OLDER ADULTS LIVING WITH CANCER: SUPPORTIVE CARE NEEDS AND UTILIZATION OF PEER SUPPORT SERVICES

by

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ABSTRACT

BACKGROUND: Cancer is primarily a disease of older adults with sixty percent of all incidences occurring in individuals 65 years and over. Coping with cancer may entail additional challenges for older adults due to co-morbidities, declining mobility, reduced social networks and ageism. To date, the majority of research examining supportive care needs has focused on younger women with breast cancer. Little attention has been paid to older adults' experience with cancer, particularly with respect to psychosocial support.

PURPOSE: The aims of the present studies were twofold: (1) to learn more about peer support services in Ontario, specifically: the type and location of available programs; extent of utilization by older adults; and factors that might facilitate or inhibit use by older adults; and (2) to gain a better understanding of the experiences and challenges facing older adults living with cancer, strategies and resources used to meet these challenges, unmet support related needs, as well as awareness of support services, principally peer support.

METHODS: First, peer support services in Ontario were identified through an environmental scan. Subsequently, interviews were conducted with 24 key contacts from a purposeful sample (based on type and geographic location) of 30 of these groups. Next, surveys were administered to participants (n=220) and facilitators (n=39) from these groups to establish a profile of current peer support users and deliverers, and examine the extent to which older adults (age ≥ 65) utilized these services. Finally, a preliminary, in-depth, qualitative exploration from the perspective of older adults living with cancer was conducted through a focus group (n=6) and interviews with 20 older adults.

RESULTS: The environmental scan yielded a total of 177 peer support cancer programs across Ontario; predominately group-based (93%). Most were located in urban centers. Few programs targeted colon cancer. In the 30 groups examined, breast and prostate cancer were the most common focus (60%). Group facilitators were primarily female (75%) and most had personally experienced cancer (77%). The male facilitators were older (p <.05) and most likely to lead the prostate groups. None of the programs systematically collected client information. Clients ranged in age from 25 to 91 years (mean = 64 ± 10.7). Many were long-term cancer survivors (average five years post diagnosis). Overall, less than half the clients were aged 65 or older. Clients over age 65 were predominately men (86%; p <.001) with prostate cancer. Almost 70% of program directors and over 90% of facilitators were unaware most individuals with cancer are over the age of 65. Interview participants were recruited primarily through the Canadian Cancer Society (CCS). Not surprisingly, 46% had participated in peer support. Older adults identified several challenges with respect to physical functioning, sexuality, emotional distress, and obtaining information. Participants utilized a variety of resources to meet informational and emotional challenges including, the Internet and the support of family and friends. Accessing routine follow-up care after the transition from ‘patient’ to ‘survivor’ was a significant unmet need.

CONCLUSIONS: The findings support the premise that cancer peer support services may be under-utilized by older adults, particularly older women. The reasons for these findings remain unclear although ageism may be a factor. Due to the reliance on a convenience sample, qualitative findings that older adults were generally able to meet their supportive care needs cannot be generalized to all older adults living with cancer. Large organizations such as the CCS need to begin systematically collecting demographic and other information on clientele to enhance program planning and delivery. Further research studies on older adults living with cancer are needed to examine their supportive care needs.

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CHAPTER 1: Introduction and Overview

1.1 Statement of the Problem

Cancer is primarily a disease of older adults with sixty percent of all cancer incidences occurring in individuals 65 years and over (Yancik & Ries, 2000). Demographic data indicates that in the next few decades the percentage of Canadians over age 65 will reach unprecedented proportions (Statistics Canada, 2003a, 2003b). Taken together, it is estimated that the total incidence of all types of cancer in Ontario will rise significantly (Cancer Care Ontario, 2002). Despite bearing a significant cancer burden, little attention has been paid to older adults and their experience with cancer particularly with respect to psychosocial support.

1.2 Study Rationale

While an extremely heterogeneous group, nonetheless, older adults ($\geq$ 65 years of age) with cancer share certain characteristics distinguishing them from younger (< 65 years of age) individuals with the disease. Compared to younger adults, cancer may present and progress in a different way (Repetto et al., 2003), treatment regimens may be tolerated differently, and the effects of treatment may be either muted or enhanced (Repetto & Balducci, 2002). Furthermore, older adults diagnosed with cancer are more likely to already be coping with other chronic health problems (Yancik, Ganz, Varricchio, & Conley, 2001). Other challenges facing older adults with cancer may include: ageism, lower literacy levels, diminishing cognitive status, increasing frailty, declining mobility, visual difficulties, and decreasing social networks (Guidry et al., 1996; Repetto et al., 2003; Wymenga, Slaets, & Sleijfer, 2001; Yancik, 1997).

Despite the recognition of challenges faced by older adults living with cancer, there is a paucity of information in the literature with respect to these older adults and the challenges facing this population. The few studies involving older adults have focused on issues such as palliative care (Brockopp, Warden, Colclough, & Brockopp, 1996; Jordhoy et al., 2003; Ragan, Wittenberg, & Hall, 2003); screening (Jernigan, Trauth, Neal-Ferguson, & Cartier-Ulrich, 2001; Mandelblatt et al., 1999; Mayo, Ureda, & Parker, 2001); or caregiving issues (Gilbar, 1999; Lowenstein & Gilbar, 2000; Teel & Press, 1999).

For the most part, older adults have been largely excluded from cancer related research (Fentiman et al., 1990; Yancik & Ries, 2000). When included in cancer studies and research in general, they are frequently grouped into one category (i.e., age 65 and over). This practice fails to consider the heterogeneity of older adults. Not only does aging proceed at a different pace for different individuals, there is a substantial variation in age-related decline, life style, work status, and physical health between a 65 year old and an 85 year old (Yancik, 1997).

