang & Winchurst, 1997; Wenzel et al., 2002; Fitch et al., 1999; Steginga & Dunn, 1997). Of those fearful of recurrence and dying, nearly half reported that they had not received sufficient help to manage these fears (Fitch et al., 1999). Knowing the possibility of a genetic link, women with ovarian cancer also report fears of the risk that the disease poses to their daughters (Howell, Fitch & Deane, 2003b).

Factors associated with psychological distress

There are a number of factors that may help to explain why some women are more distressed than others. These include disease-related factors, biological factors, age, mental health pre-diagnosis, psychosocial issues, social support and coping style.

In terms of disease factors, those who have been diagnosed with ovarian cancer or who have been diagnosed with advanced or recurrent disease have been found to have increased levels of distress (Nortan et al, 2004). This is likely to be due to these women facing very real existential concerns, as their prognosis is poor.

Although emotional distress is an understandable response to the challenges posed by the diagnosis and treatment of gynaecological cancer, biological factors may also contribute (Thompson & Shear, 1998). The treatment of gynaecological cancer usually leads to the rapid cessation of functioning of the ovaries and so a dramatic reduction in levels of oestrogen. Women who have had their ovaries removed, not necessarily because of cancer, have been found to have higher rates of depression than those going through a non-surgical menopause (Nathorst-Boos, von Schoultz & Carstrom, 1993). Oestrogen has been positively linked with the production of serotonin and norepinephrine, and when provided to postmenopausal women has been found to improve mood (Limouzin-Lamothe, Mairon, Joyce & Legal, 1994). Therefore, following treatment for gynaecological cancer, emotional distress may be amplified by hormonal imbalances.

Age has repeatedly found to be a factor influencing distress, with younger women reporting higher levels of anxiety and depression (eg., Hipkins et al., 2004; Nortan et al., 2004). This is likely to be because treatment for gynaecological cancer poses a number of threats to developmental tasks, including compromised or loss of ability to have children, concerns about reduced attractiveness and the impact of these

challenges on the ability to establish and maintain intimate relationships (Brock & Perry, 1995).

An individual's mental health prior to diagnosis has been found to be a predictor of distress in response to diagnosis and treatment. A past history of mental health difficulties has been found to be associated with poor adjustment (Rowland, 1989a), whilst wellbeing prior to treatment has been found to be associated with wellbeing at long-term follow up (Eisemann & Lalos, 1999). Psychosocial issues, particularly the co-occurrence of stressful events and having known someone who has died of cancer are also associated with increased distress (Rowland, 1989b).

Social support has also been found to influence distress, with the lowest levels of distress found in those with a partner (Zabora, Brintzenhofeszoc, Curbow, Hooker & Piantadosi, 2001; Corney, Everett, Howells & Crowther, 1992). Also, women who perceive their level of emotional support to be poor report higher levels of anxiety and depression (Hipkins et al., 2004). Coping style is thought to possibly have a mediating effect, with those taking an active stance, with a determined and realistic attitude experiencing less distress in the face of diagnosis and treatment (Juraskova et al., 2003).

Body Image

Diagnosis of any form of cancer is likely to alter the individual's perspective of their body as they adjust to the knowledge that it is harbouring a potentially lethal disease. With gynaecological cancer the individual also has to manage symbolic threats,

particularly those relating to the role of their reproductive organs in providing a sense of femininity and sexuality.

Interview data has indicated that body image suffers following the diagnosis of pre-cancerous cervical changes (Palmer et al., 1993). Those for whom gynaecological cancer is diagnosed may suffer an even greater assault through knowing that part of their body is diseased, and thereby represents death (Newell, 1991), and through the consequences of treatment (Ekman et al., 2004; Kullmer et al., 1999). Two studies have found that a quarter of women feel less physically attractive following treatment (Cull et al.,1993; Corney, Crowther, Everett & Howells, 1993).

As mentioned earlier, treatment of gynaecological cancer usually consists of either the surgical removal of reproductive organs or toxically rendering them ineffective. Body image has been found to be impaired by treatment for gynaecological cancer (eg. Kullmer et al., 1999), but disease state also influences self-perceptions. For example, Kullmer et al. (1999) found that women suffering from recurrent gynaecological cancer had a poorer body image than those in remission, and both groups had higher dissatisfaction with their bodies than normal healthy controls.

Women with gynaecological cancer have also been found to have poorer body image than those with breast cancer (Anderson & Jochimsem, 1985). In trying to explain this difference it is important to look at the symbolic meaning of the removal of the womb, the most common treatment for gynaecological cancer. For many the womb may represent maternity, feminitity, and sexuality (Northouse, 1984) and its removal poses an assault on sexual identity (Juraskova et al., 2003). For those who are

younger and yet to start or complete their family, the surgery is an additional threat

to self-identity (Northhouse, 1984), with these women having more concerns about

their femininity (Juraskova et al., 2003) and sexuality (Ekman, et al., 2004), resulting

in poorer self esteem (Juraskova et al., 2003).

Perceptions of femininity have been found to mediate feelings of loss associated with

such surgery (Juraskova et al., 2003). Those women who saw their femininity as

being associated with their ability to conceive experienced a greater sense of loss and

lower self-esteem following surgery, regardless of whether they had yet had children,

than did those women whose femininity was expressed through nurturing and caring.

However, two studies (Ekman et al., 2004; Stewart et al., 2001) have found surgery

to have little impact on women's body image. In the qualitative study by Ekman et

al. (2004), women reported experiencing their bodies no differently than they had

before surgery. It should be noted, however, that all the women interviewed had been

symptomatic prior to surgery, and symptom-free following it.

In summary, body image is often affected by the disease itself and by the treatment

that follows. There is much symbolism attached to reproductive organs and it may be

because of this that those with gynaecological cancer have poorer body image than

those with breast cancer. Those most at risk of body image difficulties are those who

are young and those for whom femininity is bound up with fertility.

Sexual Functioning

As well as having to contend with an altered body image, sexual identity and

concerns about attractiveness, women also have to manage the consequences of the

cancer treatment, which may make sexual relationships problematic.

Sexual dysfunction is a common and often long-lasting side effect of treatments used

for gynaecological cancer (Corney et al., 1992; Wenzel et al., 2002). Depending on

the treatment mode adopted, women can expect to possibly experience reduced

sexual desire, difficulties with arousal and orgasm, reduced lubrication, dyspareunia,

reduction in vaginal elasticity, a shortened vaginal cavity, vaginal atrophy and

stenosis (e.g. Andersen, 1995; Krumm & Lamberti, 1993). Women treated with

primary radiotherapy and combined surgery and radiotherapy are more likely to

report poorer sexual functioning, compared to women treated with primary surgical

treatment (Schover, Fife & Gershenson, 1989). Sexual dysfunction has been found to

occur for 50% of women in the first year post-treatment for gynaecological cancer,

with 40% of women developing chronic difficulties despite their medical treatment

having been successful (Andersen, 1993).

While treatment certainly affects women's sexual functioning there are also other

factors involved, including relationship issues, mood and the aforementioned

changes in body image. In a qualitative study, women spoke of their fears of

recommencing intercourse following treatment for cervical or endometrial cancer,

particularly that it would cause them pain or damage (Juraskova et al., 2003).

Interestingly, the women reported that these fears were shared by their partners, but

as they were not initially vocalised, the women misinterpreted the men's reluctance to initiate sexual relations as signs of disinterest or rejection.

In the absence of cancer, anxiety and depression are known to impair sexual functioning (Teusch et al., 1995). In those with gynaecological cancer, sexual difficulties have been found to be significantly associated with levels of anxiety (Corney et al., 1992) and depression (Matthews et al., 1999).

While sexual dysfunction is a problem commonly faced, it is not one that is seen as a priority by those who have only recently been treated for gynaecological cancer. Booth et al. (2005) and Juraskova et al. (2003) both found women six months or less post-treatment to be more concerned with coming to terms with the illness and treatment than with managing their sexual difficulties. Also, despite decreased satisfaction in their sexual relationships, women in one study reported that this had not led to impairment in their marital relationship (Corney et al., 1993)

Impact on Relationships

While it is important for people struggling with a diagnosis of cancer to have social support to help them to make sense of and cope with it (Wortman & Dunkel-Schetter, 1979), there are sometimes barriers that prevent them from obtaining adequate support. Loved ones may respond in ambivalent ways, wanting to hide pessimistic or fearful attitudes to the cancer in the belief that it is important to express only optimism and positivity (Wortman & Dunkel-Schetter, 1979). These unspoken fears can affect communication between partners (Howell, Fitch & Deane, 2003).

In addition to adjusting to the diagnosis themselves, women with gynaecological cancer also have to manage the reactions of others. Reactions can range from shock to dismissal of the severity of the threat, and may involve the women having to comfort and support the recipient of the news (Ekman et al., 2004). Despite wishing to gain support, women may deny themselves access to this through their desire to protect others from being further subjected to the horror of their experience, or through wanting to be treated normally as opposed to someone who is about to die (Howell, Fitch & Deane, 2003)

Social attitudes may also be a barrier to obtaining social support. Many cancer patients report a stigma attached to being diagnosed with any form of cancer (Wilson & Luker, 2006). When it may be linked with a sexually transmitted virus and so associated with perceptions of promiscuity, as is the case with cervical cancer, this stigma may be heightened (Ashign-Giwa et al., 2004). Even women with ovarian cancer, which has no connotations with sexually transmitted viruses, have reported that due to the stigma of their diagnosis there are some who have purposely avoided them (Howell, Fitch & Deane, 2003), or refused to talk to them about it (Ekman et al., 2004).

The demands of treatment can also force women with cancer to relinquish their usual activities and ability to work, and so restrict their potential to socialise and to access interpersonal resources (Bloom & Kessler, 1984; Bloom & Spiegel, 1984; Howell, Fitch & Deane 2003) at a time of greatest need (Dakof & Taylor, 1990).

A diagnosis of cancer does not just affect the individual, but also their wider system. Family members can be thought of as "second order patients" (Rait & Lederberg, 1989), having to manage the changing family dynamics. Spouses often have to take on new roles to compensate for those no longer fulfilled by the woman (Howell, Fitch & Deane, 2003), and at the same time struggle to support their partners (Van de Wiel, Weijmar-Schultz, Hallensleben & Thurkow, 1990). Marital relationships have been found to be more vulnerable to deterioration for younger patients; older patients have reported minor changes or even some improvement in the quality of their relationship (Sewell & Edwards, 1980 cited in Corney et al., 1992)

Summary

From the results of the research to date it can be concluded that the majority of women with gynaecological cancer experience mild to moderate anxiety and depression, with a third of women experiencing levels of anxiety and depression at a clinically significant level. For some, the anxious and depressive symptoms have been found to be longstanding, while for others they return to levels normal for the general population. Emotional responses are not restricted to anxiety and depression, but also encompass fear, shame and guilt. There are a number of factors that increase the risk of distress, particularly advanced stage of disease and younger age at diagnosis. In addition to psychosocial explanations for the experience of distress there are also biological reasons for heightened vulnerability.

The body image of women with gynaecological cancer suffers a number of assaults. The knowledge that the body is harbouring a potentially deadly disease, combined with the symbolic consequences of removing the womb, threatens the women's self-

identity, sexuality and femininity. Sexual dysfunction is a common and long-lasting side effect of treatment for gynaecological cancer, with women experiencing a range of physical difficulties that may preclude the recommencement of a sexual relationship. They may also experience psychological barriers such as fear of causing pain or damage and low mood. However, this area of functioning is often a low priority for those who have only recently completed treatment.

Women with gynaecological cancer may not receive desired levels of social support for a number of reasons. These include a desire to protect those around them, a need to be treated normally, the stigma attached to the particular form of cancer, limited contact with their social network, and the ambivalent responses of loved ones. The wider system may also struggle to respond to the changing roles and dynamics brought about by the cancer.

However, there are a number of methodological limitations to the research examining psychological difficulties in gynaecological cancer patients. Firstly, there are very few longitudinal studies with long-term follow ups. Secondly, the impact of staging of disease on results has often not been taken into account. Finally, cross-sectional studies have often measured current symptom levels and equated them to levels of disorder. However, the symptoms may not be experienced long enough to be classified as such (Thompson & Shear, 1998). Further research is needed to address these areas.

Research to date has focused primarily on examining the prevalence of psychological symptoms in women with gynaecological cancer. While this has brought an

understanding of the prevalence of distress, it now seems time to go beyond the symptomatic approach and examine in greater detail emotional responses other than anxiety and depression. A few studies have noted the stigma and shame associated with this particular type of cancer, and this is an area that needs to be explored further. There is also a need for more longitudinal studies to identify the different emotional responses across the trajectory. Current research clearly indicates that a significant minority of women report clinically significant levels of distress, requiring psychological interventions tailored to the specific challenges they face in adjusting to their experience of gynaecological cancer. The following section reviews the research on interventions that have been designed to try and meet this need.

Psychosocial interventions

There has been a general paucity of research into psychosocial interventions specifically for women with gynaecological cancer. For this reason, a summary of the findings of research into psychosocial interventions for cancer patients in general will be provided before presenting the findings of the few intervention studies aimed at women with gynaecological cancer. A number of intervention formats have been evaluated for use with cancer patients, the majority of which have been group based. An overview will be presented of the research literature evaluating the effectiveness of professionally-led, peer-led and social support group interventions. The small number of interventions designed specifically for women with gynaecological cancer will then be described in detail. Following this, the methodological limitations of the intervention literature to date will be discussed. Finally, future directions of intervention research for women with gynaecological cancer will be discussed, with

particular focus on the need for improved outcome measures and comparison designs.

Psychosocial interventions for cancer patients

The majority of interventions reported in the research literature in this field have adopted group formats. The reason behind this is unclear. It may be due to cost effectiveness, professional time constraints or a belief in the power of peer support. Additionally, the incidental finding of Spiegel et al. (1989), that women with metastatic breast cancer attending their year long weekly supportive-expressive therapy group intervention lived for 18 months longer than those in the no-treatment control arm of the intervention, may have spurred research into group interventions.

Within the group intervention literature, differences exist both in the content and focus of the groups, but also in whether they are led by professionals, peers, or a combination of the two. Interventions have generally focused on providing individuals with increased knowledge of their cancer and treatment, coping strategies, and facilitating the expression of emotions. Professionally-led groups vary in the extent to which they are founded on a therapeutic stance such as supportive expressive therapy, or on the provision of information and coping skills. Peer-led support groups for individuals with cancer exist in their multitude. The premise on which they are based is that those who have experienced a condition or concern are uniquely able to provide support and understanding to others managing the same challenges.

Interestingly, although there are growing numbers of psychologists working in oncology, there are relatively few published studies presenting the outcomes of individual therapeutic interventions. Those that have been carried out have varied hugely in their content, including provision of an orientation session about the clinic (Wells et al., 1995) relaxation audiotapes (Larsson & Starrin, 1992) and cognitive therapy for coping with stress (Davis, 1986). Many of these interventions have focused specifically on managing the side effects of cancer treatment and anticipatory nausea and vomiting and will not be reviewed here (see reviews by Trijsburg, van Knippenberg & Rijpma, 1992 and Newell, Sanson-Fisher & Savolainen, 2002).

Reviews of research into psychosocial interventions for cancer patients

The accumulated literature on psychological interventions for cancer patients is vast. It was therefore necessary to summarise the findings of review papers. The six review papers were selected for discussion below because they were published in the last ten years and comprehensively cover the professionally-led, peer-led and social support intervention literature. As will be seen, different conclusions about the effectiveness of the interventions can be reached, depending on the focus and the inclusion and exclusion criteria selected. The reviews have been divided into those examining professionally-led interventions (Meyer & Mark, 1995; Fawzy, 1999; Newell, Sanson-Fisher & Savolainen, 2002; Edwards, Hailey & Maxwell, 2004), and those examining peer-led and social support interventions (Helgeson and Cohen, 1996; Campbell, Phaneuf & Deane, 2004). Some of the reviews have only included studies which have adopted randomised controlled designs (Meyer & Mark, 1995; Newell, Sanson-Fisher & Savolainen, 2002; Edwards, Hailey & Maxwell, 2004;),

others have included studies using a wide range of designs (Campbell, Phaneuf & Deane, 2004), while some have not stated the methodological basis on which they included studies (Fawzy, 1999). The majority of the literature has focused on the effectiveness of interventions for women with breast cancer.

Professionally-led interventions

In their meta-analysis of psychosocial, behavioural or psychoeducational individual or group interventions for adult cancer patients, Meyer and Mark (1995) included 45 studies, each of which adopted a randomised controlled design and measured behavioural, emotional, physiological or mental state as an outcome. They concluded that behavioural, educational, social support, and counselling interventions successfully promote emotional adjustment, functional adjustment and the management of treatment and disease related symptoms, with the various interventions showing comparable, although small, effect sizes.

Fawzy (1999) described thirteen studies evaluating individual or group interventions that he felt best summarised the current knowledge in the area of psychosocial interventions for cancer patients. He concluded that whilst some intervention studies have had mixed outcomes, the results have been generally positive both in the short- and long-term, with interventions including education, coping skills and emotional support usually being helpful. The interventions seem to have greater and longer-lasting impact when the strategies are provided in combination, as this provides the individual with increased coping resources.

Newell, Sanson-Fisher and Savolainen (2002), in their comprehensive review of

psychological therapies for cancer patients, criticised earlier reviewers for their

inclusion of studies that were methodologically inadequate. From the original 627

papers elicited through searches, only 82 randomised controlled studies with

psychosocial, side-effect, conditioned side-effect or survival outcomes met the

authors methodological standards. The authors still felt that the methodology of

many of the included studies was 'suboptimal' and so reached cautious conclusions.

They found that group therapy, education, structured and unstructured counselling

and cognitive behavioural therapy all showed promise for having positive medium-

and longer-term psychosocial outcomes. Interestingly, they found a comparative lack

of immediate and short-term effects, and therefore they underline the importance of

studies including longer-term follow-up.

The most stringent review of the intervention literature to date is the Cochrane

review carried out by Edwards, Hailey and Maxwell (2004) on psychosocial

interventions for women with metastatic breast cancer. Following their strict

inclusion and exclusion criteria only five randomised controlled studies were found

to be sufficiently methodologically adequate to be included in their review; these

were two cognitive behavioural therapy group interventions (Cunningham, et

al.,1998 and Edelman, et al., 1999) and three supportive expressive group therapy

interventions (Spiegel et al.,1989, Koopman et al., 1998 and Goodwin et al., 2001).

On the basis of their evaluation of these studies, the authors concluded that whilst

these interventions did lead to short-term psychological improvements these were not

maintained at later follow up, and that there is insufficient evidence to advocate the

widespread adoption of group psychosocial interventions for women with breast

cancer. The authors also noted that the wide variety of outcome measures and follow-up points made it more difficult to reach conclusions.

Peer-led and social support interventions

The importance of social support to good mental health is well established (Rhodes & Lakey, 1989). As a consequence interventions designed to promote perceived social support both led by professionals and peers have grown in number. Helgeson and Cohen (1996) reviewed the effectiveness of professionally-led social support interventions on adjustment to cancer. Having established in the first part of their review that emotional support is the type of support most desired by cancer patients, the authors reviewed the ability of interventions to meet this need, particularly comparing the effectiveness of peer discussion groups and educational groups. They concluded that education interventions increase cancer knowledge, and improve psychological and physical adjustment in comparison with no-treatment controls. The authors were more cautious in reaching conclusions about the effectiveness of peer discussion groups, because there have been relatively few studies in which the interventions have been compared with no-treatment controls; however, they did point to the positive findings of the longer-term group therapy interventions. In studies that have compared peer discussion groups with education group interventions within a randomised design, education has been found to be superior in promoting cancer adjustment. The authors suggested mechanisms by which social interactions may improve adjustment, such as through enhancement of self esteem, restoration of perceived control and instilling optimism about the future. They concluded that, based on the findings of the current literature, educational groups may affect more of these mechanisms than the peer discussion groups.

Campbell, Phaneuf & Deane (2004) reviewed seventeen volunteer-delivered peer support programmes for individuals with cancer. The programmes had been delivered through a variety of means, including groups, one-to-one, internet and telephone, to patients with a range of cancer types, although predominantly breast cancer. Included in the review were studies adopting a wide variety of designs, including exploratory research and focus groups. The descriptive studies indicated a number of benefits of attending peer support programmes, including how the commonality of experience led to bonding, increased openness and self-disclosure. Participants also reported that by having an alternative forum to gain support they were less dependent on their families to meet their emotional support needs. Telephone and internet were described as helpful mediums of providing support, particularly to those with rarer types of cancer and those for whom practical difficulties or a desire to preserve privacy made face-to-face interventions less desirable. However, the findings of the five studies using randomised designs, three of which were reporting on the same trial, were less positive. Those who attended peer support groups were found to have negative outcomes in the short-term on certain variables, but positive findings at long-term follow-up on social functioning and mental health.

Summary

In summary, reviews of the effectiveness of psychosocial interventions for cancer have generally indicated positive outcomes, particularly for educational interventions, although reviewers have varied in the strength of their conclusions. Given the positive findings from the peer support interventions evaluated using

qualitative methods, the lack of findings from the randomised literature may be due to an issue of whether the measures are sufficiently sensitive to detect the effect of this type of intervention.

All the review authors noted the need for further studies to adopt randomised designs, to compare the effectiveness of interventions and to incorporate longer follow ups, and stated that they were only able to make cautious conclusions due to the limited number of methodologically sound studies. The majority of the reviews only included studies with randomised controlled designs, in so doing there is the risk of missing out on the valuable information that can be gained from the findings of studies that have used quasi-experimental, descriptive, correlational and qualitative designs.

Psychosocial interventions for women with gynaecological cancer

While there are a number of similarities between the experiences of women with gynaecological cancer and other cancer patients, such as the impact of diagnosis, facing ones own mortality and so on, there are also some distinct differences. As was mentioned in the first section of this review, in having a cancer that affects their reproductive organs, women with gynaecological cancer have to contend with challenges to their sexuality, body image and ability to have sexual relationships and reproduce. So, whilst the current literature can inform the future direction of intervention research with women with gynaecological cancer, assumptions cannot be made that what has been found to be effective for other cancer patients will automatically translate to this particular patient group.

Psychosocial interventions have scarcely been evaluated with women with gynaecological cancer. Women with gynaecological cancer have occasionally been included in mixed cancer intervention trials, but they have always been very much in the minority. Following an extensive search of the literature, only five studies were identified as being targeted at women with gynaecological cancer, and three of these were conducted more than twenty years ago. While small in number, the studies have, however, examined a range of psychosocial interventions, from peer support to individual and group therapy. All of the interventions were targeted at women who were newly diagnosed with gynaecological cancer.

Chan et al. (2005) randomly assigned 155 newly diagnosed Chinese women with a variety of gynaecological cancers to a treatment-as-usual control group or to an individual psychotherapy intervention. Whilst the intervention was tailored to meet the needs of individual patients, it included a number of core components, including psychoeducation and supportive care, stress management, brief crisis counselling, relaxation, and management of affective disorders using cognitive behavioural therapy. No significant differences were found between the groups on any of the measures, including quality of life, depression, trauma, self-efficacy and self-esteem, at any of the follow-up points. Time since diagnosis was found to be the most important predictor of outcome and adjustment, with a trend for improved quality of life and functional status over time for both groups.

There are a number of possible reasons why this study failed to find any significant effects of the intervention. All patients reported only a mild level of anxiety and depression at baseline, in fact, extremely low in comparison with other studies. The

low level of reported difficulties may be a cultural artefact, with Chinese women

possibly reluctant to report distress. Studies have demonstrated that Chinese women

are less likely to report sexual difficulties as a result of gynaecological cancer (Cain

et al. 2003). Due to this floor effect, the intervention would therefore have had to

have had a very strong effect for it to be significant.

Capone, Good, Westie and Jacobson (1980), using a non-randomised controlled

design, also examined the impact of an individual psychological intervention with

women newly diagnosed with mixed gynaecological cancers (n=56); however, they

found more positive results. The intervention, described as crisis intervention

counselling, was provided during the women's initial hospitalization for cancer

treatment and consisted of a minimum of four sessions focusing on the expression of

emotions, understanding of the disease, self-esteem, femininity, sexuality and

interpersonal relationships. The content and number of sessions were tailored to meet

the needs of the women. Compared with those in the no-treatment control group

(n=41), women receiving counselling reported significantly reduced sexual

dysfunction and enhanced rate of return to previous levels of sexual activity, and also

showed less confusion and contradiction in terms of their self-perception three

months post-treatment. At one year follow-up, the intervention also seemed to

enhance return to work, although this finding did not reach significance. However,

no details were supplied as to the maximum or average number of sessions those in

the intervention arm received.

The comparative effectiveness of an individual and a group intervention was

examined in the randomised controlled study by Cain, Kohorn, Quinlan, Latimer and

Schwartz (1986), with women newly diagnosed endometrial, cervical, ovarian or vulval cancer. The authors compared the impact of an eight session thematic counselling individual intervention (n=21) with the same intervention provided in a group format (n=28), and standard care (n=31). The intervention sessions were focused on providing information about the disease and treatment and also enhancing positive health behaviours, through highlighting the importance of diet, exercise and relaxation. At the three month follow-up the individual intervention was found to be more effective in reducing anxiety. However, by the six month follow-up the intervention formats were found to be equally effective, with women in both interventions reporting significant reductions in anxiety and depression, increased knowledge about the disease, better relationships with caregivers, less sexual dysfunction, and greater leisure activities, than those receiving standard care.

Carlsson and Strang (1998), using a quasi-experimental design, also evaluated the effectiveness of a group intervention, but they employed an educational support programme targeted at women with mixed gynaecological cancers and their spouses. Unlike the other studies reviewed here, the intervention was open not just to women who were newly diagnosed but also to those undergoing treatment and those who had completed treatment. The control arm of the study was composed of 26 women who, because of geographic difficulties, were unable to attend the intervention sessions. In the intervention arm, 36 women and 8 spouses attended seven sessions at which the group leader and 'guest speakers' provided information on a variety of topics, including living with the diagnosis, changing family relations and roles, pain, diet and common psychological reactions. The intervention was generally positively received. Compared to those in the control arm, those who received the intervention

perceived they had a greater knowledge of cancer. However, there was no significant

difference between the intervention and control groups on the assessment of mood,

although there was a trend in the intervention group for improvements in anxiety,

confusion, and anger.

In the studies so far discussed the interventions were all provided by professionals. In

contrast, Houts, Whitney, Mortel and Bartholomew (1986) evaluated the impact on

emotional distress of a telephone support intervention provided by peer helpers.

Thirty-two women were randomly assigned to either receive professional support as

usual or professional support combined with telephone support from a former cancer

patient, who was also a social worker. (It is unclear, however, whether the former

cancer patient had suffered from a gynaecological cancer.) Women were called by

one of the two helpers on three occasions: prior to hospitalization, 5 weeks after

discharge and 10 weeks after discharge. The conversations were strategy-focused

with the women being encouraged to maintain normal routines and relationships,

make positive plans for the future, and ask questions of staff. The peer helpers also

provided the opportunity for the women to share their feelings and concerns. The

women were also given audiotapes that further explained the coping strategies and

provided accounts of how other gynaecological cancer patients had found them

useful. Follow-up measures were taken 6 weeks and 12 weeks after the intervention

began. No group differences were found on measures of emotional distress, although

the majority of those who had received the peer support intervention rated it

positively. The lack of findings may be attributed to a number of factors. Firstly, the

intervention may have been too brief- it consisted of only three phone calls- for it to

have an impact on distress. Secondly, the pre-existing support provided by the

service may have been comprehensive enough. Thirdly, the final follow-up assessment took place just two weeks after the final phone call, and so the follow-up period may not have been long enough to detect any gradually developing effects. Finally, the sample size was very small for effects to be detected.

Summary

In summary, the number of interventions evaluated with women with gynaecological cancer is very small. As the results of the studies have been mixed, and the designs, outcome measures and length of follow-ups have all varied widely, it is not possible to reach firm conclusions. However, considering how few studies have been carried out with this patient group, the effectiveness of a wide variety of types of interventions have been examined. The findings to date do seem to indicate the importance of providing interventions where there is clinical need, of sufficient length to have an impact and using a large enough sample for effects to be detected. Given that the one study that compared a group format with an individual intervention found both equally effective (Cain et al., 1986), one could tentatively conclude that, on the grounds of cost-effectiveness, this may be a suitable mode for other services to replicate.

Methodological issues

The methodological adequacy of the intervention research to date has been questioned by many (eg., Newell, Sanson-Fisher & Savolainen, 2002). There are a number of concerns about various aspects of the research designs employed and the measures used to assess outcomes.

A key issue is whether the outcome measures typically used are sensitive to, and appropriate for, the interventions being delivered. The focus on psychological symptoms in the psychosocial literature has translated into a similar focus on measuring symptoms in the intervention literature. In so doing, the full range of possible outcomes of interventions have not been captured. While there is a need for standardized measurement, it is first necessary to design sufficiently sensitive measures. For example, measures of anxiety and depression fail to capture the proposed range of likely benefits for peer interventions, including hope, increased personal control, shared experience, reduced isolation and increased confidence (Campbell, Phaneuf & Deane, 2004), or subtle changes in emotional adjustment, particularly existential issues (Edwards, Hailey & Maxwell, 2004). Qualitative research is needed to establish from the participant's perspective the most salient constructs to measure.

Other important methodological issues include levels of clinical need, length of follow-up and sample size. It is important that those entering into an intervention display a clinical need. In many of the studies the women were displaying such low levels of distress at the start that a ceiling effect was created and intervention effects were harder to establish (Meyer & Mark, 1995). As a number of the studies only showed intervention effects at later follow-up, it is possible that the benefits of psychosocial interventions gradually develop with time and so long-term follow-up, of at least one year, is necessary. The majority of studies also evaluated interventions with such low numbers of participants that they lacked the power to detect effects if they did exist.

Conclusions and future directions

The first section of this review highlighted the specific challenges and concerns faced by women with gynaecological cancer, and the need of a significant proportion of women to receive tailored psychological interventions. The second section showed that a wide range of interventions have been evaluated with cancer patients in general, and even in the small literature specific to women with gynaecological cancer. While the results have been mixed, there are an encouraging number of interventions showing positive effects.

In terms of future directions for the research in this area, there is a need to understand which interventions are the most effective for women with gynaecological cancer, what works for whom, and the mechanisms by which psychosocial interventions are effective. Interventions should be compared to establish which are the most effective, with attention paid to the factors that predict which individuals benefit from which interventions. Some authors have begun to think about the mechanisms by which psychosocial interventions may have their effect (e.g., Helgeson & Cohen, 1996) but there is a need for greater evaluation of this. Through establishing how the interventions work, it is also possible to design measures more sensitive to the effects of interventions, enabling more rigorous evaluation.

One particular area deserving further research is the role of peer support in interventions for cancer patients, and for women with gynaecological cancer in particular. Peer support has become increasing popular, through a number of mediums including support groups, the internet and charity run phone support. It is thought to be a key component in the effectiveness of professionally-led group

interventions, but surprisingly little research has examined peer support in gynaecological cancer. This may be particularly beneficial for women with gynaecological cancer, as the stigma and personal issues that are raised by diagnosis and treatment may lead the experience to be difficult to discuss with others. It is important to gain a greater understanding of what peers are able to provide that professionals are unable to, and the mechanisms by which this can be helpful.

Final conclusions

In answer to the question, what are the psychosocial needs of women with gynaecological cancer, the current literature has primarily focused on identifying symptoms of anxiety and depression. However, broader issues are raised by the trauma of the diagnosis and treatment of gynaecological cancer, such as body image, sexuality, femininity, and the impact on relationships. Through focusing on symptoms, the literature has effectively neglected wider aspects of the experience. There is a particular lack of research allowing women to describe, from their own perspective, the nature of their needs.

In thinking about how the needs of women with gynaecological cancer can best be met, few interventions have been evaluated with this patient group, and the types of interventions and outcome measures have been so varied that it is not possible to reach conclusions. While there is a larger literature evaluating the effectiveness of psychosocial interventions for cancer patients in general, it is not possible to generalise from these findings because, as has been described, gynaecological cancer provokes some distinct challenges. Through establishing what the needs of the women are, it will then be possible to design not only effective interventions but also

measures that are sensitive enough to detect the impact of such interventions. There is therefore a need for further research in this area.

REFERENCES

Andersen, B.L. (1993). Predicting sexual and psychologic morbidity and improving the quality of life for women with gynaecological cancer. *Cancer*, 7, 1678-1690.

Andersen, B.L. (1995). Quality of life for women with gynecologic cancer. *Current Opinion in Obstetrics and Gynecology*, 7, 69-76.

Andersen, B.L., & Jochimsen, P.R. (1985). Sexual functioning among breast cancer, gynecologic cancer, and healthy women. *Journal of Consulting and Clinical Psychology*, 53, 25-32.

Andersen, B.L., & Turnquist, D.C. (1989). Psychological issues. In J.S. Berek and N.F. Hacker (Eds.), *Practical Gynecologic Oncology (pp631-656)*. Baltimore: Williams & Wilkins.

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

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, 709-728.

Bloom, J.R., & Kessler, L. (1994). Emotional support following cancer: A test of the stigma and social activity hypotheses. *Journal of Health and Social Behaviour*, 35, 118-133.

Bloom, J.R., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. *Social Science and Medicine*, 19, 831-837.

Bodurka-Bevers, D., Basen-Engquist, K., & Carmack, C.L. (2000). Depression, anxiety , and quality of life in patients with epithelial ovarian cancer. *Gynecological Oncology*, 78, 302-308.

Booth, K., Beaver, K., Kitchener, J., O'Neill, J., & Farrell, C. (2005). Women's experiences of information, psychological distress and worry after treatment for gynaecological cancer. *Patient Education and Counselling*, 56, 225-232.

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

Cain, E., Kohorn, E., Quinlan, D., Schwartz, P., Latimer, K., & Rogers, L. (1983). Psychosocial reactions to the diagnosis of gynecological cancer. *Obstetrics and Gynecology*, 62, 635-641.

Cain, E.N., Kohorn, E.I., Quinlan, D.M., Latimer, K., & Schwartz, P.E. (1986). Psychosocial benefits of a cancer support group. *Cancer*, 57, 183-189.

Cain, V.S., Johannes, C.B., Avis, N.E., Mohr, B., Schocken, M., Skurnick, J., & Ory, M. (2003). Sexual functioning and practices in a multi-ethnic study of midlife women: baseline results from SWAN. Journal of Sexual Research, 40, 266-76.

Campbell, H.S., Phaneuf, M.R., & Deane, K. (2004). Cancer peer support programs-do they work? *Patient Education and Counseling*, 55, 3-15.

Cancer Research Campaign (1997). *Fact Sheet 17.1 Ovarian Cancer-UK.* London:CRC

Capone, M.A., Good, R.S., Westie, K.S., & Jacobson, A.F. (1980). Psychosocial rehabilitation of gynecologic oncology patients. *Archives of Physical Medicine and Rehabilitation*, 61, 128-132.

Carlsson, M.E., & Strang, P.M. (1998). Educational support programme for gynaecological cancer patients and their families. *Acta Oncologica*, 37, 269-275.

Chan, Y.M., Ngan, H.Y.S., Yip, P.S.F., Li, B.Y.G., Lau, O.W.K., & Tang, G.W.K. (2001). Psychosocial adjustment in gynaecologic cancer survivors: a longitudinal study on risk factors for maladjustment. *Gynecological Oncology*, 80, 387-394.

Chan, Y.M., Lee, P.W.H., Fong, D.Y.T., Fung, A.S.M., Wu, L.Y.F., Choi, A.Y.Y., Ng, T.Y., Ngan, H.Y.S., & Wong, L.C. (2005). Effect of individual psychological intervention in Chinese women with gynecologic malignancy: A randomised controlled trial. *Journal of Clinical Oncology*, 23, 4913-4924.

Corney, R.H., Everett, H., Howells, A., & Crowther, M.E. (1992). Psychosocial adjustment following major gynaecological surgery for carcinoma of the cervix and vulva. *Journal of Psychosomatic Research*, 36, 561-568.

Corney, R.H., Crowther, M.E., Everett, H., Howells, A., & Shepard, J.H. (1993). Psychosexual dysfunction in women with gynaecological cancer following radical pelvic surgery. *British Journal of Obstetrics & Gynaecology*, 100, 73-78.

Cull, A., Cowie, V.J., Farquharson, D.I.M., Livingstone, J.R.B., Smart, G.E., & Elton, R.A. (1993). Early stage cervical cancer: Psychosocial and sexual outcomes of treatment. *British Journal of Cancer*, 68, 1216-1220.

Cull, A., Stewart, M., & Altman, D.C., (1995). Assessment of and intervention for psychosocial problems in routine oncology practice. *British Journal of Cancer*, 72, 229-235.

Cunningham, A., Edmonds, C., Jenkins, G., Pollack, H., Lockwood, G., & Warr, D. (1998). A randomized controlled trial of the effects of group psychological therapy on survival in women with metastatic breast cancer. *Psycho-Oncology*, 7, 508-517.

Dakof, G.A.., & Taylor, S.E. (1990). Victims' perceptions of social support: What is helpful from whom? *Journal of Personality and Social Psychology*, 58, 80-89.

Davis, H. (1986). Effects of biofeedback and cognitive therapy on stress in patients with breast cancer. *Psychological Reports*, 59, 967-974.

Department of Health (1999). *Improving health outcomes in gynaecological cancer.* London:DoH.

Edelman, S., Lemon, J., Bell, D., & Kidman, A.. (1999). Effects of group CBT on the survival time of patients with metastatic breast cancer. *Psycho-Oncology*, 8, 474-481.

Edwards, A.G.K., Hailey, S., & Maxwell, M. (2004). Psychological interventions for women with metastatic breast cancer. *The Cochrane Database of Systematic Reviews*.

Eisemann, M., & Lalos, A. (1999). Psychosocial determinants of well-being in gynaecologic cancer patients. *Cancer Nursing*, 22, 303-306.

Ekman, I., Bergbom, I., Ekman, T., Berthold, H., & Mahsneh, S.M. (2004). Maintaining normality and support are central issues when receiving chemotherapy for ovarian cancer. *Cancer Nursing*, 27, 177-182.

Fawzy, F.I. (1999). Psychosocial interventions for patients with cancer: What works and what doesn't. *European Journal of Cancer*, 35, 1559-1564.

Fitch, M.I., Gray, R.E., DePetrillo, D., Franssen, E., & Howell, D. (1999). Canadian women's perspective on ovarian cancer. *Cancer Prevention and Control*, 3, 52-60.

Goodwin, P., Leszcz, M., Ennis, M., Koopmans, J., Vincent, L., Guther, H., Drysdale, E., Hundleby, M., Chochinov, H., Navarro, M., Speca, M., & Hunter, J. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine*, 345, 1719-1726.

Guidozzi, F. (1993). Living with ovarian cancer. *Gynecological Oncology*, 50, 202-207.

Helgeson, V.S., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15, 135-148.

Hipkins, J., Whitworth, M., Tarrier, N., & Jayson, G. (2004). Social support, anxiety and depression after chemotherapy for ovarian cancer: A prospective study. *British Journal of Health Psychology*, 9, 569-581.

Howell, D., Fitch., & Deane, K.A. (2003a). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, 26, 10-17.

Howell, D., Fitch., & Deane, K.A. (2003b). Impact of ovarian cancer perceived by women. *Cancer Nursing*, 26, 1-9.

Houts, P.S., Whitney, C.W., Mortel, R., & Bartholomew, M.J. (1986). Former cancer patients as counselors of newly diagnosed cancer patients. *Journal of the National Cancer Institute*, **76**, 793-796.

Juraskova, I., Butow, P., Robertson, R., Sharpe, L., McLeod, C., & Hacker, N. (2003). Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psycho-oncology*, **12**, 267-279.

Karlsson, J.A., & Andersen, B.L. (1986). Radiation therapy and psychological distress in gynaecologic cancer patients: Outcomes and recommendations for enhancing adjustment. *Journal of Psychosomatic Obstetrics and Gynaecology*, **5**, 283-294.

Knapp, R.C., & Berkowitz, R.S. (1986) *Gynecologic oncology*. New York: Macmillan

Koopman, C., Hermanson, K., Diamond, S., Angell, K., & Spiegel, D. (1998). Social support, life stress, pain and emotional adjustment to advanced breast cancer. *Psycho-Oncology*, **7**, 101-111.

Krause, H., & Krause, J. (1981). Cancer as a crisis: The critical elements of adjustment. *Nursing Research*, **31**, 96-101.

Krumm, S., & Lamberti, J. (1993). Changes in sexual behavior following radiation therapy for cervical cancer. *Journal of Psychosomatic Obstetrics and Gynaecology*, **14**, 51-63.

Kullmer, U., Stenger, K., Milch, W., Zygmunt, M., Sachsse, S., & Munstedt, K. (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 and Gynecology*, **82**, 101-106.

Larrson, G., & Starrin, B. (1992). Relaxation training as an integral part of caring activities for cancer patients: Effects on well-being. *Scandinavian Journal of Caring Sciences*, **6**, 179-185.

Limouzin-Lamothe, M., Mairon, N., Joyce, C.R., & Legal, M. (1994). Quality of life after the menopause: influence of hormonal replacement therapy. *American Journal of Obstetrics and Gynecology*, **170**, 618-624.

Matthews, A.K., Aikens, J.E., Helmrich, S.P., Anderson, D.D., Herbst, A.L., & Waggoner, S.E. (1999). Sexual functioning and mood among long-term survivors of clear-cell adenocarcinoma of the vagina or cervix. *Journal of Psychosocial Oncology*, **17**, 27-45.

Meyer, T.J., & Mark, M.M. (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, **14**, 101-108.

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. *International Journal of Gynecological Cancer*, **13**, 111-119.

Nathorst-Boos, J., von Schoultz, B., & Carstrom, K., (1993). Elective ovarian removal and estrogen replacement therapy- effects on sexual life, psychological well-being and androgen status. *Journal of Psychosomatic Obstetrics and Gynaecology*, **14**, 283-293.

Neijt, J., ten Bokkel Huinink, K., & van der Burg, M. (1991). Long-term survival in ovarian cancer. *European Journal of Cancer*, **27**, 1367-1372.

Newell, S.A., Sanson-Fisher, R.B., & Savolainen, N.J. (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute*, **94**, 558-584.

Newell, R. (1991). Body-image disturbance: Cognitive behavioural formulation and intervention. *Journal of Advanced Nursing*, **16**, 1400-1405.

Newport, D.J., & Nemeroff, C.B. (1998). Assessment and treatment of depression in the cancer patient. *Journal of Psychosomatic Research*, **45**, 215-237.

Norton, T.R., Manne, S.L., Rubin, S., Carlson, J., Hernandez, E., Edelson, M.I., Rosenblum, N., Warshal, D., & Bergman, C. (2004). Prevalence and predictors of psychological distress among women with ovarian cancer. *Journal of Clinical Oncology*, **22**, 919-926.

Northouse, L. (1984). The impact of cancer in the family: An overview. *International Journal of Psychiatry and Medicine*, **14**, 215-242.

Office for National Statistics (2002). *Cancer Statistics registrations: Registrations of cancer diagnosed in 2002* England

Palmer, A.G., Tucker, S., Warren, R., & Adams, M. (1993). Understanding women's responses to treatment for cervical intra-epithelial neoplasia. *British Journal of Clinical Psychology*, **32**, 101-112.

Pistrang, N., & Winchurst, C. (1997). Gynaecological cancer patients' attitudes towards psychological services. *Psychology, Health & Medicine*, **2**, 135-147.

Rait, D. & Lederberg, M. (1989). The family of the cancer patient. In J.C. Holland and J.H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer (pp585-597)*. New York: Oxford University Press

Redd, W.H. (1989). Management of anticipatory nausea and vomiting. In J.C. Holland and J.H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer (pp369-382)*. New York: Oxford University Press

Rhodes, G.L., & Lakey, B. (1999). Social support and psychological disorder: Insights from social psychology. In R.M. Kowalski & M.R. Leary (Eds.), *The social psychology of emotional and behavioural problems: Interfaces of social and clinical psychology (pp281-309).* Washington DC: APA.

Rowland, J.H. (1989a). Interpersonal resources: coping. In J.C. Holland and J.H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer (pp44-57).* New York: Oxford University Press

Rowland, J.H. (1989b). Developmental stage and adaptation: adult model. In J.C. Holland and J.H. Rowland (Eds.), *Handbook of psychooncology: psychological care of the patient with cancer (pp25-43).* New York: Oxford University Press

Saegrov, S., & Halding, A.G. (2004). What is it like living with the diagnosis of cancer? *European Journal of Cancer Care,* **13,** 145-153.

Schover, L.R., Fife, M., & Gershenson, D.M. (1989). Sexual dysfunction and treatment for early stage cervical cancer. *Cancer,* **63,** 204-212.

Sewell, H.H., & Edwards, D.W. (1980). Pelvic genital cancer: Body image and sexuality. In J.M. Vaeth, R.G. Blomberg, & Adler (Eds.), *Front Radiat Ther Oncol.* Basel: Karger cited in Corney, R.H., Everett, H., Howells, A., & Crowther, M.E. (1992). Psychosocial adjustment following major gynaecological surgery for carcinoma of the cervix and vulva. *Journal of Psychosomatic Research,* **36,** 561-568.

Spiegel, D., Bloom, J., Kraemer, H., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *The Lancet,* **2,** 888-891.

Steginga, S.K., & Dunn, J. (1997). Women's experiences following treatment for gynaecologic cancer. *Oncology Nursing Forum,* **24,** 1403-1406.

Stewart, D.E., Wong, F., Duff, S., Melanchon, C.H., & Cheung, A.M. (2001). "What doesn't kill you makes you stronger": An ovarian cancer survivor survey. *Gynecological Oncology,* **83,** 537-542.

Teusch, L., Scherbaum, N., Bohme, H., Bender, S., Eschmann-Mehl, G., & Gastpar, M. (1995). Different patterns of sexual dysfunctions associated with psychiatric disorders and psychopharmacological treatment: Results of an investigation by semi-structured interview of schizophrenic and neurotic patients and methadone-substituted opiate addicts. *Pharmacopsychiatry,* **28,** 84-92.

Thompson, D.S., & Shear, M.K. (1998). Psychiatric disorders and gynecological oncology: A review of the literature. *General Hospital Psychiatry,* **20,** 241-247.

Trijsburg, R.W., van Knippenberg, F.C., Rijpma, S.E. (1992). Effects of psychological treatment on cancer patients: a critical review. *Psychosomatic Medicine,* **54,** 489-517.

Van de Wiel, H.B., Weijmar-Schultz, W.C., Hallensleben, A., & Thurkow, F.G. (1990). Sexual functioning of women treated for cancer of the vulva. *Sexual and Marital Therapy*, **5**, 73-82.

Wells, M.E., McQuellon, R.P., Hinkle, J.S., & Cruz, J.M. (1995). Reducing anxiety in newly diagnosed cancer patients: A pilot program. *Cancer Practice*, **3**, 100-104.

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**, 142-153.

Wilson, K., & Luker, K.A. (2006). At home in hospital? Interaction and stigma in people affected by cancer. *Social Science & Medicine*, **62**, 1616-1627.

Wortman, C.B., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer: A theoretical analysis. *Journal of Social Issues*, **35**, 120-155.

Zabora, J., Brintzenhofeszoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-oncology*, **10**, 19-28.

Part 2: Empirical Paper

Peer support for women with gynaecological cancer

ABSTRACT

Women with gynaecological cancer report high levels of emotional distress, but few psychosocial interventions have been evaluated with this patient group. This study used a qualitative, multiple case approach to examine women's experiences of a new, telephone peer support service. Gynaecological cancer patients were matched with 'peer helpers' (former patients), who provided support over a three-month period. Participants were six patients and five peer helpers (one peer helper supported two women). Semi-structured interviews were conducted with the patients before and after they received support, and with the peer helpers at the end of the support period. The transcripts were analysed using interpretative phenomenological analysis. This led to the identification of twelve themes organised into four domains: 'Processes of support', 'Issues in providing support', 'Impact on patients', and 'Impact on peer helpers'. Overall, both patients and peer helpers described their experience of peer support positively. Interestingly, not only those receiving support, but also those providing support found the experience to be therapeutic, with both parties reportedly benefiting from the opportunity to reflect on their experiences.

Key words: gynaecological cancer, peer support, informal helping, qualitative, interpretative phenomenological analysis (IPA).

INTRODUCTION

Gynaecological cancers are the second most common form of malignancies found in women (Andersen, 1984). The diagnosis and treatment of gynaecological cancer can be enormously stressful: the diagnosis may raise concerns about one's own mortality and the current state of one's life (Weisman & Worden, 1976) and treatment can be very unpleasant. Understandably, it can have a wide range of psychological sequelae, including anxiety and depression (e.g. Cull, et al., 1993), intrusive thoughts and avoidance (Palmer, Tucker, Warren & Adams, 1993), poor body image (Andersen & Jochimsem, 1985), sexual dysfunction (e.g., Crowther, Corney, & Shepherd, 1994) and deterioration in marital relationships (Sewell & Edwards, 1980). In some women these difficulties may last for a considerable length of time (Corney, Everett, Howells & Crowther, 1992).

An extensive body of literature suggests that social support promotes well-being and protects people from the negative effects of stressful life events, such as cancer (Cohen, 2004). In their review, Helgeson and Cohen (1996) found social support to be an important predictor of adjustment to cancer, with emotional support being the most desired and having the greatest impact. Conversely, the absence of social support has been found to have an adverse impact on adjustment to cancer. For example, in a study of women with ovarian cancer poor perceived social support was one of the principal factors in predicting symptoms of anxiety three months post-chemotherapy (Hipkins et al., 2004). However, whilst correlational and descriptive studies have strongly indicated the connection between social support and adjustment

to cancer, the few intervention studies, many of which have been methodologically

flawed, have shown less convincing evidence (Helgeson & Cohen, 1996).

Whilst family and friends may be able to provide sufficient support for general

stressors, it has been found that they may sometimes behave in unhelpful ways when

the stressor is a diagnosis of cancer because of their lack of experience of the illness,

their desire not to upset the person, or their difficulties managing their own distress

(Bolger, Foster, Vinokur, & Ng, 1996). For example, they may minimize the

problem, force cheerfulness or avoid the person (Helgeson & Cohen, 1996). All these

behaviours prevent the person from discussing their experience and gaining

emotional support. For these reasons peer support has become particularly important

in this context. Peers, that is those who have suffered from a similar problem, can

offer the unique contribution of "experiential knowledge" (Borkman, 1990). Unlike

existing social support networks, peers can understand the individual's experience,

provide empathy and validation for negative feelings, and, through acting as a role

model, can provide reassurance of the possibility that they too could recover

(Helgeson & Cohen, 1996). In their review of the research literature examining peer

support in the context of cancer, Dunn, Steginga, Rosoman & Millichap (2003) noted

that peer support can also reduce social isolation and stigma, and normalise

experiences.

A number of mechanisms have been proposed to explain how peer support can be

helpful. Through providing emotional support, allowing the expression of negative

feelings and presenting the opportunity for social comparison (Helgeson & Gottlieb,

2000), peers can enhance self-esteem, restore perceived control, instil optimism for

the future, provide meaning for the experience and foster emotional processing (Helgeson & Cohen, 1996).

Peer support interventions have increased in popularity in recent years and have taken many forms, including self-help groups, electronic support groups and buddy networks. In a review of peer support for cancer patients, Campbell, Phaneuf and Deane (2004), identified a number of benefits of attending peer support programmes. In particular, commonality of experience was found to lead to bonding, increased openness and self-disclosure. By having an alternative forum to gain support participants also reported that they were less dependent on their families to meet their emotional support needs. These findings were echoed by Ussher, Kirsten, Butow and Sandoval (2006), who interviewed members of nine different cancer peer support groups. Participants described how the groups provided a unique sense of community, unconditional acceptance, information and empowerment.

Most of the literature evaluating psychosocial interventions for cancer patients has focused on breast cancer sufferers. While there are similarities in experience across cancer sites, women with gynaecological cancer face some particular difficulties. As was mentioned earlier, women with gynaecological cancer have to manage challenges to their sexuality, body image and ability to have sexual relationships and reproduce. Only a small number of studies have evaluated the effectiveness of psychosocial interventions for women with gynaecological cancer. However, they have employed a variety of intervention formats; individual psychotherapy (Chan et al., 2005), crisis intervention counselling (Capone, Good, Westie & Jacobson, 1980), individual and group thematic counselling (Cain, Kohorn, Quinlan, Latimer &

Schwartz, 1986), educational support groups (Carlsson & Strang, 1998), and brief

peer support (Houts, Whitney, Mortel & Bartholomew, 1986). The results of these

studies have been mixed, and the often small sample sizes, varying designs, outcome

measures and length of follow-ups all preclude the ability to reach conclusions.

In the context of this current research, the Houts et al. (1986) study is of particular

interest. Women newly diagnosed with gynaecological cancer were paired with

former cancer patients, who provided telephone support on three occasions. It is

unclear, however, whether the former cancer patient had suffered from a

gynaecological cancer. The conversations were strategy-focused with the women

being encouraged to maintain normal routines and relationships, make positive plans

for the future, and ask questions of staff. The peer helpers also provided the

opportunity for the women to share their feelings and concerns. The researchers

found no difference in terms of psychological distress between those who were

provided with this support and those who were not. However, the lack of findings

may be due to the brevity of the intervention.

Helgeson and Cohen (1996), in their review of the social support and cancer

literature, commented on the paucity of research into the effectiveness of peer dyad

interventions. Given that poor perceived emotional support among women with

gynaecological cancer has been associated with increased psychological difficulties

(Hipkins et al., 2004), there is a need to develop adjunctive sources of support.

Previous research suggests that women with gynaecological cancer value the

opportunity to speak to other women who have gone through the same experience,

but that a group format may not be practical or desirable for all patients (Pistrang &

Winchurst, 1997). There is therefore a need to evaluate further the effectiveness of one-to-one peer support with this patient group.

The present study investigated the experiences of women participating in a new telephone peer support service for women with gynaecological cancer. It aimed to examine, through in depth interviews, the perceptions of peer support from the perspectives of those giving and those receiving it. Because little is known about the processes or impact of peer support, a multiple case study design using a qualitative approach was chosen. Qualitative methodology is particularly suited to the early exploration of an area of research as it allows participants the opportunity to provide unexpected or novel responses (Smith & Osborn, 2003). Interpretative Phenomenological Analysis (IPA- Smith & Osborn, 2003) was selected as the approach to conducting the interviews and analysing the data because it is particularly suited to exploring individual experiences. The focus was on identifying both commonalities across participants' accounts as well as unique experiences.

The main research questions were:

1. How do women with gynaecological cancer experience receiving peer support? In what ways to do they perceive it to be helpful or not helpful?

2. How do peer helpers experience providing peer support? What approaches do they use to support women and what challenges do they face?

A secondary aim of the study was to investigate whether any changes pre- and post-support could be captured by standard quantitative measures of psychosocial functioning.

METHOD

Ethical Approval

The study was granted ethical approval by the Local Research Ethics Committee (see

Appendix A). All participants were provided with information sheets about the study

(see Appendix B), before then giving written consent (see Appendix C).

The Peer Support Service

Aims and structure

The telephone peer support service was set up and run through the Gynaecological

Oncology Department of a London cancer centre. Women, who had previously been

treated for gynaecological cancer (referred to as 'peer helpers') provided telephone

support to women who were currently receiving, or had recently completed, treatment

(referred to as 'patients'). The aims of the service were to provide patients with the

opportunity to freely discuss their worries and concerns, reduce distress and feelings of

isolation, and help them feel more able to cope. Patients were matched with peer helpers

as much as possible on the basis of cancer site, treatment and other factors such as age

and life circumstances. The recommended structure was that the peer helpers would

telephone the patients once a week for approximately three months. However, this was

flexible to allow the support provided to be responsive to the needs of the patients, and

so was negotiated by each pair. The women were free to continue contact after the

evaluation period had ended.

Selection and training of peer helpers

Prior to the start of the research, nine women were selected and trained as peer helpers. They were selected by the Consultant Clinical Psychologist and the senior Clinical Nurse Specialist working in the Gynaecological Oncology Department. Women were selected on the basis of several criteria: they had been out of treatment for at least one year and were judged to have good interpersonal skills and to have adjusted well (both physically and emotionally) to their cancer experience. All nine peer helpers attended an orientation session run by two members (Clinical Psychologists) of the project team. The session focused on discussion of effective support strategies, such as empathic listening and providing basic information, as well as strategies to avoid, such as giving advice and overuse of self-disclosure. Following the orientation session, all women consented to being involved in the project as peer helpers.

The peer helpers were provided with monthly telephone supervision from project staff. The supervision sessions allowed the peer helpers the opportunity to raise any concerns they had about the physical or mental health of the women they were supporting, and any difficulties they were experiencing in the relationship with the patient. During supervision the peer helpers were also provided with support to help them to manage the issues that emerged for them in the process of carrying out their role.

Participants

The participants were six patients and five peer helpers, comprising six patient-peer helper pairs (one peer helper provided support to two patients).

Patients

Women attending the Gynaecological Oncology clinic (i.e., who were currently

receiving treatment or being followed up after treatment) were invited into the project by

the Clinical Nurse Specialist or Consultant Clinical Psychologist. They were selected on

the basis of perceived need for support and whether there was a suitable peer helper

available to match them with. Eleven women were invited to participate. Four decided

not to be involved as they were currently receiving treatment and felt that the timing was

not right. Of the seven women who were interested in participating, one later declined

because she wished to be matched with a peer helper who had received exactly the same

treatment, which turned out not to be possible. Six women consented to receiving the

peer support service.

The mean age of the six patients was 55 years (range: 33-66). Five described their

ethnicity as White British, and one as Asian. Three women had no further education

beyond secondary school and three had achieved degree level qualifications. Two

patients were single, two were married or living with a partner and two were separated

or divorced. Three of the women had cervical cancer, two had ovarian cancer and one

had endometrial cancer. Four of the women had completed their treatment for cancer,

while two were still currently receiving treatment when they started receiving peer

support. None of the patients had attended a cancer support group, but four had seen a

professional therapist on a regular basis. Further details about each of the individual

women who participated are not provided, in order to protect confidentiality.

Peer helpers

Five peer helpers participated (as mentioned above, one peer helper provided support to two patients). Their mean age was 47 years (range: 33-55). Four described themselves as White British, and one as White Other. Three of the peer helpers did not have qualifications beyond secondary school, while two had degree level qualifications. Four peer helpers were married or living with a partner, and one was separated or divorced. Three of the peer helpers had had ovarian cancer and two had cervical cancer. The peer helpers had been out of treatment on average 4 years (range 3-5years). Three had attended cancer support groups and one had seen a professional therapist. None of the peer helpers had previously trained or worked as a counsellor. Again, details about individual peer helpers are not provided in order to protect confidentiality.

Amount of contact of patient-peer helper pairs

The patient-peer helper pairs varied in the frequency of their contacts. However, most spoke once weekly or once fortnightly. One patient felt that she did not need such frequent contact, and spoke with her peer helper on just two occasions during the three month research period. Calls varied in their length from 15minutes to 80minutes. Table 1 presents a summary of each pair's contact.

Table 1. Frequency and length of patient-peer helper contacts

Description of each pair's contact over the three month research period		
Pair	Number of contacts	Average length of calls (minutes
1	7	60
2	10	70
3	10	30
4	2	70
5	5	45
6	6	40

The Researcher

In a study I worked on previously in the field of women's health, I recruited participants through support groups. The women from these groups described how highly they valued the opportunity to speak to others in a similar position. With this experience in mind, I entered into this research believing that women with gynaecological cancer may benefit from this also.

As a trainee on placement within the medical department in which the research was based, I was involved in the setting up and running of the peer support service in addition to evaluating it. I was aware of the department's strong reputation for its involvement in medical trials and hoped to show the value of psychosocial interventions. For these reasons I was conscious that I might have a tendency to skew the data positively, and so was mindful to take an actively neutral stance, from which I was open to accepting both positive and negative responses.

My clinical work in the department also led me to hear the accounts of women with gynaecological cancer who were not involved in the research. In analysing the data I was aware of the possibility of being influenced by these other women's experiences, and so tried to make sure that the analysis was based solely on the transcripts of the interviews with women participating in the research.

Semi-structured Interviews

The semi-structured interview schedules for both the patient and peer helper interviews were developed based on the existing literature and the research questions to be addressed. While each interview had a broad focus of areas to be explored, the questioning did not strictly follow the schedules; rather an "open-ended conversational style" was adopted as recommended by Pidgeon (1996). This allowed interesting avenues of discussion to be followed up and helped to establish rapport. Prompts, reflections and summaries were all used to facilitate the process of exploring the experiences of the women.

All interviews, apart from one, took place in the university department, which is separate from the hospital the women were recruited from. One interview was conducted in the patient's home. The interviews were conducted either by just the researcher or jointly with a member of the project staff. The interviews lasted an average of one hour and, with the women's consent, were all audiotaped and transcribed verbatim.

Patients

The patients were interviewed on two occasions, once prior to receiving support and the second at the end of the three-month period of speaking with the peer helper. The focus of the initial interview was on their experience of gynaecological cancer and its treatment, their current levels and perceived adequacy of received support, their support needs and their expectations of the peer support intervention. They were also asked how they would know if they had benefited from receiving support, a question based on systemic ideas.

The follow-up interview enquired into the patient's experience of the peer support service, particularly in what ways they found it to be helpful or not, how they thought the peer helper tried to support them, the impact of this, and their perceptions of the processes through which any benefits came about. The women were also asked if the hopes and expectations they raised at the initial interview had been met. In addition, as previous research has indicated that receiving support from a peer helper may enable individuals to increase their access to support from within their natural support networks (Rudy et al., 2001), the women were asked whether they felt more able to talk about their concerns with others following their experience of peer support.

Peer Helpers

The peer helpers were interviewed at the end of the intervention period about their experience of being a peer helper. Questions focused on the strategies they employed to support the patients, how they thought the patients may have benefited, the challenges

and dilemmas they faced in providing support, their perception of the process of

providing support, and the personal impact of their involvement.

The interview schedules for the patient and peer helper interviews can be found in

Appendix D.

Quantitative measures

The opportunity was taken to pilot a number of standardised measures that had

previously been used in the psychosocial intervention literature for their applicability

and sensitivity in evaluating the effectiveness of peer support. The measures were

completed by the patients at the initial and follow-up interviews. The 'Perception of peer

support' questionnaire was only completed at follow-up interview. The measures can all

be found in Appendix E.

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) was selected as a measure of anxiety and

depression as it is designed and standardised for medically ill patients, and has been

widely used with cancer patients (Herrman, 1997). It is a well-established scale with

good reliability (Zigmond & Snaith, 1983). The 14-item questionnaire omits somatic

symptoms of anxiety and depression as they may overlap with symptoms of illness.

Separate total scores are calculated for anxiety and depression and range from 0-21, with

scores over 8 on either subscale indicating clinical caseness.

Impact of Events Scale (IES)

A version of the 7-item intrusion subscale of the IES (Horowitz, Wilner & Alvarez,

1979; Zilberg, Weiss & Horowitz, 1982) modified for cancer patients by Cordova et al.

(1995) was used to assess intrusive traumatic thoughts about cancer. The responses to

the items on the 5-point Likert scale are totalled, resulting in scores ranging from 0-35.

High scores indicate higher levels of intrusive traumatic thoughts.

Distress Thermometer

The Distress Thermometer forms part of the National Comprehensive Cancer Netork

Distress Management Measure (Holland, 1999) and was specifically designed for use

with cancer patients. A visual analogue scale, the Distress Thermometer is designed to

be a simple tool to identify levels of distress from 0-10; 'No Distress' to 'Extreme

Distress'. The individual simply circles the number equivalent to their current level of

distress on the thermometer. A score of four or higher indicates possible distress with a

recommendation for referral to appropriate resources. The reliability of this measure is

yet to have been established in this country.

Perception of peer support questionnaire

This questionnaire was adapted from one designed by Dennis (2002) to evaluate the

effectiveness of a breastfeeding peer support intervention. The 10-item questionnaire

asks about perceptions of the peer helper's provision of emotional, informational and

appraisal based supportive behaviours. An example of an item designed to assess

perceived emotional support is "My peer helper listened to what I had to say". For each

item, respondents indicate their level of agreement on a 5-point Likert scale. The

responses to each item were totalled and then divided by 10 to establish an average

score, with 5 indicating the highest level of perceived support and zero the lowest level.

Telephone contact logs

Peer helpers were asked to keep a log of their contacts with participants, noting down

when they spoke to the women, the call duration and the topics discussed.

Qualitative data analysis

The interview transcripts were analysed using Interpretative Phenomenological Analysis

(Smith & Osborn, 2003). This method was chosen as it is designed to explore in depth

how individuals make sense of experiences and the meaning they attribute to them. The

approach is idiographic, with themes evolving into categories of increasing abstraction.

Recognition is given to the influence of the researcher in the dynamic process of

analysis (Smith, Jarman & Osborn, 1999).

The analysis followed the steps as set out by Smith and Osborn (2003). Transcripts were

first checked for accuracy and any identifying information was removed to preserve

anonymity. They were then read repeatedly before being annotated with summaries,

themes, ideas and associations in the left-hand margin. After this was completed, more

abstract conceptualisations of the data were noted in the right-hand margin (see

Appendix F). Coversheets were then created for each transcript, consisting of the main

themes illustrated with quotes (see Appendix G).

The initial (pre-support) interviews provided important information about the context within which the peer support was received. However, as the research questions focused on the patients' and peer helpers' experiences of providing and receiving support, attention was placed on the themes derived from the follow-up interviews from this point of the analysis onwards. By comparing and contrasting themes generated from one transcript with those of other transcripts, higher level categories were developed that subsumed the earlier themes (see Appendix H). Through this cyclical, inductive process categories were integrated to form four domains, comprising twelve themes.

To verify the credibility of the analysis as a true reflection of the data, good practice guidelines for qualitative research were followed (Elliott, Fischer, & Rennie, 1999). These included verifying that each theme was grounded in the data, and situating the perspective of the researcher. In addition, a consensus approach was adopted (Barker & Pistrang, 2005). This involved a second researcher reading all the interview transcripts, before extensively debating with the first researcher the best way of representing the data, until a consensus was reached. This process helped to ascertain that a coherent narrative ran from the raw data to the final themes.

Quantitative data

Due to the small sample size, the quantitative data were used for descriptive purposes only.

RESULTS

The results are presented in two parts. The first, substantive, section reports the

results of the qualitative analysis of the interviews with the patients and peer helpers.

The second, briefer, section presents the quantitative, descriptive data on the pre- and

post-intervention measures.

For clarity, the participants who provided support will be referred to exclusively as

'peer helpers'; participants who received support will be referred to interchangeably

as 'women' or as 'patients'. The source of each quotation is indicated by 'P' or 'PH',

standing for patient or peer helper, followed by the participant's number. The

pairings are indicated by the participant's number, such that patient 1 (P1) was

matched with peer helper 1 (PH1), and so on.

Qualitative findings

Overall, there was considerable consistency across the accounts of both the patients

and the peer helpers, with most perceiving their involvement positively. They

detailed in their accounts the processes, challenges and impact of providing and

receiving support.

The interpretative phenomenological analysis led to the identification of twelve

themes grouped into four domains (see Table 2). The first domain, processes of

support, is composed from the perspectives of both patients and peer helpers. The

remaining domains, issues in providing support, impact on patients and impact on

peer helpers are based on the accounts of either the peer helpers or the women

receiving support.

Table 2. Domains and themes

Domain	Theme
1.Processes of support	1.1 Talking openly
	1.2 Understanding
	1.3 Information and advice
	1.4 Laughing together
	1.5 'It's a two-way thing'
2. Issues in providing support	2.1 'Have I said the right thing?'
	2.2 Involvement vs detachment
3. Impact on patients	3.1 'I'm not the only one'
	3.2 Feeling cared for
	3.3 Moving on
4. Impact on peer helpers	4.1 'Knowing that my very bad experience has benefited somebody else'
	4.2 'Reflecting on my own cancer experience'

Domain 1: Processes of support

There was high convergence between what the peer helpers reported they tried to do in their efforts to be supportive and what the patients found to be helpful from the interactions. From the peer helpers' perspective, the focus was on providing an environment in which the patients felt safe to talk openly about their experiences, as they recognised from their own experiences that this might not be available within their social network. Empathy rooted in shared experiences and understanding seemed to facilitate this process. The informal nature of the interactions promoted the development of friendships and also allowed the opportunity to laugh about their experiences.

Theme 1.1: Talking openly

One of the key aspects of peer support, highlighted by both the patients and the peer helpers, was that the women could talk openly about their experiences of cancer and their concerns. This was particularly valued when it contrasted with their interactions with friends and family members.

> *"Because unlike my family my friends, and so on, she is the only person I talk [to] very openly" (P2)*

The women spoke of their difficulty talking to family and friends about distressing aspects of their cancer experience, particularly their fears of dying. This was partly due to the reluctance of people in their support networks to engage in such conversations, often not wishing even to contemplate the possibility of death. In addition, the women already felt responsible for causing upset to those closest to them, and so wanted to protect them from further distress. This inability to talk about difficult issues increased feelings of isolation.

"Well if I say to [partner]...I sort of bring the subject up. He will just say 'you're going to be fine, you're going to absolutely, you're going to be alright, you know, don't talk like that, it's not going to happen', and won't entertain it at all." (P3)

" .... You as a patient are protecting them from being upset about your cancer. It's such a complex set of issues. You don't want to make them sad." (P1)

While women discussed how gynaecological cancers had a less 'wholesome' image than other cancers, those women with cervical cancer were particularly aware of the stigma associated with it. As the development of cervical cancer is often linked with a sexually transmitted infection, the women were conscious of societal labels attaching this diagnosis with promiscuity. These women felt a particular need to speak to others in a similar situation.

"...they're the Cinderella cancers that we don't talk about at the dinner table." (P1)

"...they [news broadcasts] also start talking about teenage promiscuity, and talk about cervical cancer in terms of promiscuity. And people have actually not said it to my face but have said it to friends of mine who have said that they have a friend with cervical cancer 'oh was she promiscuous?'" (P6)

In this context the women greatly valued the opportunity to talk openly to their peer helpers. They spoke of how their peer helpers assumed an accepting and non-judgemental stance and were prepared to listen to anything they wished to share, and because of this they were able to talk about their greatest fears.

"I mean neither of us know what our life expectancy's going to be. We can talk about, other people don't want to talk about that, 'oh don't talk'. You know your family and your friends don't want you to talk that way. But you have to." (P1)

"...the fact she accepted it and she was, she didn't show any shock, judgement, nothing... you can say whatever's on your mind without her being shocked... I

*find being able to talk completely frankly and open has helped me probably
more than anything. " (P5)*

One woman, however, described her inhibitions to disclosing to her peer helper,

particularly her feelings of depression. She was concerned about burdening 'another

person who's had cancer', and felt the need to protect the peer helper in the same

way she did with others. She contrasted this to her experience with professional

therapists, whom she did not have to be concerned about upsetting or burdening. In

the absence of being able to talk openly, this woman felt that she had gained less

from the experience of talking to a peer helper.

> *"But emotionally I didn't feel like I could express myself. But maybe I think I
> might just be like that anyway and only feel like I can do that when I'm in a
> professional situation (laughs). Where I feel like, it's partly to do with not
> wanting to take up space, or feeling like I'm not important or worrying about
> the other person too much. "(P6)*

Like the patients, the peer helpers also described how talking openly was a

fundamental part of the support process. They reported having experienced similar

difficulties in talking openly with those around them, and so recognised the

importance of providing a space where the women could feel comfortable to talk and

could feel heard. They recognised that listening was key to helping the women feel

able to talk openly and, showed their willingness to listen by taking an interest and

asking questions.

> *"Well listen I think's important, because I think people just being able to talk to
> somebody who's been through it is beneficial. So I try and listen as much as I
> can... " (PH5)*

> *"... Well by letting her talk I suppose and by responding to that. And by asking
> questions if I thought there was a question there to be asked...if she touched on
> something then to ask another question along the same line not just kind of
> 'hmm hmm'. You know if I sensed that we were on the edge of something there*

I would probably you know ask something else that kept the interest in that topic. " (PH4)

One peer helper made explicit at the start the expectation that she and the woman she was supporting be open and honest with each other, something that was greatly appreciated by the patient.

> *"I don't know whether it helped by my first call, I, I told her to be very, be as open with me as she possibly felt as if she wanted to be. " (PH2)*

> *"What she said to me was 'let us be totally honest'", so it was, we kind of laid our cards on the table so to speak and how. Her expectations were total honesty, openness and so on. So they were expectations that I really appreciated, and there was no way it could go wrong...I think it was her, the way she approached it, the way she made me feel at ease saying 'lets be very honest, lets be very open.' (P2)*

Theme 1.2: Understanding

Hand in hand with being able to talk openly, was the women's sense that the peer helpers had a real understanding of what they had gone through. They described how this level of understanding was only possible from another "cancer club" member.

> *"...the only people who really understand now are the people who have had a diagnosis of cancer. If you've never had one you will never really understand, because it's indescribable. All your worst things that could possibly happen, that's it. " (P1)*

> *"Well she understands everything, obviously...because she's been through it...Because that person can just really understand. That's the important thing. You know, more than anybody really" (P3)*

Patients described two main ways by which the peer helpers showed their understanding. Firstly, their responses were empathic rather than sympathetic. The women described how support from others sometimes left them feeling pitied. This contrasted with the support from the peer helpers which, in coming from shared experience, was on a more equal level.

"I know that the oohs and aahhs that she is making is because she is in the same situation, not somebody that's trying to give me sympathy." (P4)

Secondly, the peer helpers asked questions, which in themselves were identifiers of understanding. The peer helpers' awareness of the different situations the women might be facing led them to be able to develop discussions by asking relevant questions. The women were surprised by the peer helpers' insight, seeming to know which question to ask next. The peer helpers' accounts also indicated that the asking of questions was one way of showing their interest in the patient and her experiences.

"You do get that sense well she know what I'm talking about because she asks the questions" (P5)

"I'm actually interested in her and her experiences, so hopefully asking questions that show that I was interested, but without being invasive I guess." (PH4)

In addition to being able to understand the women's experiences, the peer helpers were sometimes also able to provide the women with an alternative perspective, giving them another way of making sense of their experience. For example, one peer helper offered an alternative explanation for her patient's son's misbehaviour, suggesting that rather than him choosing to play up at the most inopportune time, that it might be his way of coping with his mother's illness. This was based on her experience of her own children's differing responses to her cancer diagnosis.

"I think it's maybe making her look at things sometimes in a different way." (PH2)

"She'll just sort of give you her personal scenario of, you know, when that might have happened or "oh yes", you know. She just sort of gives you another side to it, so that's quite nice." (P4)

70

Theme 1.3: Information and advice

The peer helpers reported how principally they listened to the concerns of the

women, only giving advice and information sparingly, and when it was asked for.

They were very conscious of not imposing their ideas, but instead offering them as

suggestions. From the patient's perspective the advice that was provided was more

meaningful than that offered from other sources because it was based on shared

experience and understanding. The women found the peer helpers to be a valuable

source of information, particularly in managing side effects of treatment and the

process of recovery. They felt that the peer helpers managed to strike the right

balance between listening, providing advice and sharing their experience.

> *"She got the right amount of sympathy, the right amount of practical, you know, the right amount of anecdotal evidence."* (P5)

> *"... she's done it so she's giving me some advice because she's done something similar so, it's not like 'have you tried it, I haven't, but you know' and so on...so it was from her own experiences or knowledge, so it was. It's much better when it comes that way"* (P2)

As the women felt comfortable raising personal concerns with their peer helpers,

they sometimes broached subjects that they felt uncomfortable discussing with their

medical team. When medical concerns were raised by patients, the peer helpers were

very conscious of not straying into the realms of medical expertise and encouraged

the women to seek professional assistance.

> *"When you come up to see the consultant, you're just like 'Oh yeh I'm fine'...and then you go home and you're like oh I should have said about this and I should have said about that. Whereas when you're just generally chatting on the phone you sort of can, you're able to ask questions that you don't, that usually you feel quite put on the spot about."* (P4)

> *"Because a couple of times I've said 'oh have you asked your team about that', because she's been worried about the bleeding, I said 'have you spoken with them about that' and she said 'yes I'll ask it, I'll ask them next time'..."* (PH5)

Theme 1.4: Laughing together

Laughter was frequently mentioned as a feature of the conversations, with humour serving a number of functions and seeming to be an important part of the process of helping. It not only lightened the tone of the conversations, and promoted bonding, but also seemed to provide a safe way to talk about the more serious, upsetting topics. Peer helpers and patients described how they had laughed about aspects such as losing their hair or being violently sick following chemotherapy.

> "We'd have a good laugh, even if it was a serious topic, we could still laugh about it." (P1)

Some women also mentioned the use of 'black' or 'gallows' humour in their conversations. This particular form of humour, which was focused on death, was said to result from their having faced their own mortality and the realisation of how easy it is to die. This type of humour was described as being something that could only be shared with other cancer patients, as others could not understand or find it funny. The use of humour was also seen as a way of processing and accepting difficult experiences. The women saw it as a very human way of making sense of what they had been through and neutralising the horror of it.

> "Yeh the gallows humour comes into it quite a lot. But it only works if you're a fellow cancer patient I think, so you're laughing at your own situation. Death, is tits up time, things like that...and it's part of being a human, being human, and we've all gone through very dehumanising processes, so it's part of bringing back a sense of self, normalising things. I don't think it's anything to do with, what's that phrase when you're not acknowledging something, not avoiding it, denial. You know it's not denial, it's the acceptance of it and working with it and moving on. And also a great way of handling some very, very horrible situations." (PH1)

One peer helper explained how she strongly believed in the role of humour in maintaining a spirit of survival. She described how she saw the alternative to

72

laughing about the experience to be sitting down and crying, and those that she knew of who did the latter had died.

Theme 1.5: 'It's a two way thing'

For most of the patient-peer helper pairs, reciprocity was an important part of their relationship. While conversations initially focused on the patients' illness and treatment concerns, they soon became two-way dialogues in which both patients and peer helpers shared their cancer experiences. This mutual sharing was seen by both parties as fundamental to the process of helping, and provided a sense of equality that was absent in relationships with professionals.

"In the beginning I noticed that it was mainly me listening and she was sort of unburdening herself, and her worries and things like that, and then as the relationship progressed, its more like a two-way dialogue now." (PH3)

"We are both sharing experiences, it isn't just me, so that helps...It's not like if I go and see a counsellor or someone. They are very focused, and we don't know anything about them and you do feel that doctor-patient relationships (indicating in her gestures that doctors are at a higher level), you know. In her case it isn't that at all, it's more on equal basis." (P2)

Although the women initially bonded over their common experiences, the conversations quickly extended beyond cancer into wider aspects of their lives, their interests, families, careers, and so on, and the relationships developed into friendships. When the issue of endings was raised at the follow-up interview, some of the peer helpers and participants felt that they had made a lasting friend and could not conceive of losing touch with the person they had been paired with.

"We were sharing very personal things as well, it wasn't just the cancer...we do talk like we are best friends, close friends" (P2)

"We talk like old friends...our conversations have been like two good friends" (PH2)

While most of the women seemed to find that the reciprocity furthered their discussions, one patient felt constrained by this. She became concerned when she spoke that she was 'hogging' the conversation. This patient reported preferring the clarity of a one-way professional relationship as she did not want to share her supportive space.

> "...And also what is expected of you, are you an equal buddy, peer, are you sharing or are you being supported by someone. Because when you're in that low energy recovery thing I don't really think you've got that much energy to be sharing in a way." (P6)

The peer helpers were conscious of only sharing their experiences when prompted by the women, mindful not to dominate the conversation. However, one peer helper was so hesitant to talk about her experiences without being invited to, that this became an obstacle inhibiting her from being able to share the details of her cancer experience. The woman that she was paired with expressed her regret at not having enquired further into her experiences, but was concerned that her peer helper did not want to talk about her experiences.

> "So I don't know what her treatment or what cancer she [had]. She asks about me, and of course. Then you feel like you want to ask her about her but you don't really want to because maybe she doesn't want to talk about it" (P3)

> "So, if people ask me direct questions I'm really happy to respond and perhaps I could have given more of my own experiences. But I was just very aware that I, you know, maybe too aware that I didn't want to not burden, it was sort of for her rather than for me, and I've had plenty enough time to talk about it...But perhaps there is a line where I could say 'would it be useful to know about my experiences in that area?'" (PH3)

Domain 2: Issues in providing support

Although most of the peer helpers felt that providing support to another patient was a fairly "natural" process, they also described some ways in which it was challenging. The challenges fell broadly into two areas: (1) concerns about saying the right thing, and (2) managing the balance of, on the one hand, becoming involved with and feeling concerned for the patient, but, on the other hand, being able to detach following the phone calls, so that they were able to carry on with their daily lives.

Theme 2.1: 'Have I said the right thing?'

The peer helpers were very thoughtful about their contributions to the telephone conversations. They reported being conscious of trying to encourage the women they were paired with to talk about their experiences and feelings, whilst also being mindful not to seem intrusive. In trying to achieve this, they spoke of allowing the women to lead the conversations but then furthering discussions of issues raised by asking questions.

The main anxiety that seemed to be evoked in the peer helpers was the fear of saying "the wrong thing". For one peer helper this anxiety was appeased by completing and sending the 'telephone log' of the conversation to the researchers. She felt that in doing this she was able to pass on the worry, as she would be contacted if it was felt that she had acted inappropriately.

> "I'm very conscious of not saying anything that I shouldn't be really...I think writing it down to you helps, because I feel like I've offloaded it then. I've put down what I've said and then, if I don't receive a phone call saying 'what the heck have you said', then I know I'm ok." (PH5)

For another peer helper this sense of uncertainty was more pervasive, extending to role definition and boundaries. The perceived lack of clarity seemed to inhibit her from sharing her own experiences and asking more about the experiences of the woman she was supporting. This peer helper felt that her uncertainty would have been relieved if clearer guidelines had been in place.

> "I suppose it's just the uncertainty as to whether you're doing the right thing...I think I'd welcome more of a structure...So in conversation one you sort of set, without being prescriptive, but to give some sort of framework, so this is what you want to achieve by then...to help us if we've moved a bit off track."(PH4)

Theme 2.2: Involvement vs detachment

While the peer helpers were concerned about the wellbeing of the patients, they were also aware that they needed to keep a degree of emotional distance to protect themselves from becoming too involved. The use of the telephone seemed to help some peer helpers to strike the right balance between involvement and detachment. They described how it enabled them to feel less drawn into the women's difficulties than if they had met in person, and they felt safe in the knowledge that if they were to become distressed by the content of the discussion, the patients would not be able to see their reaction. Peer helpers also felt that the distance provided by the telephone made it easier to separate the peer support from the rest of their lives and also made the prospect of ending the support more manageable.

> "...although I can be emotional with her on the phone...it's not making me depressed...although I care about her and I'm concerned about her, I suppose because I haven't actually met her in body form." (PH2)

> "I'm probably quite glad it's on the phone really, because I think it's slightly less personal than when you're face to face with somebody... you're slightly removed aren't you on the phone... I think on the phone if somebody's upset you can still slightly remain distant from it." (PH5)

However, some peer helpers commented that there were drawbacks to providing

support via the telephone, as they were unable to infer from body language how the

patient was feeling or responding to the conversation. They did report, though, that

they could tell a lot from the tone of their voice. Two of the peer helpers described

how they might have preferred face-to-face contact, as they felt that this would have

facilitated the process of providing support by enabling them to develop a stronger

bond more quickly.

> *"Well when you're with someone you can see body language, can't you. But just on the phone you just sort of go by the tone of the voice. I mean there's no eye contact." (PH3)*

> *"Yes you'd have to make more effort to get to a place, but the rewards might have been greater because you can pin stuff down, you're in a sort of mutual environment." (PH4)*

The peer helpers also took certain steps to separate providing support from the rest of

their lives. This included taking the calls in a specific part of their home and at a time

when they would not be disturbed, and arranging to go and do something after the

call so that they would be distracted from thinking about the concerns of the woman

they were supporting.

> *"I would set aside a morning for it, so that I wasn't interrupted, I wasn't sidetracked by anything else... it was like having to close a book physically, just to leave it there, you know, instead of going into school and taking it into school with me." (PH1)*

> *"I always make sure there's not going to be anyone calling, you know I've got no appointments, so my phone call can go on. If there's other people in the, well there's only my husband, but if he happens to be home, I go to another extension away from him." (PH2)*

However, despite such efforts, one peer helper found herself worrying about the low

mood of the woman she was supporting for sometime after the call ended.

"I probably was worrying about her and it was staying on my mind a while afterwards." (PH5)

Domain 3: Impact on patients

For most patients, being able to speak to someone who had shared their experiences had a number of benefits. In discovering that they were not the only ones to have gone through distressing experiences, they felt less isolated and felt that their emotional and physical responses were validated. Some also felt a strong sense of being cared for by another person. Finally, for some, peer support helped in coping with the transition back into normal life.

Theme 3.1: 'I'm not the only one'

For the patients, the greatest impact seemed to come from knowing that they were not alone, that someone else had experienced something similar to them. For one woman, who knew of no one else in a similar position, this was particularly powerful, and she reported it as being the single most important element for her.

"It's not even, she doesn't even have to respond in some ways, it's just me knowing that she's in the same situation." (P4)

Being able to talk to someone who could understand what it was like to live with an uncertain future, or how difficult it was to live with the after effects of treatment, was said to "lighten the load" and be a source of comfort. This shared experience reduced the women's sense of isolation.

"It's a comfort. It's another cancer sufferer. Another one that's faced with an uncertain future." (P1)

"I mean when you talk to people, it helps, it lightens the load so much, it's amazing...it lightens it because then you, you know you're not the only person feeling that way or having horrible feelings."(P3)

Sharing their experiences also helped the women to understand that their emotional responses were normal reactions to the difficult circumstances they had faced. One woman described how having someone listen and share her own similar experiences validated her emotional reactions and physical problems in the aftermath of treatment.

"By her admitting to it and telling me that she has been through all the different symptoms, all the different treatments etc. gave validation to my pain... and so on that I went through." (P2)

The women spoke of the comfort of knowing that their peer helper was there for them, should they need it. One patient referred to this as her "safety mechanism", another spoke of how her relationship with her peer helper provided her with choices such that when she felt lonely, she could either "wallow in it" or she could choose to access the support that she trusted would help her.

"It's a calming thing. I know if I got in a big flap. It's kind of like a safety mechanism really. You know there's somebody there you can talk it over with. And somebody like [peer helper] would apply her rational, sort of, northern humour and good sense. So it's nice knowing that's there, and I could just pick up the phone whenever."(P1)

"I know I don't have to feel lonely anymore... When you know that you can very easily pick up the phone and ring this person. Then, you know, it is your choice, you either choose to sit and wallow in it and feel down, or you can ring this person who you know is going to be there for you...If I am down I have that choice, ring her, talk to her, clear my head or I can just wallow in it."(P2)

Theme 3.2: Feeling cared for

The women's reports were characterised by a powerful, implicit sense of feeling cared for by the peer helpers, which came from knowing that somebody was there for

them. The women described how the tone of the peer helpers' voice and the content of the discussion showed that the peer helpers cared about them and were concerned about their wellbeing. The care was also described as being holistic, with the women reporting feeling treated as a whole person rather than just a person with cancer. This contrasted with their experiences within the medical setting where they reported feeling like a number and, conscious of the time constraints, sometimes felt unable to talk to the staff.

"And she was talking to me about taking care of myself and so on, but it wasn't at all intrusive, it was very gentle... Because it all helps in my, you know, wellbeing, looking good, you know." (P2)

"I mean they've been kind the consultants and, but I've just felt like a number really." (P1)

For one woman, the project being set up through her hospital was symbolic of the hopsital caring about her. She had previously felt lost in the hospital system, and saw being offered the service as a powerful demonstration that her hospital cared for her as a person and was interested in her welfare. This patient had been thinking of switching hospitals, and reported that her decision to stay was influenced by this experience.

"I mean it's been set up by my hospital, or connections with my hospital. And set up to do something for the patients that could be a great benefit. And just that alone, regardless of how [peer helper] had been, is very nice. In fact I was on the verge of switching hospitals and I think this has been an element that's kept me here...And I think to me that's the biggest thing of all. That somebody's cared to do this, and it makes you think well at least there's an element of the hospital that's looking out for my welfare and my happiness. Because I don't feel that much." (P1)

The women also commented on the context in which the peer support was received, namely the lack of services available to make women with gynaecological cancer

feel cared for. They remarked upon the contrast with the facilities available for those

with breast cancer, such as centres where women can receive alternative therapies.

> *"And, you know, the kind of support for women with cervical cancer is not, you know, compared to breast cancer. There's a place a friend of mine with breast cancer went to called The Haven, which is all alternative health....Why isn't there something like that for cervical cancer?" (P6)*

Theme 3.3: Moving on

For those women who had completed treatment, speaking to the peer helpers seemed

to be an important aid in the process of 'moving on'. The opportunity to talk about

their experiences enabled them to understand and make sense of their experiences, so

that they were able to think more about the future. The women felt encouraged by the

peer helpers to recognise the talents that they had prior to the cancer and to take up

opportunities, such as courses, that would help them to readjust to normal life. The

peer helpers also provided a model of how it was possible to move on from the

cancer experience.

> *"...talking about it gets it off the top of your head, and then you can move on to something else." (P5)*

In addition, the peer helpers understood the difficulties of the task of moving on. The

women described how support from family and friends, which often had been

overwhelming during treatment, was withdrawn after treatment ended, and

expectations and pressure both from their social networks and from themselves grew

for their lives to return to normal. The women were surprised and frustrated to

discover that this was much harder than they thought it would be as they were still

dealing with the after-effects of treatment, particularly fatigue. In hearing from their

peer helpers that the process did take time and that it was normal to struggle with this transition, feelings of failure were reduced.

> *"And so like I kind of tend to give myself a bit of a bad time like 'there's nothing wrong with you now, like just get on with it, just go on do things' sort of thing, and then get really upset that I can't and feel really frustrated with myself as if I'm malingering. Malingering is the thing. And so having somebody who understood that how long it takes to get over having cancer and understanding that it's not, you're not malingering if months later you still feel too tired to do anything." (P6)*

One woman, whose prognosis was less positive, described how her peer helper's accepting attitude and perspective helped her to learn how to accept her situation. This, she explained, helped her to move on from a position of anger.

Domain 4: Impact on peer helpers

Most peer helpers reported how they too had benefited from the experience of supporting the women. They described how the process had given meaning to their own experience of cancer. Supporting someone for whom the cancer experience was more 'raw', reminded them of how far they themselves had come and how they should not take life for granted.

Theme 4.1: 'Knowing that my very bad experience has benefited somebody else'

Peer helpers described the benefits of knowing that they were contributing positively to another's life by making their difficult experience in someway easier, or helping the person to move on even if only by the slightest amount. In making something good come out of something bad, a sense of purpose also seemed to be given to their experience, with the cancer being seen as having provided them with an opportunity to help others.

"And so if this is a part even of getting her to somewhere else then you know fantastic." (PH4)

"I've walked away feeling really happy, that my very bad experience has benefited somebody else." (PH6)

"It helps me, you know, it makes sense of what I've been through. To survive something like that then to learn to put it to good use I suppose." (PH3)

Peer helpers also reported how it felt good to redress the balance in some way, having received support and medical care when they were unwell. They explained how they wanted to find a way to give back, and while they recognised the value of giving money to charity, they also saw the value of giving their time.

"I think because we all feel when we've experienced something like this that it's nice to be able to help in some way, because so many people have helped us I think that, you know, from the medical profession, that I think you feel it's nice to try and be able to put something back a little bit." (PH5)

Theme 4.2: 'Reflecting on my own cancer experience'

Some peer helpers also described finding the process of supporting the women therapeutic for themselves. In sharing with the patients, the peer helpers were forced to relive some of their experiences. However, this did not arouse negative emotions; rather, it encouraged the peer helpers to reflect on their experiences, particularly on how far they had come. In focusing on the women's difficulties in the present, they were able to put their own difficulties into perspective and into the past. For one peer helper who had not had the chance to speak to another woman in a similar situation, supporting the patient provided an opportunity to normalise her own experiences.

"I've found it quite therapeutic for myself, I know that." (PH3)

"It helps me to move forward, I think too. You know, you're not looking back on your own experiences, you're sort of looking on someone else's, and you're trying to help them move on. Because sometimes you find, well I find myself

*that you can dwell on it too much...Whereas now it's, it's further back in my
past. And this with [patient] and [hospice] has in fact taken precedence to what
I've been through. You know it sort of puts it in the background more, where it
should belong more."(PH3)*

*"You re-live things a little bit, things at the back of your mind come to the fore,
but it's not a bad thing, you realise you've moved forward."(PH5)*

The peer helpers reported how the experience of having faced their own mortality

had taught them not to take life for granted. However, as their lives began to return to

normal the strength of this sense had attenuated. In speaking with women for whom

the cancer experience was more current, they were reminded both of how lucky they

were to be in remission and also of the value of life.

*"As time goes on, as I said, you don't forget but life starts to get a habit
again...but I think then that you start to take life for granted, whereas talking to
somebody that's not as far down the line or, in her case, that the outcome's not
so great, it makes you sit back and reflect again."(PH2)*

Quantitative findings

Patients' scores on the quantitative pre- and post- measures, as well as their scores on

the 'Perception of Peer Support Questionnaire', which was administered post-

intervention, are presented in Table 3. Due to the small sample size and the lack of a

comparison group, comments can only be made on the trends in the data.

As can be seen, all but one of the patients showed a decrease in scores on the HADS

anxiety subscale. Four of the women reported lower scores on the depression

subscale, while two women's scores slightly increased post-intervention. On the IES

intrusion subscale, four of the women showed quite substantial drops in scores post-

intervention, while two women reported a slight increase. The Distress Thermometer

presented a more mixed picture with two women's scores remaining unchanged, two

women reporting less distress, and two women reporting slightly increased distress post-intervention. Finally, scores on the Perception of Peer Support Questionnaire indicate that all women apart from one were highly satisfied with the support they received.

In summary, there were reductions in scores across a number of domains post-intervention. However, in the absence of a comparison group, it is not possible to infer causality, as these changes may have resulted from increased time since diagnosis and treatment, or other factors.

Table 3. Quantitative results

Patient	HADS- Anxiety[a]		HADS-Depression[a]		IES[b]		Distress thermometer[c]		Perception of peer support (Post)[d]
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	
1	16	12	8	6	24	19	9	9	4.6
2	16	7	9	2	16	7	7	4	5
3	7	6	3	1	8	9	5	0	4.5
4	3	7	3	6	16	19	2	3	4.9
5	5	3	6	4	8	4	3	5	4.6
6	12	10	8	11	21	12	8	8	2.9

[a] Hospital Anxiety and Depression Scale. Scores range from 0-21; with 8 or above indicating clinical caseness.
[b] Impact of Event Scale intrusion subscale. Scores range from 0-35 with higher scores indicating high levels of intrusive thoughts
[c] Distress thermometer. Scores range from 0-10 with scores over 4 indicating significant distress.
[d] Perception of peer support. Scores range from 0-5 with high scores indicating higher levels of satisfaction.

DISCUSSION

This study aimed to explore how a new peer support service for women with gynaecological cancer was experienced by both the peer helpers and the women they were supporting. Overall, both parties reported their experiences to be positive. In supporting the women, the peer helpers used a number of strategies commonly employed by professional therapists. Interestingly, not only those receiving support, but also those providing support found the experience to be therapeutic, with both parties reportedly benefiting from the opportunity to reflect on their experiences.

The results of this study add to the accumulating body of research indicating the value of peer support. Dunn et al. (2003), in their review of the research literature examining peer support in the context of cancer, concluded that, because of its basis in shared experience, the emotional and informational support provided by peer helpers validates emotions, enhances optimism about the future, reduces social isolation and stigma and normalises experiences. The findings of the current research are consistent with these conclusions.

Processes of helping

Peer support can be conceived as being located on a continuum of psychological helping, where informal support from untrained helpers lies at one end and professional therapy at the opposing end (Orford, 1992; Guerney, 1969, cited in Barker & Pistrang, 2002). The strategies employed by the peer helpers in this study bore a strong resemblance to some of those used by professional therapists. This is consistent with the idea of there being generic processes of helping shared by both

formal and informal helpers; these include establishing a 'therapeutic' or 'helping' relationship, making meaning and promoting change (Barker & Pistrang, 2002).

From the perspective of the patients, the peer helpers established a helping relationship by creating a space where they were able to talk openly, and receive non-judgemental acceptance and empathy rather than sympathy. These were aspects that were particularly valued by the women, and, interestingly, are akin to Rogers' (1957) ideas of the important foundations of therapy: the therapist's empathy, unconditional positive regard and genuineness.

Peer helpers reported the importance of the bond that they developed with the patients, and their efforts to develop and maintain it. In doing so, peer helpers employed strategies known to positively impact on the therapeutic alliance, including facilitating the expression of affect, affirming, understanding and attending to the patient's experience (Ackerman & Hilsenroth, 2003). They were also sensitive to potential ruptures in the bond and were mindful not to say the wrong thing.

Within support groups it has been recognised that a positive self-reinforcing loop can develop, wherein trust in the group facilitates self-disclosure, leading to the receipt of empathy and acceptance, which further enhances trust in the group (Yalom, 1995). The findings of this study are consistent with this idea. In the one patient-peer helper pair where the patient did not feel safe enough to disclose, the loop did not complete and she found the experience of peer support to be less beneficial.

The peer helpers recognised that providing emotional support, particularly empathy, was their primary role, and that information or advice giving was secondary to this. Emotional support has been found to be the type of support most desired and valued by cancer patients (Helgeson & Cohen,1996). The peer helpers were also mindful to self-disclose only in moderation. Recipients of peer support report that it is the peer helper's provision of high levels of empathy combined with the appropriate sharing of their own experience that are key to effective helping (Pistrang, Solomons & Barker, 1999).

Through receiving empathic understanding of their distressing experiences, the women were helped to make meaning of them. The peer helpers used their "experiential knowledge" (Borkman, 1990) to first validate the women's experiences and then provide alternative perspectives. In hearing these viewpoints, the women were encouraged to step back and further reflect on their experiences and the meaning they had made from them.

The peer helpers also attempted to bring about change e.g. through making suggestions, but did so subtly. Previously, informal helpers have been found to rely too heavily on providing advice (Barker & Lemle, 1987; Knowles, 1979 cited in Barker & Pistrang, 2002). However, in the current study the peer helpers were sparing in their provision of information and advice, responding only to explicit requests by the women. Previous findings indicate that informational support is perceived to be helpful only when supplied by health professionals (Helgeson & Cohen,1996). However, the women greatly valued the suggestions made by the peer helpers, with their experiential knowledge seeming to enhance the validity of their

remarks. The peer helpers also supported and encouraged the women's efforts to re-engage in the 'normal world' and empathised with their difficulties in managing this transition.

Peer helpers faced a number of challenges that, interestingly, are similar to those experienced by novice therapists, such as managing boundaries, and fears of saying the wrong thing. The peer helpers intuitively developed strategies to help them to manage the conflict of being sufficiently involved in the patients' experiences to support them, whilst maintaining a level of detachment to allow them to separate at the end of the call. Conscious of the potential impact of speaking inappropriately, the peer helpers spoke of their awareness of their own contributions to the calls. Some were left worrying after the call had ended that they had said the wrong thing.

While there were many commonalities between the peer support and professional therapeutic relationships, there were also some key distinctions. The relationships between the peer helpers and patients were characterised by informality, equality, reciprocity and humour, aspects that would not be expected from a professional relationship, and were valued by most.

Impact on patients

The women described their acute awareness of the restrictions on talking about their experiences within their social networks, and the stigma associated with gynaecological cancer, and thus valued the opportunity to connect with another woman who had experienced this form of cancer. Through speaking with the peer helpers, the women gained a sense of relief that came from the realisation that they

were not alone, that others had struggled with similar experiences. This process of discovering that one's feelings and experiences are not unique and the consequent relief this engenders has been termed 'universality' (Yalom, 1995). According to Yalom, this awareness of shared experience is a humanising process, as the individual feels less separate from the rest of the world. This is said to be particularly powerful for those whose difficulties are characterised by isolation and secrecy, which is often the case with gynaecological cancer.

The majority of women described how the empathic responses of their peer helpers facilitated disclosure of aspects that they felt unable to share with others. In knowing that their peer helper would understand them, the women felt safe to talk about existential issues and traumatic treatment experiences. The peer helpers provided the women with an opportunity for catharsis, free of fears of burdening or causing upset.

Yalom (1995) has proposed that while the experiences of universality and catharsis are valued by individuals struggling to make sense of difficult personal experiences, it is the acceptance following disclosure that is key, as it challenges beliefs of repugnance. While these ideas come from Yalom's work with psychotherapeutic groups, the reports of the patients' in the present study supports their broader application. The women spoke of how the peer helpers' adoption of a non-judgemental accepting stance enabled them to feel safe to share their most personal experiences, and the understanding they received validated their pain and helped them to make sense of their experiences. This is also consistent with the finding that emotional support promotes adjustment in individuals with cancer (Helgeson & Cohen, 1996).

Impact on peer helpers

The peer helpers reported how they too benefited from the process of helping, describing the experience as 'therapeutic'. This is consistent with the idea of the 'helper-therapy principle' (Riessman, 1965 cited in Roberts et al., 1999), that those providing help gain increased feelings of competence, equality, social usefulness, independence and social value. Providing help has also been found to promote psychosocial adjustment (Roberts et al., 1999), and the findings of the current study support this. Through empathising with the women's current difficulties, the peer helpers inevitably reflected on their own experiences. By extracting what they had learnt from those experiences, they were able to gain emotional distance and perspective, and give meaning and purpose to them. The peer helpers were also reminded of having faced their own mortality, but in the context of thinking how fortunate they had been. From this position, they resolved to move forward and not to take life for granted.

Cancer is a traumatic experience involving a psychosocial transition that can lead to both positive and negative outcomes (Cordova & Andrykowski, 2003). The peer helpers spoke of how being able to contribute positively to another's wellbeing helped them to make meaning of their own cancer experience and create something good from a bad experience. The process of providing support may provide conditions facilitative of post-traumatic growth, as positive reinterpretation of traumatic experiences has been linked with consequent growth (Linley & Joseph, 2004).

Limitations

The findings of this study should be considered in the context of some methodological limitations. Areas of concern include sampling issues, the participant pairs varying on a number of aspects, social desirability of responses, validity issues in qualitative analysis, and restrictions on interpretation of quantitative results.

A qualitative approach was adopted to allow for an in-depth analysis of the process and outcome of peer support. While the small sample size facilitated this detailed exploration, the peer helpers and patients were not representative of the larger patient population. The peer helpers were carefully selected by senior members of the departmental psychosocial team; the recipients of the support were selected not only on the basis of need, but also on the suitability of their match with the peer helpers available. In addition, the women involved all stated from the outset their desire for the service to be successful. They believed in the value of peer support, and were keen for additional sources of support to be made available to women in a similar situation.

The pairs of peer helpers and patients varied considerably on several variables. These included the point in the patient's cancer experience at which the intervention was received, i.e. during or post-treatment, and the frequency and length of the conversations. Whilst in part this is a reflection of the strength of the design of the intervention, as it enabled the support to be flexible and sensitive to the needs of the patients, it does, however, hamper the ability to examine more closely how the process of helping relates to outcome.

While it was made clear that the participants' involvement in the study was distinct from their medical care, and that their interview responses would be kept confidential, there may have been concerns that this confidentiality would be breached as the researcher also worked in the gynaecological oncology department. For these reasons, women may have felt reluctant to provide negative accounts of their experience of the peer support service. However, steps were taken to avoid this, with the women being encouraged to share all aspects of their experience, both positive and negative.

There were also limitations in the analysis of the qualitative data, although good practice guidelines (Elliott et al., 1999) were followed. Restrictions in time meant that it was not possible to obtain feedback from participants on the analysis of their interviews, a process known as respondent validation (Barker & Pistrang, 2005). Limited time also meant that it was necessary to be selective as to which parts of the large data set were to be the focus of the analysis. While the initial pre-support interviews provided interesting information, the analysis primarily focused on the follow-up interviews as the content of these addressed the research questions. Analysing common themes across patient-peer helper pairs is also only one of several possible ways of looking at the data. One interesting alternative would be to take a dyadic approach, comparing the experience of an individual patient with that of her peer helper.

The quantitative data yielded results consistent with the accounts provided in the follow-up interviews that, overall, the patients were satisfied with the support received and may have benefited from it. While the measures piloted do seem to be

sensitive to change over time, the lack of a comparison group, and the small sample size, preclude making any conclusions about whether the changes detected on these measures were brought about by the intervention.

Future directions

This study represents the first step in the evaluation of a peer support service for women with gynaecological cancer. There is a need for a more rigorous evaluation of the intervention with a larger sample. Before this is possible, however, measures sensitive to the impact of such an intervention need to be identified or developed. The psychosocial intervention literature has primarily relied on the measurement of symptoms as an outcome variable. While it is easier to measure symptomatic outcomes, they may fail to capture the impact of peer support interventions. In this study, the outcomes reported by patients included the importance of knowing that someone else had similar experiences, feeling cared for and being able to 'move on' from their cancer experience. The standardised measures used in this study did not address these issues. More work is needed to identify the mechanisms of the impact of peer support interventions so that appropriate measures can be developed. Recording the telephone calls and examining the process of the conversations may be one way of doing this. In addition, studies using comparison groups are needed to separate out intervention effects from the effects of increased time since diagnosis and treatment, so that interpretations can be made about possible causality.

Dunn et al. (2003) noted in their review of peer support in the context of cancer the absence of research examining professionally supervised non-face-to-face support, such as was the focus of the current research. While there have been many studies

evaluating the effectiveness of face-to-face peer support, particularly in group

settings, dyadic support using more distant modes such as the telephone or internet

has been relatively neglected. The current study indicates that this area shows

promise and warrants further examination.

Clinical implications

This study has highlighted how peer support can be a valuable adjunct to the help

provided by professionals. However, it is important to establish the most appropriate

and effective time in the cancer experience to provide such support. In the current

study there was considerable variability in the time points at which the women

received peer support, and so this remains unclear. As other researchers have

commented (e.g. Dunn, Steginga, Occhipinti & Wilson, 1999), it is important to

increase understanding of this issue so that support can be provided at the time of

greatest need.

Clinical psychologists have an important role in supporting and facilitating the work

of peer helpers. While many of the peer helpers demonstrated intuitive clinical skills

and judicious use of advice and self-disclosure, they all reported how the initial

training, monthly supervision and back-up from the project team enabled them to feel

more confident and secure in the support they provided to patients. The ongoing

supervision also provided a valued space for the peer helpers to share issues that

were raised for them in hearing another individual describe experiences similar to

their own.

Clinical psychologists also have a role in screening potential peer helpers as well as patients. Peer helpers need to be selected on the basis of adjustment to their cancer experience and interpersonal skills, and clinical psychologists are well placed to make those decisions. Screening of potential patients is also important to identify those women unsuited to peer support or those who need additional professional psychological input. Increasingly clinical psychologists are being encouraged to take on consulting and indirect working roles, and this type of project provides such opportunities.

Peer support provides a cost-effective way of providing support. Such services place low demands on the time of professionals but allow for the support of a larger number of individuals than is possible through individual therapy. It is also a way of supporting those women who do not meet clinical criteria for individual therapy, or who do not wish to receive such therapy.

REFERENCES

Ackerman, S.J., & Hilsenroth, M.J. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review*, **23**, 1-33.

Andersen, L. (1984). Psychological aspects of gynaecological cancer in A. Broome and L.Wallace (Eds.) *Psychology and Gynecological Problems*. London: Tavistock Publications.

Andersen, B.L. & Jochimsem, P.R. (1985). Sexual functioning among breast cancer, gynaecologic cancer, and health women. *Journal of Consulting and Clinical Psychology*, **53**, 25-32.

Barker, C., & Lemle, R. (1987). Informal helping in partner and stranger dyads. *Journal of Marriage and the Family*, **49**, 541-547.

Barker, C., & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology*, **35**, 201-212.

Bolger, N., Foster, M., Vinokur, A.D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology*, **70**, 283-294.

Borkman, T. J. (1990). Experiential, professional, and lay frames of reference. In T. J. Powell (Ed.) *Working with Self-Help*. Silver Springs, MD: NASW Press.

Cain, E.N., Kohorn, E.I., Quinlan, D.M., Latimer, K., & Schwartz, P.E. (1986). Psychosocial benefits of a cancer support group. *Cancer*, **57**, 183-189.

Campbell, H.S., Phaneuf, M.R., & Deane, K. (2004). Cancer peer support programs-do they work? *Patient Education and Counseling*, **55**, 3-15.

Capone, M.A., Good, R.S., Westie, K.S., & Jacobson, A.F. (1980). Psychosocial rehabilitation of gynecologic oncology patients. *Archives of Physical Medicine and Rehabilitation*, **61**, 128-132.

Carlsson, M.E., & Strang, P.M. (1998). Educational support programme for gynaecological cancer patients and their families. *Acta Oncologica*, **37**, 269-275.

Chan, Y.M., Lee, P.W.H., Fong, D.Y.T., Fung, A.S.M., Wu, L.Y.F., Choi, A.Y.Y., Ng, T.Y., Ngan, H.Y.S., & Wong, L.C. (2005). Effect of individual psychological intervention in Chinese women with gynecologic malignancy: A randomised controlled trial. *Journal of Clinical Oncology*, **23**, 4913-4924.

Cohen, S. (2004). Social relationships and health. *American Psychologist*, 676-684.

Cordova, M.J., & Andrykowski, M.A., (2003). Responses to cancer diagnosis and treatment: Posttraumatic stress and posttraumatic growth. *Seminars in Clinical Neuropsychiatry*, **8**, 286-296.

Cordova, M.J., Andrykowski, M.A., Kenady, D.E., McGrath, P.C., Sloan, D.A., & Redd, W.H. (1995). Frequency and correlates of post-traumatic stress disorder-like symptoms after treatment for breast cancer. *Journal of Consulting and Clinical Psychology*, **63**, 981-986.

Corney, R.H., Everett, H., Howells, A. & Crowther, M.E. (1992). Psychosocial adjustment following major gynaecological surgery for carcinoma of the cervix and vulva. *Journal of Psychosomatic Research*, **36**, 561-568.

Crowther, M.E., Corney, R.H. & Shepherd, J.H. (1994). Psychosexual implications of gynaecological cancer. *British Medical Journal*, **308**, 869-870.

Cull, A., Cowie, V.J., Farquharson, D.I.M., Livingstone, J.R.B., Smart, G.E. and Elton, R.A. (1993). Early stage cervical cancer: psychosocial and sexual outcomes of treatment. *British Journal of Cancer*, **68**, 1216-1220.

Dennis, C. (2002). Breastfeeding peer support: Maternal and volunteer perceptions from a randomized controlled trial. *Birth*, **29**, 169-176.

Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, **38**, 215-229.

Guerney, B.G. (1981). *Psychotherapeutic agents: new roles for nonprofessionals, parents and teachers.* New York: Holt, Rinehart and Winston, cited in C. Barker, & N. Pistrang (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology*, **35**, 201-212.

Helgeson, V.S. & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational and intervention research. *Health Psychology*, **15**, 135-148.

Helgeson, V.S. & Gottlieb, S. (2000). Support groups. In S. Cohen, L.G. Underwood & B.H. Gottlieb (Eds.) *Social Support Measurement and Intervention: A Guide for Health and Social Scientists.* Oxford:OUP.

Herrmann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale: A review of validation data and clinical results. *Journal of Psychosomatic Research*, **42**, 17-41.

Hipkins, J., Whitworth, M.., Tarrier, N. & Jayson, G. (2004). Social support, anxiety and depression after chemotherapy for ovarian cancer: A prospective study. *British Journal of Health Psychology*, **9**, 569-581.

Holland, J. (1999). Update: NCCN practice guidelines for the management of psychosocial distress. *Oncology*, **13**, 459-507.

Horowitz, M.J., Wilner, N., & Alvarez, W. (1979). Impact of Events Scale: A measure of subjective stress. *Psychosomatic Medicine*, **41**, 209-218.

Houts, P.S., Whitney, C.W., Mortel, R.. & Bartholemew, M.J. (1986). Former cancer patients as counselors of newly diagnosed cancer patients. *Journal of the National Cancer Institute*, **76**, 793-796.

Knowles, D. (1979). On the tendency for volunteer helpers to give advice. *Journal of Counseling Psychology*, **26**, 352-354, cited in C. Barker, & N. Pistrang (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology*, **35**, 201-212.

Linley, P.A., & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, **17**, 11-21.

Orford, J. (1992). *Community psychology: theory and practice*. Chichester: Wiley.

Palmer, A.G., Tucker, S., Warren, R. & Adams, M. (1993). Understanding women's responses to treatment for cervical intra-epithelial neoplasia. *British Journal of Clinical Psychology*, **32**, 101-112.

Pidgeon, N. (1996). Grounded theory: theoretical background. In J.T.E. Richardson (Ed.) *Handbook of Qualitative Methods: For Psychology and the Social Sciences* (pp. 75-85). England: BPS Books.

Pistrang, N. & Winchurst, C. (1997). Gynaecological cancer patients' attitudes towards psychological services. *Psychology, Health and Medicine*, **2**, 135-147.

Riessman, F. (1965). The 'helper' therapy principle. *Social Work*, **10**, 27-32.

Roberts, L.J., Salem, D., Rappaport, J., Toro, P.A., Luke, D.A., & Seidman, E. (1999). Giving and receiving help: interpersonal transactions in mutual-help meetings and psychosocial adjustment of members. *American Journal of Community Psychology*, **27**, 841-868.

Rogers, C.R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, **21**, 95-103.

Rudy, R.R., Rosenfeld, L.B., Galassi, J.P., Parker, J., & Schanberg, R. (2001). Participants' perceptions of a peer-helper, telephone-based social support intervention for melanoma patients. *Health Communication*, **13**, 285-305.

Sewell, H.H. & Edwards, D.W. (1980). Pelvic genital cancer: Body image and sexuality. In J.M. Vaeth, R.C. Blomberg and L.M. Adler (Eds.). *Frontiers of Radiation Therapy and Oncology*. Basel: Karger.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds), *Qualitative Health Psychology: Theories and Methods*. (pp218-240). London: Sage.

Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage

Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine*, 62, 2565-2576.

Weisman, A.D. & Worden, J.W. (1976). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 7, 1-15.

Yalom, I.D. (1995). *The theory and practice of group psychotherapy*. New York: Basic Books

Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Zilberg, N.J., Weiss, D.S., & Horowitz, M.J. (1982). Impact of Events Scale: A cross validation study and some empirical evidence supporting a conceptual model of stress response syndromes. *Journal of Consulting and Clinical Psychology*, 50, 407-414.

Part 3: Critical Appraisal

Peer support for women with gynaecological cancer: A critical appraisal

Introduction

This paper discusses some issues that were raised in conducting the research reported in Part 2 of this thesis. The first two sections concentrate on issues that arose during the process of the research, while the last two sections focus on ways of taking the findings of this research further.

Issues in conducting research in a clinical setting

Over the course of the Doctoral training, we have been encouraged to adopt a scientist-practitioner approach to working as a clinical psychologist. Accordingly, the aim is to combine work as a clinician with furthering the empirical basis of psychology, as well as integrating research into practice (Barker, Pistrang & Elliott, 2002). In carrying out the current research in the hospital department in which I was also working as a clinician, I became aware of a number of benefits but also some particular challenges of this way of working.

There were a number of practical benefits to combining roles as a researcher and as a clinician. Firstly, my presence in the gynaecological oncology department facilitated recruitment of participants into the research, as I was able to remind staff about the project and suggest that they approached patients who matched the available peer helpers. Secondly, I was available to answer staff questions about the research as they arose. Thirdly, I was able to assign time flexibly to research and clinical

purposes, which meant that I could conduct the research interviews at times convenient for the participants. Fourthly, close links with the medical professionals allowed me to gain answers easily to the medical questions or concerns raised by the peer helpers. Finally, the participants may have felt safer knowing that the research was based within the medical department.

There were also personal benefits to combining researcher and clinician roles. In addition to enjoying the opportunity to be involved in setting up and evaluating a new service, my involvement in the research also stimulated my thinking about my clinical work. Through the interviews with the patients, I was reminded of the importance of thinking about individuals in their wider systems, in particular, the support they may be receiving from informal sources. While some of the women described how they felt unable to obtain the desired emotional support from those in their social network, the success of the peer support intervention underscored how helpful informal sources of support can be. As was noted by Barker and Pistrang (2002), there is a tendency for clinicians to forget that outside of the therapeutic context patients are receiving support from a wider network of supporters.

There were, however, a number of conflicts and challenges raised by my being a member of the clinical team as well as being involved in the research. Firstly, there were confidentiality issues. As a member of the team, I attended meetings at which the results of medical investigations were discussed. I was therefore privy to more personal information than the participants consented to my having in my role as a researcher. There were also challenges to maintaining the confidentiality of the

participants, as staff, understandably, wanted to know how their patients were finding being involved in the study.

Secondly, there were challenges to keeping an unbiased perspective to completing the qualitative analysis. While I tried to enter into the analysis process with as few prejudgements as possible, this was sometimes complicated by hearing the perspectives of staff in the department on some of the participants. In addition, I did not want to see research participants in my clinical capacity, as this may have influenced both their accounts and my analysis. Those women involved in the study who wished to see a clinical psychologist were referred to another member of the clinical psychology department. Conducting this type of research in a service in which there is only one psychologist would have presented additional difficulties.

Thirdly, according to the project guidelines approved by the ethics committee, only departmental staff (not including myself as a trainee), could approach women to invite them to receive the peer support service. The criteria for selection were that additional support was judged by staff as appropriate and that a suitable match with a peer helper was available. However, sometimes it seemed that there were idiosyncratic reasons for inviting some women into the study over others, for example, staff feeling 'stuck' in their efforts to support a particular patient or responding to a patient who was particularly vocal. While these are legitimate reasons for offering further support, it may have meant that women who also needed support, but who were less vocal, failed to be recognised.

Finally, there were also challenges in carrying out psychosocial intervention research in a medical setting. The department within which the peer support service was run had a strong reputation for its involvement in medical research, and was well set up for conducting this type of research, for example, having dedicated research nurses. There was, however, a certain level of wariness amongst clinical team members about becoming involved in psychosocial research. It seemed that some, in wanting to protect their patients, were hesitant to refer to the service until it had been found to be effective. As positive feedback from patients receiving the service circulated, medical staff became more open to referring women they thought might benefit. For these reasons, setting up psychosocial intervention research within medical settings can take time.

Similarities and differences between research and clinical interviews

In many ways the research interviews, particularly those conducted with the patients prior to receiving the peer support service, were similar to clinical interviews. At the initial interviews the patients were encouraged to give details of their illness and treatment experience to date. While only brief details were sought, it became apparent from the lengthy accounts that followed, that many of the women had not had the opportunity to talk openly about their experiences. As they described the restrictions on the discussion of their experiences with those in their social network, and with the medical team, I felt it was important to allow them the space to share these.

The topic was an understandably emotional one and the accounts were often very raw. One initial interview took place immediately after the patient had been informed of the recurrence of her cancer. In addition, for a few, the trauma of the cancer experience brought to mind other traumatic or distressing life experiences such as childhood sexual abuse, dysfunctional childhoods and divorce. The nature of the disclosures required the use of clinical skills to contain the emotions raised and allow the women to feel safe and heard. As has been noted by Rosenblatt (1995), when interviews are emotionally charged the boundaries between research and therapy can become blurred. Indeed, through providing a supportive, cathartic space patients did report finding the interview sessions therapeutic.

To a certain extent it was also necessary for the initial interviews to be similar to a clinical assessment as, in addition to providing data for the research, the women were being screened for their suitability to receive the peer support service. Several women were identified as possibly needing additional professional support, and so were offered referrals to the clinical psychologist at the end of the interview.

On the other hand, there were ways in which the interviews differed from what might be expected from a clinical context. While the patients were given the space to talk about their experiences, and the semi-structured nature of the interviews allowed for interesting avenues of discussion to be followed up, there was an agenda of topics on the interview schedule to be covered. As the emphasis was on maintaining an easy conversational style (Pigeon, 1996) the schedule was used mainly as a prompt, and a way of regaining focus. However, the content of this schedule contrasted with the typical focus of a clinical interview in that the aim was not to identify and explore

the individual's psychological difficulties. It was also necessary to be mindful that the interviews were not part of ongoing therapy. Therefore, when women disclosed difficult experiences, they were acknowledged, but were not explored in the same way as would take place in a clinical assessment.

Qualitative data and analysis

In the current study, the analysis of the interview data focused on identifying themes that occurred across the accounts of the patients and of the peer helpers. While this yielded interesting findings, this is just one of a number of ways the analysis of the data could be approached. For example, the analysis could have focused on each patient-peer helper pair, examining the degree of convergence in terms of how the peer helper provided support and how helpful the support was perceived to be. Indeed, a brief examination of the data in this way did identify some discrepancies between accounts, which would have been interesting to explore further. In addition, the analysis of the patients' initial interviews was limited to focusing on the context in which the peer support was received. However, it would have been interesting to identify from these accounts the women's illness and treatment perceptions and, in particular, whether these influenced what they gained, or hoped to gain, from peer support.

The analysis that was carried out also relied upon self-reported accounts of giving and receiving peer support. One way of further developing the understanding of the process of peer support would be to tape-record the patient-peer helper calls and analyse the conversations using discourse analysis (Potter & Wetherell, 1987). This

approach, in focusing on the communication between patient and peer helper, would

aim to identify the repertoires of discourse the peer helpers draw on to provide

support and the positioning of both peer helper and patient.

The peer helpers were asked in the current study to complete telephone logs detailing

the content of the conversations and the ways in which they tried to provide support.

Such data could be further elaborated by asking the patients to note down after each

conversation the ways in which they perceived their peer helper tried to support them

and how effective this was. The content of these two records could then be

compared.

One particular limitation of the analysis was that, due to time constraints, procedures

for establishing 'testimonial validity' (Barker & Pistrang, 2005), were not

undertaken. This is the process of gaining feedback from participants on the analysis

of their transcripts or the analysis as a whole. By including the participants in this

way, not only would they have been able to confirm that the analysis was true to their

accounts, but the commentary that they would have provided may have enriched the

analysis further.

Measuring outcomes

Qualitative analysis is a useful first step when exploring an area in which there has

been little previous research, and where the focus is looking in depth at individuals'

perceptions of their experience (Smith & Osborn, 2003). In doing so, new ways of

understanding experiences can be uncovered (Smith & Osborn, 2003). This approach

can also be empowering for the participant as it gives them a voice to be able to present their perspective. There are, however, limitations to this approach. While qualitative analysis does provide a detailed account of individuals' experiences, this can only be done with a small sample and is time consuming to complete. In order to evaluate the effectiveness of peer support with a larger number of patient-peer helper pairs, it will be necessary to identify or develop quantitative measures sensitive to the process and impact of this type of intervention.

In the current research, a few measures were piloted. Because of the small sample size and lack of a comparison group, it was not possible to reach conclusions as to whether the peer support intervention led to change, or how sensitive the measures were to any impact of the intervention. However, the Impact of Event Scale (Horowitz, Wilner & Alvarez, 1979) which measured intrusive thoughts about cancer, did seem to show promise. This needs to be explored further in future research, as do the mechanisms by which peer support may influence levels of intrusive thoughts.

The literature examining women's experiences of gynaecological cancer has primarily focused on the presence and magnitude of affective disturbance. Consequently, research evaluating psychosocial interventions for this patient group has principally used measures of anxiety and depression to assess the impact of interventions. The current study also incorporated the use of such measures. However, as has been noted in Part 1 of this thesis, these are not the only emotional responses to the experience. Indeed other responses include shame, anger, confusion and disappointment (Andersen & Turnquist, 1989; Ekman et al., 2004).The impact

of psychosocial interventions on these aspects of women's response to gynaecological cancer is as yet unexplored.

The findings of the current study suggest that peer support may impact upon subtler constructs than anxiety and depression, and so presents challenges to developing suitably sensitive measures. The patients reported benefiting from the opportunity to talk openly about existential issues with another person who could understand their concerns through having shared this experience. The process of helping seemed to hinge on the ideas of universality, catharsis and acceptance (Yalom, 1995). Other researchers have found that peer support provides the opportunities to gain hope, increase personal control, reduce isolation and increase confidence (Campbell, Phaneuf & Deane, 2004). It is unlikely that a general measure of emotional adjustment would capture all these aspects, and so new measures may need to be developed. The results of qualitative studies such as this one can be used to inform the development of quantitative questionnaires.

The current study also indicates that peer helpers can benefit from the experience of providing support in terms of reflecting on their own experiences. A fruitful avenue for further research would be to try to identify a measure sensitive enough to detect this benefit. The accounts of the peer helpers may fit with the concept of post-traumatic growth, that is the experience of positive change as a consequence of trauma or adversity (Linley & Joseph, 2004). Cancer patients have been found to experience this type of personal development (Weiss, 2002). A number of measures have been developed to measure this concept, for example the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1995), and these may warrant investigation.

Summary

The experience of conducting the research raised a number of interesting issues and challenges. The main challenge to working clinically in the same setting as I was conducting the research, was maintaining a neutral stance. This was complicated by hearing the perspectives of others and the pressures to take on a full clinical caseload. These challenges, however, were offset by the improved opportunities for recruiting participants.

There was much overlap between the research interviews and a clinical interview. This was partly because of the subject matter, but also the strong sense that the women needed the opportunity to talk and feel supported.

We were fortunate that the participants were able to describe articulately their experiences, and so we were able to gather a large body of data. In the future, this data set could be used for further analysis by assuming a different perspective, such as through comparing the accounts of each patient-peer helper pair. Given more time, it would have been beneficial to have involved the participants more in the process of analysis.

Both peer helpers and patients reported benefiting from their experiences of providing or receiving peer support. The research literature has primarily focused on judging the effectiveness of psychosocial interventions based on changes on measures of anxiety or depression. The empirical study indicates that peer support interventions may have a more subtle effect, impacting on aspects of experience that

have so far not been explored, and so, consequently, appropriate measures are

lacking. There is therefore a need for further research.

REFERENCES

Andersen, B.L., & Turnquist, D.C. (1989). Psychological issues. In J.S. Berek and N.F. Hacker (Eds.), *Practical Gynecologic Oncology (pp631-656)*. Baltimore: Williams & Wilkins.

Barker, C., & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology*, **35**, 201-212.

Barker, C., Pistrang, N., & Elliott, R.(2002). *Research methods in clinical psychology: An introduction for students and practitioners*. Chichester: John Wiley & Sons.

Campbell, H.S., Phaneuf, M.R., & Deane, K. (2004). Cancer peer support programs-do they work? *Patient Education and Counseling*, **55**, 3-15.

Ekman, I., Bergbom, I., Ekman, T., Berthold, H., & Mahsneh, S.M. (2004). Maintaining normality and support are central issues when receiving chemotherapy for ovarian cancer. *Cancer Nursing*, **27**, 177-182.

Horowitz, M.J., Wilner, N., & Alvarez, W. (1979). Impact of Events Scale: A measure of subjective stress. *Psychosomatic Medicine*, **41**, 209-218.

Linley, P.A., & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, **17**, 11-21.

Pidgeon, N. (1996). Grounded theory: theoretical background. In J.T.E. Richardson (Ed.) *Handbook of Qualitative Methods: For Psychology and the Social Sciences* (pp. 75-85). England: BPS Books.

Potter, J., & Wetherell, M.(1987). *Discourse and social psychology*. London: Sage.

Rosenblatt, P.C. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies*, **19**, 139-155.

Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage

Tedeschi, R.G., & Calhoun, L.G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. London:Sage.

Weiss, T. (2002). Posttraumatic growth in women with breast cancer and their husbands: An intersubjective validation study. *Journal of Psychosocial Oncology*, **20**, 65-80.

Yalom, I.D. (1995). *The theory and practice of group psychotherapy*. New York: Basic Books.

Appendices

Appendix A: Ethical Approval

Website: www.uclh.nhs.uk

09 June 2005

Dr Nancy Pistrang
Senior Lecturer in Clinical Psychology
University College London
Sub-Department of Clinical Health Psychology
UCL, Gower Street
London
WC1E 6BT

Dear Dr Pistrang

Full title of study: **Women Helping Women: Peer support in gynaecological cancer**

REC reference number: **05/Q0502/37**

Thank you for your letter of 17 April 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		11 March 2005
Investigator CV Nancy Pistrang		(None Specified)
Protocol	2	(None Specified)
Covering Letter		10 March 2005
Summary/Synopsis	1	08 March 2005
Peer Review		05 December 2004
Compensation Arrangements		04 March 2005
Interview Schedules/Topic Guides	1	08 March 2005
Copy of Questionnaire		(None Specified)

An advisory committee to North Central London Strategic Health Authority

Letters of Invitation to Participants	2	11 May 2005
GP/Consultant Information Sheets	1	08 March 2005
Participant Information Sheet	2	11 May 2005
Participant Consent Form	1	08 March 2005
Telephone Record Sheet	1	12 May 2005
Letter of invitation to peer volunteers	2	11 May 2005
Information Sheet for Peer Volunteers	2	11 May 2005

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation(s) that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

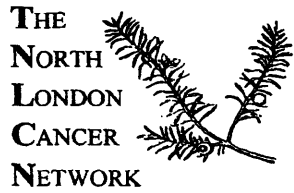| 05/Q0502/37	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely

Enclosures:

Standard approval conditions
Site approval form (SF1)

SF1 list of approved sites
An advisory committee to North Central London Strategic Health Authority

Appendix B: Information Sheets

University College London Hospitals NHS

NHS Trust

THE
NORTH
LONDON
CANCER
NETWORK

Department of Gynaecological Oncology
UCLH Gynaecological Cancer Centre
Elizabeth Garrett Anderson Hospital
Huntley Street
LONDON
WC1E 6DH

Women Helping Women

Information for participants

We are inviting you to take part in a research study evaluating a new "peer support" service for women being treated for gynaecological cancer at UCLH. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?
We know that being diagnosed with and treated for gynaecological cancer can be very distressing, and that emotional support from others can help to reduce the worries and concerns that women have. Support provided by "peers" – that is, women who have been through the experience themselves – may be particularly valuable: women who have completed treatment are uniquely placed to understand the concerns that women who are starting treatment may have.

This project will set up a telephone "peer support" service. Women who have completed treatment ("peer volunteers") will provide support by telephone on a weekly basis, over a 3-month period, for women receiving treatment. The peer volunteers will receive brief training and will be backed up by hospital staff. The service will aim to:

- provide an opportunity for women to freely discuss their worries and concerns
- reduce distress and feelings of isolation
- help women cope better with their treatment

The aims of this pilot study are to identify the strengths of the service and how it can be improved. The evaluation will focus on women's experiences of the service. We hope that this information will help us to make the service better before we expand it so that more women can take part.

ctd./

What does taking part involve?

If you decide to take part, you will be matched with a "peer volunteer" (another woman who has had treatment similar to yours) who will telephone you weekly over 3 months.

A member of the project team will also meet with you on two occasions:

- Before the peer volunteer contacts you, you will be asked to participate in an interview with the researcher, lasting about 40 minutes. The interview will focus on your experience of being diagnosed and treated for gynaecological cancer and what sort of support you might find helpful. You will also be asked to complete some short questionnaires, taking 15-20 minutes.

- At the end of the 3 months, you will be asked to participate in another interview lasting about an hour. It will focus on your experience of the peer support service and in what ways it was helpful or not. You will also be asked to complete the questionnaires again. A member of the project team will also look in your medical records so that we can obtain some details of your treatment.

The meetings with the researcher will take place either in your home or at UCL, whichever you prefer; travel expenses will be paid if you come to UCL. With your permission, we will tape record the interviews so that we have a complete record of what was said. A written summary of the telephone conversations will be kept by the peer volunteer so that we have information about the kinds of topics discussed; we may also audiotape a sample of the conversations, with your permission.

Why have I been chosen?

We are inviting only about 15-20 women to take part, as the peer support service is just being established and this is a pilot study to see how it works. At this stage, we are selecting only those women for whom we have a peer volunteer available – that is, another woman who has received similar treatment to yours.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form, and you will be given this information sheet and the signed consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason either to the researchers or to the peer volunteer with whom you have been matched. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Will the information be confidential?

All information that is collected about you during the course of the research will be kept confidential. A code number, rather than your name, will be used so that you cannot be identified. Written records will be made of the tape-recorded research interviews, with any identifying information removed, and then the tapes will be destroyed. The peer volunteer's written summaries of the telephone conversations will be kept, again with any identifying information removed; any tapes of the conversations will also be kept, with identifying information removed. Dr Nancy Pistrang will be responsible for the safety and security of all data, which will be stored at UCL. Only the project team will have access to the data. Your consultant at UCLH will be notified of your participation in the study, but the specific information you provide will not be passed on to the consultant without your permission; the only exception to this would be if any information gives us cause for concern about your health or safety or that of others.

What will happen to the results of the study?

The results of the study will be used by the project team to identify ways of improving the peer support service. The project is due to be completed in October 2006, after which we will send you a written summary of the results. We may also write up the results for publication in a scientific journal. You will not be identified in any report or publication.

What are the possible benefits and risks?
We hope that this project will benefit the women who participate: having another woman to talk to about your concerns as you go through treatment may help you to feel better able to cope. It is possible, however, that talking about your experiences, both with the peer volunteer and with the researcher, could be upsetting. The project team will ensure that you are given extra support should it be needed.

What if something goes wrong?
If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints mechanisms should be available to you.

Who has reviewed the study?
All research projects in the NHS are reviewed by an ethics committee before they can proceed. This project has been reviewed by the Joint UCL/UCLH Committee on the Ethics of Human Research.

Contact for further information
Please do not hesitate to contact one of the project team (contact details below) if you have any questions about the study.
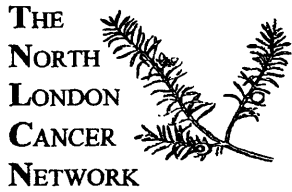
Thank you for thinking about taking part in this project!

Dr Nancy Pistrang	Dr Sue Gessler	Heather Pratt	Zara Jay
Senior Lecturer in	Consultant Clinical	Lead Clinical Nurse	Trainee Clinical
Clinical Psychology	Psychologist	Specialist	Psychologist
020 7679 5962	020 7387 9300 ext. 2582	020 7387 9300 ext. 8919	020 7679 5962
n.pistrang@ucl.ac.uk	sue.gessler@uclh.org		zarajay@hotmail.com

University College London Hospitals NHS

NHS Trust

THE
NORTH
LONDON
CANCER
NETWORK

Department of Gynaecological Oncology
UCLH Gynaecological Cancer Centre
Elizabeth Garrett Anderson Hospital
Huntley Street
LONDON
WC1E 6DH

Version: 2
Date: 11.5.05
Project ID: 05/Q0502/37

Women Helping Women

Information for "Peer volunteers"

We are inviting you to take part in a research study evaluating a new "peer support" service for women being treated for gynaecological cancer at UCLH. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?
We know that being diagnosed with and treated for gynaecological cancer can be very distressing, and that emotional support from others can help to reduce the worries and concerns that women have. Support provided by "peers" – that is, women who have been through the experience themselves – may be particularly valuable: women who have completed treatment are uniquely placed to understand the concerns that women who are starting treatment may have.

This project will set up a telephone "peer support" service. Women who have completed treatment ("peer volunteers") will provide support by telephone on a weekly basis, over a 3-month period, for women receiving treatment. The peer volunteers will receive brief training and will be backed up by hospital staff. The service will aim to:

- provide an opportunity for women to freely discuss their worries and concerns
- reduce distress and feelings of isolation
- help women cope better with their treatment

The aims of this pilot study are to identify the strengths of the service and how it can be improved. The evaluation will focus on women's experiences of the service. We hope that this information will help us to make the service better before we expand it so that more women can take part.

ctd./

What does taking part involve?

If you decide to take part as a "peer volunteer" you will:

- Participate in two orientation sessions, each lasting one-and-a-half hours. The sessions will focus on effective support strategies (and strategies to be avoided!), and will take place at UCL.

- Provide telephone support on a weekly basis, over a 3-month period, to a woman currently receiving treatment. We will ask you to keep a written summary of the telephone contacts so that we have information about the kinds of topics discussed; we may also audiotape a sample of the conversations, with your permission.

- Participate in monthly supervision sessions with a member of the project team, either by telephone or at UCL/UCLH, depending on your preference.

- Participate in a research interview at the end of the 3-month period. The interview will focus on your experiences of being a peer volunteer and will last about one hour. It will take place either in your home or at UCL, whichever you prefer. With your permission, we will tape record the interview so that we have a complete record of what was said. At the start of the project, a member of the project team may also look in your medical records to obtain some details of your treatment.

Once the 3-month period ends, we will ask you if you are interested in providing support to another woman. We are hoping that each peer volunteer might be able to provide support to 2 or 3 women, although you would support only one woman at any one time.

The costs of all telephone calls (to the woman you are supporting and to the project team for supervision) will be covered by the project: you will be given either a mobile phone specially designated for the project or phone cards for use from home, whichever you prefer. Travel expenses will also be paid for any visits that you make to UCL/UCLH.

Why have I been chosen?

We are inviting about 5-10 women to take part as peer volunteers, as the service is just being established and this is a pilot study to see how it works. At this stage, we are selecting women who are known by the project team and who we think would be able to provide effective support to other women. We are also looking for a range of peer volunteers (in terms of age and the type of treatment they received) so that we can match them to a range of women currently receiving treatment.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form, and you will be given this information sheet and the signed consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason either to the researchers or to the woman you have been supporting. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Will the information be confidential?

All information that is collected about you during the course of the research will be kept confidential. A code number, rather than your name, will be used so that you cannot be identified. A written record will be made of the tape-recorded research interview, with any identifying information removed, and then the tape will be destroyed. Your written summaries of the telephone conversations with the woman you are helping will be kept, again with any identifying information removed; any tapes of the

conversations will also be kept, with identifying information removed. Dr Nancy Pistrang will be responsible for the safety and security of all data, which will be stored at UCL. Only the project team will have access to the data. Your consultant at UCLH will be notified of your participation in the study, but the specific information you provide will not be passed on to the consultant without your permission; the only exception to this would be if any information gives us cause for concern about your health or safety or that of others.

What will happen to the results of the study?
The results of the study will be used by the project team to identify ways of improving the peer support service. The project is due to be completed in October 2006, after which we will send you a written summary of the results. We may also write up the results for publication in a scientific journal. You will not be identified in any report or publication.

What are the possible benefits and risks?
The main benefits are intended for those women receiving peer support: by having another woman to talk to during treatment they may feel better able to cope. We also hope that the project will be interesting and useful for the peer volunteers: research suggests that the process of helping others can be beneficial in itself. It is possible, however, that listening to another woman's concerns could be upsetting. Should this be the case, Dr Sue Gessler and Dr Nancy Pistrang will be available for discussion and support and will provide counselling sessions if necessary.

What if something goes wrong?
If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints mechanisms should be available to you.

Who has reviewed the study?
All research projects in the NHS are reviewed by an ethics committee before they can proceed. This project has been reviewed by the Joint UCL/UCLH Committee on the Ethics of Human Research.

Contact for further information
Please do not hesitate to contact one of the project team (contact details below) if you have any questions about the study.

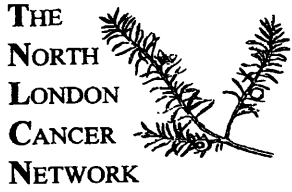Thank you for thinking about taking part in this project!

Dr Nancy Pistrang	Dr Sue Gessler	Heather Pratt	Zara Jay
Senior Lecturer in	Consultant Clinical	Lead Clinical Nurse	Trainee Clinical
Clinical Psychology	Psychologist	Specialist	Psychologist
020 7679 5962	020 7387 9300 ext. 2582	020 7387 9300 ext. 8919	020 7679 5962
n.pistrang@ucl.ac.uk	sue.gessler@uclh.org		zarajay@hotmail.com

Appendix C: Consent Form

University College London Hospitals **NHS**
NHS Trust

THE
NORTH
LONDON
CANCER
NETWORK

Department of Gynaecological Oncology
UCLH Gynaecological Cancer Centre
Elizabeth Garrett Anderson Hospital
Huntley Street
LONDON
WC1E 6DH

UCLH Project ID number: 05/Q0502/37
Form version: 1
Date: 8.3.05
Patient Identification Number for this study:

CONSENT FORM

Title of project: Women Helping Women

Name of Principal investigator: Dr Nancy Pistrang

Please initial box

1. I confirm that I have read and understood the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions.

2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that sections of any of my medical notes may be looked at by responsible individuals from UCL/UCLH or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

5. I understand that the research interviews will be tape recorded. I give permission for quotations from the interviews to be used in reports or scientific publications, with all names and other identifying information removed.

6. I agree to take part in the above study.

University College London Hospitals **NHS**

NHS Trust

UCLH Project ID number: 05/Q0502/37
Form version: 1
Date: 8.3.05
Patient Identification Number for this study:

Consent form continued

_____   _____   _____
Name of patient   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

_____   _____
Researcher (to be contacted   Email/phone number
if there are any problems)

Comments or concerns during the study:

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.

1 form for participant
1 to be kept as part of the study documentation
1 to be kept with hospital notes

Appendix D: Interview Schedules

Women Helping Women

Interview Schedule for Interview 1
(before peer support begins)

Background

Could you tell me a bit about when you were diagnosed with [type of cancer] and what's happened so far?

What treatment have you had/ are you expecting to have?

What has your experience of medical treatment been like so far?

Are there any aspects of the treatment you're particularly concerned about?

Sources of support

Who, if anyone, have you turned to for support during the last weeks/months/since you were diagnosed?

How have they attempted to help?

What kind of support have you wanted from them? (probe for emotional, practical/instrumental, informational support)

To what extent have they been able to provide the support you wanted?

Are [the people described above] the same or different from those who you usually turn to/receive support from when you're going through something difficult in your life?

To what extent can you share your feelings or talk openly about your concerns with him/her?

Do you know anyone else who's had [type of cancer] or something similar?

Have you talked to him/her about what you're going through?

Has anyone tried to support you and it not been helpful? (If yes:) What was less helpful about their support?

Expectations of the peer support service

When you first heard about the peer support service, what did you think?

What do you think it's going to be like?

What would you like to get out of it?

How would you know if it had been beneficial?

Women Helping Women

Interview Schedule for Interview 2
(after peer support ends)

.

Overall experience of the peer support project

What was your overall experience of talking to your 'peer helper'?

What were some of the best things about it?

What were the things you didn't like, or things that could have been better?

Processes of support

What sort of things did you talk about with your peer helper?

In what ways did she try to help?

What was it about your conversations that you think helped/ didn't help?

How was talking to your peer helper similar to, or different from, talking to other people you would normally talk to (or to people you had talked to before)?

Impact

Do you think you benefited in any way?

Were there any ways in which it was unhelpful or caused problems?

Did it have any impact on your feelings or how you responded to things emotionally?

Did it have any impact on how you coped with the treatment (or with the time after treatment ended)?

Did it have any impact on who else you talked to, or how much you talked to other people, about your experience of cancer?

Practicalities of the peer support project

What are your views about how the peer support project worked in practice? I'm thinking about such things as when is the best time to offer support, how long it should go on for, etc.

Prompts to cover:
(1) the timing of the support
(2) the duration (e.g., is 3 months about right?)
(3) the frequency of phone calls
(4) the initiation of phone calls
(5) telephone vs. face-to-face vs. internet support

What could be done to improve on how it's set up?

What would you tell others about it? Would you recommend it to women in a similar situation?

Would you consider becoming a peer helper yourself?

Women Helping Women

Interview Schedule for Peer Helpers
(after peer support ends)

Overall experience of the peer support project

Overall, what was your experience of being a 'peer helper'?

What were some of the best things about it for you?

What were the things you didn't like, or things that could have been better?

Processes of support

What sort of things did you talk about with the woman you were supporting?

In what ways did you try to help?

What was it about your conversations that you think helped/ didn't help her?

What difficulties, or dilemmas, did you face in trying to be supportive?

Impact

Do you think the woman you were supporting benefited in any way?

Were there any ways in which you think it was unhelpful or caused problems for her?

Do you think that *you* benefited in any way?

Were there any ways in which it was unhelpful or caused problems for *you*?

Practicalities of the peer support project

What are your views about how the peer support project worked in practice? I'm thinking about such things as when is the best time to offer support, how long it should go on for, etc.

(Peer Helper Interview/ctd.)

Prompts to cover: (1) the timing of the support
                             (2) the duration (e.g., is 3 months about right?)
                             (3) the frequency of phone calls
                             (4) the initiation of phone calls
                             (5) telephone vs. face-to-face vs. internet support

What could be done to improve on how it's set up?

What are your views about the orientation session(s) you went to? In what ways could it be improved?

As a peer helper, did you get enough support from the project team? In what ways were the supervision sessions helpful/ not helpful?

What would you tell others about the project? Would you have wanted to talk to a peer helper when you were going through treatment?

Would you recommend becoming a peer helper to other women? Would you do it again yourself?

Appendix E: Quantitative Measures

HAD Scale

Date:
Code:

This questionnaire asks about your feelings and well-being. Please read each item and tick the box opposite the reply which is closest to how you have been feeling in the past week. There's no need to take a long time over your answers; it's better just to give your immediate response.

Tick only one box in each section

I feel tense or 'wound up':
  Most of the time ....
  A lot of the time ....
  Time to time. Occasionally ....
  Not at all ....

I feel as if I am slowed down:
  Nearly all the time ....
  Very often ....
  Sometimes ....
  Not at all ....

I still enjoy the things I used to enjoy:
  Definitely as much ....
  Not quite so much ....
  Only a little ....
  Hardly at all ....

I get a sort of frightened feeling like 'butterflies' In the stomach:
  Not at all ....
  Occasionally ....
  Quite often ....
  Very often ....

I get a sort of frightened feeling as if something awful is about to happen:
  Very definitely and quite badly ....
  Yes, but not too badly ....
  A little, but it doesn't worry me ....
  Not at all ....

I have lost interest in my appearance:
  Definitely ....
  I don't take so much care as I should.....
  I may not take quite as much care ....
  I take just as much care as ever ....

I can laugh and see the funny side of things:
  As much as I always could ....
  Not quite so much now ....
  Definitely not so much now ....
  Not at all ....

I feel restless as if I have to be on the move:
  Very much indeed ....
  Quite a lot ....
  Not very much ....
  Not at all ....

Worrying thoughts go through my mind:
  A great deal of the time ....
  A lot of the time ....
  From time to time but not too often ..
  Only occasionally ....

I look forward with enjoyment to things:
  As much as ever I did ....
  Rather less than I used to ....
  Definitely less than I used to ....
  Hardly at all ....

I feel cheerful:
  Not at all ....
  Not often ....
  Sometimes ....
  Most of the time ....

I get sudden feelings of panic:
  Very often indeed ....
  Quite often ....
  Not very often ....
  Not at all ....

I can sit at ease and feel relaxed:
  Definitely ....
  Usually ....
  Not often ....
  Not at all ....

I can enjoy a good book or radio or TV programme:
  Often ....
  Sometimes ....
  Not often ....
  Very seldom ....

The Impact of Event Scale

Participant ID: _____

Date: _____

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how much you were distressed or bothered by each one DURING THE PAST SEVEN DAYS, with respect to your diagnosis or treatment.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I had waves of strong feelings about it.	0	1	2	3	4
7. I had dreams about it	0	1	2	3	4

BRIEF SCREENING TOOL AND PROBLEM
LIST J.C. Holland (adapted)

Instructions: First please circle the number
(0-10) that best describes how much distress
you have been experiencing in the past week
including today.

EXTREME
DISTRESS

10
9
8
7
6
5
4
3
2
1
0
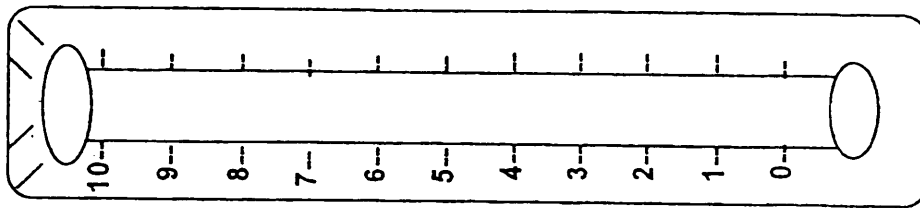
NO DISTRESS

Second, please indicate if any of the following has been a
problem for you in the past week including today please tick the box
next to it, or leave blank if not relevant

Practical Problems

☐ Child care
☐ Housing
☐ Insurance
☐ Transportation
☐ Work/school

Family Problems

☐ Dealing with children
☐ Dealing with partner

Emotional Problems

☐ Depression
☐ Fears
☐ Nervousness
☐ Sadness
☐ Worry
☐ Anger

Spiritual/religious concerns

☐ Loss of faith
☐ Relating to God
☐ Loss of meaning or
   purpose of life

Physical Problems

☐ Appearance
☐ Bathing/dressing
☐ Breathing
☐ Changes in urination
☐ Constipation
☐ Diarrhoea
☐ Eating
☐ Fatigue
☐ Feeling Swollen
☐ Fevers
☐ Getting around
☐ Indigestion
☐ Mouth sores
☐ Nausea
☐ Nose dry/congested
☐ Pain
☐ Sexual
☐ Skin dry/itchy
☐ Sleep
☐ Tingling in hands/feet
☐ Metallic taste in mouth

Other Problems: _____

Perception of Peer Support Questionnaire

Participant ID: _____

Date: _____

We are interested in how you felt about your experience with the peer helper. Please circle the appropriate number for each of the statements below.

	Disagree strongly	Disagree moderately	Neither agree nor disagree	Agree moderately	Agree strongly
1. My peer helper listened to what I had to say	1	2	3	4	5
2. My peer helper provided me with useful information	1	2	3	4	5
3. My peer helper showed concern for my feelings	1	2	3	4	5
4. I felt better after talking to my peer helper	1	2	3	4	5
5. My peer helper cared about how my treatment had gone	1	2	3	4	5
6. My peer helper gave helpful suggestions	1	2	3	4	5
7. I felt a sense of trust with my peer helper	1	2	3	4	5
8. I felt more confident after talking to my peer helper	1	2	3	4	5
9. I could call on my peer helper during times of trouble	1	2	3	4	5
10. My peer helper told me what to expect in certain situations	1	2	3	4	5

Appendix F: Preliminary Analysis

IPA preliminary analysis- First and second stages

Extract from the initial interview with patient 1

First stage of analysis		Second stage of analysis
▪ Distinction between normal life and cancer world	Yes and this is what, where this barrier comes between your normal, what used to be your normal life. You know my partner	▪ Cut off from normality
▪ Partner gets upset	gets really upset if, because, you know, the first thing you do, you come back from the appointment	
▪ Diagnosis leads to thoughts about death	having been told you've got cancer and you're looking round the room and you're thinking "oh	▪ Dealing with an uncertain future
▪ Planning for death	yeh so and so always said they'd like that, that vase" and then you look at that and I said to "(names husband) would you like that	▪ Facing own mortality
▪ Partner unable to tolerate discussion of death and dying	overmantle" and he said "stop it, I'm not going to listen to this!" But this is how your brain works.	▪ Others prohibiting the discussion of existential fears
▪ 'Tell you off'	And they tell you off because it's	
▪ Death is all you can think about	all you think about, well it's very difficult not to. And I think it	
▪ Only another cancer sufferer can understand	takes, it takes another cancer sufferer to understand that, that's why this is so important.	
▪ Consultants don't understand	Consultants aren't going to understand, unless they've had	▪ Only 'cancer club' members can understand
▪ Joining a new club you didn't want to join.	cancer. It's like joining a new club. A club you didn't want to join, you're forced into it, whether you like it or not	

Appendix G:
Main themes emerging from each transcript

IPA Stage 3

Main themes from the follow-up interview with Patient 3

Understanding through shared experience *"Well she understands everything, obviously...because she's been through it" (pg.1) "Because that person can just really understand. That's the important thing. You know, more than anybody really" (pg.8)*

Advice given based on experience *"Well if I say I've got constipation...then we can sort of discuss that. And she's told me what she used to take for it, so that, and sort of things like that really" (pg1)*

Talking 'lightens the load'- *"I mean when you talk to people, it helps, it lightens the load so much, it's amazing" (pg.2)*

Two way thing *"well we generally talk about what's stage I'm at of the treatment. And then I'll ask her how she is, and she'll tell me what she's been doing" (pg.3)*

Not appropriate/permitted to discuss existential fears with others *"Well if I say to (partner)... I sort of bring the subject up. He will just say "you're going to be fine, you're going to absolutely, you're going to be alright, you know, don't talk like that, it's not going to happen", and won't entertain it at all. A couple of people have said that, so it's not always appropriate" (pg.4)*

Being permitted to talk about death *"And she's up for it, she's up for it to talk about it, because she's been there. And that is the main thing really. And that's the ultimate thing isn't it, it's the cancer and then you've got death, so." (pg.4)*

Asking the right questions *"she knows what's going on, so she can ask the appropriate questions" (pg.5)*

Normalises experience *"it lightens it because then you, you know you're not the only person feeling that way or having horrible feelings" (pg.10)*

Distinction with professional support- "it's a two-way thing"- *"Well with a therapist or a counsellor it's only about you isn't it? And it's not. It's about the other person as well. And that's the difference" (pg.11) "But that's the same as any conversation with a friend, isn't it? Really it's a two-way thing"(pg.12)*

Reducing isolation - *"well it's just a connection with somebody that's, that's had it." (pg.13)*

Wanting to move on *"I want to kind of put it behind me" (pg4)*

Main themes from interview with peer helper 5

Shared experience provides a unique perspective *"So I think, although they're very supportive her friends and family I think when you've been through something like we have you're seeing it from a different perspective really"* *(pg.1)*

Advising from own experience *"I was trying to remember how I progressed through things and what I did and didn't do and everything, so I think she's found that helpful to know that"* *(pg.1)*

Not just about the cancer *"I think that's perhaps quite nice as well she can share other things as well with me"* *(pg.2)*

Patient feeling able to be open to share intimate aspects of her experience *"I was surprised perhaps that she's been quite as open as she has been with me. Because she's spoken, we've spoken about quite personal intimate side of things"* *(pg.3)*

Showing interest by asking questions *"I would also ask her questions back sometimes, without being too intrusive I think, just to try and lead on maybe from what she'd been saying"* *(pg.11)*

Not seeming fazed by anything *"I try not to sound to fazed by anything really"* *(pg.5)*

Importance of listening *"Well listen I thinks important, because I think people just being able to talk to somebody who's been through it is beneficial"* *(pg.5)*

Letting patient lead the conversations *"I usually take her lead"* *(pg.5)*

Worrying about the patient if they're feeling down *"I probably was worrying about her and it was staying on my mind a while afterwards"* *(pg.2)*

Not wanting to suggest too much *"I mean you don't want to say too much to people in way of suggestion because I think it's not my place"* *(pg.4)*

Worrying about saying the wrong thing *"I'm very conscious of not saying anything that I shouldn't be really"* *(pg.5)* *"That's another thing that I find a bit difficult after I've said it I think "gosh maybe I shouldn't have said that".so."* *(pg.6)*

Phone- 'less personal', provides emotional distance *"I'm probably quite glad it's on the phone really, because I think it's slightly less personal than when you're face to face with somebody... you're slightly removed aren't you on the phone"* *(pg.4)* *"I think on the phone if somebody's upset you can still slightly remain distant from it"* *(pg.12)*

Passing on the worry *"I think writing it down to you helps, because I feel like I've offloaded it then. I've put down what I've said and then, if I don't receive a phone call saying "what the heck have you said", then I know I'm ok"* (pg. 10)

Normalises her experiences *"I think it's quite nice for me that I've got somebody else in a similar situation that I know, if she's saying things I'm thinking "oh yes I'm not, it's not unusual then for me to be this way" so, that's, that's sort of beneficial to me I think."* (pg.2)

Being able to give back *"I think because we all feel when we've experienced something like this that it's nice to be able to help in some way, because so many people have helped us I think that, you know, from the medical profession, that I think you feel it's nice to try and be able to put something back a little bit"* (pg.1)

'Rewarding'- *"I think it's rewarding"* (pg.14)

Re-appreciating life *"I think it's something, it's important that we, we're aware of how lucky we've been I think, so I think sometimes looking back and thinking "golly yeh I was lucky that that happened and this happened, so. Because sometimes we go through life and we'll moan about something, and I think well no I've got to think about that"* (pg.8)

Appendix H: Higher Level Themes

IPA Stage 4

Extracts coded under Theme 1.2: Understanding through shared experience

"...the only people who really understand now are the people who have had a diagnosis of cancer. If you've never had one you will never really understand, because it's indescribable. All your worst things that could possibly happen, that's it" (P1)

"And everything I talk about she understood. There wasn't anything in my life that I talked to her about that she said erm I'm not so sure about that. Never, it was 'and when it happened to me, this is how', or we would have a laugh or would think about what we both had shared" (P2)

"Because she has been through all that trauma etc...when I talk about certain things that's happened to me she is able, yes and it happened to me" (pg.1) "And everything I talked about she understood." (P2)

"I mean I'm not saying that my family and my close friends and my sister don't support me. Of course they do, but it's a different kind of support. Yes I do talk to them about everything that's going on but I don't think that they really understand as much as (peer helper) does." (P2)

"I think because sort of friends and family despite, as much as they'd like to understand, they don't...because they're not in my position...whereas (peer helper) might get the same sort of awkward situations" (P4)

"Well she understands everything, obviously...because she's been through it...Because that person can just really understand. That's the important thing. You know, more than anybody really" (P3)

"I know that the oohs and aahhs that she is making is because she is in the same situation, not somebody that's trying to give me sympathy." (P4)

"She listens, she's very good at listening to what you've got to say and I think she understands what I'm talking about. This is the main thing, that she understands what you're talking about. (P5)

"you do get that sense well she know what I'm talking about because she asks the questions...she knows what questions to ask...well we talked about the dilation and the bleeding. She knew, she said "well how does that affect you", you know, she knew exactly...Int:Were they questions that other people maybe haven't asked" P5: "Oh definitely, because that's not the sort of thing that you tend to volunteer, you say you've had a cancer op and that's it" (P5)

"She'll just sort of give you her personal scenario of, you know, when that might have happened or "oh yes", you know. She just sort of gives you another side to it, so that's quite nice" (P4)

"I'm actually interested in her and her experiences, so hopefully asking questions that show that I was interested, but without being invasive I guess." (PH4)

"I think it's maybe making her look at things sometimes in a different way" (pg. 7), journey to the retreat (PH2)

"Well she told me that it was good to talk to someone that knew exactly how she felt" (PH3)