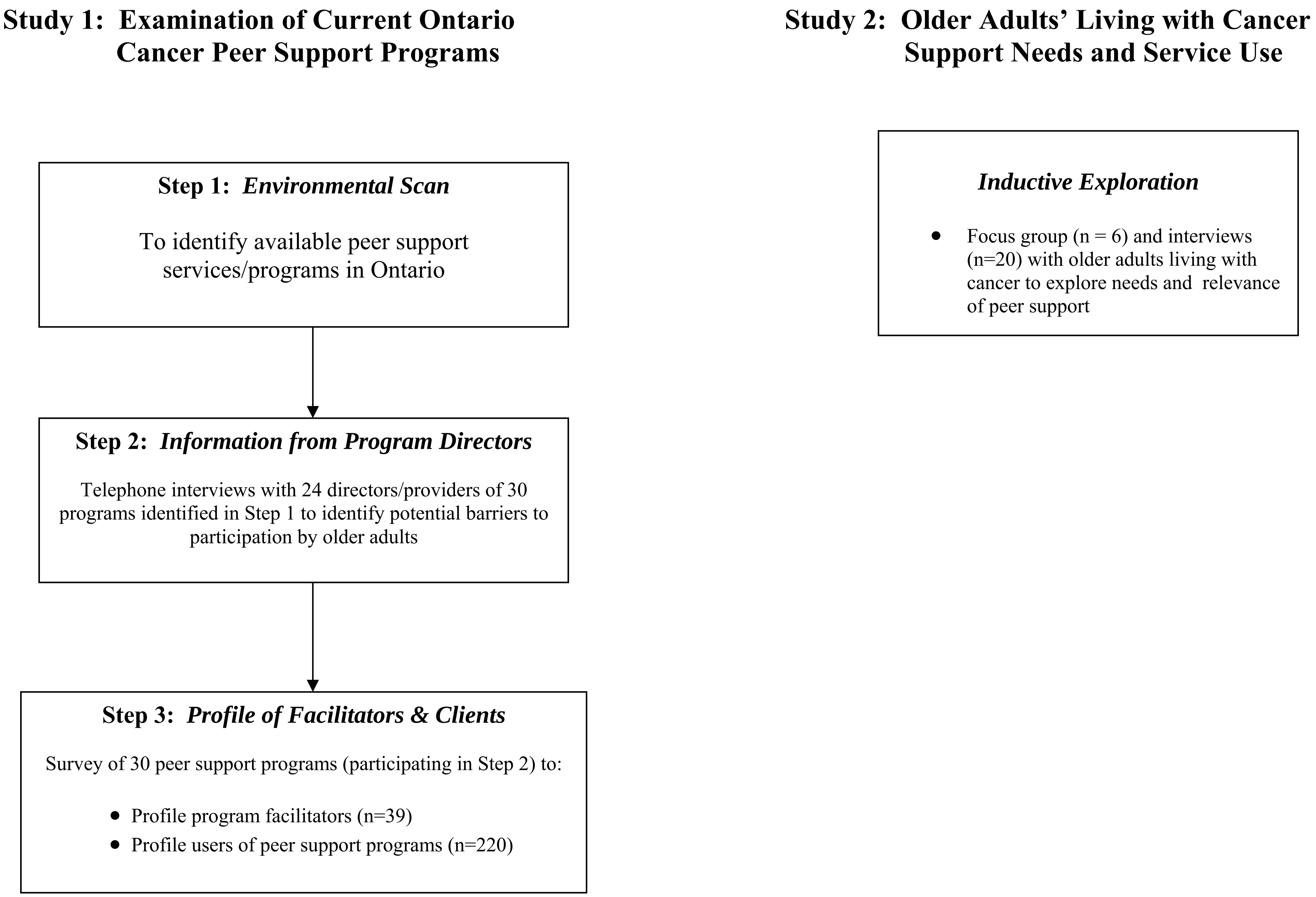
Examination of the literature pertaining to cancer peer support programs suggested that these services may not be reaching all segments of the affected population (Campbell, Phaneuf, & Deane, 2004). With one exception, namely prostate support groups, participants of peer support services appear to be primarily under age 65 and over-represented by breast cancer patients (Ashbury, Cameron, Mercer, Fitch & Neilson, 1998; Coreil & Behal, 1999; Stevens & Duttlinger, 1998). Furthermore, it is unclear whether study participants are representative of peer support participants in general. Few of the studies compared sample characteristics to program users as a whole, perhaps because this information is not systematically collected or examined by programs (Campbell et al., 2004). Moreover, the supportive care needs of older adults remain unexamined. Given the paucity of available information, further research into the utilization of peer support services by older adults, as well as their supportive care needs is needed.

1.3 Overview

The present project was based on the premise that little is known about the supportive care needs of older adults' with cancer particularly with respect to peer support. The overall aim of this project was to gain a better understanding of the role of peer support services in the lives of older adults. As illustrated in Figure 1.1 two separate studies were conducted. The first study examined existing Ontario peer support programs, while the second examined the perspective of older adults concerning their supportive care needs.

Chapter Two provides a detailed examination of the published literature concerning community based peer support services. The chapter begins by examining the relationship between aging and cancer. Next, supportive care is defined and presented as a framework for the delivery of cancer care services. The sections that follow entail a detailed description of face-to-face peer support services including: underlying theory; modes of delivery; participant characteristics; general barriers to participation; feasibility of use by older adults; as well as available evidence for program efficacy and effectiveness.

Chapters Three and Four present Study 1 and Study 2, respectively. For each study, the rationale and objectives are outlined followed by the methods, results and a discussion of the findings. The purpose of Study 1 was to learn more about peer support services in Ontario, specifically: the type and scope of available programs; extent of utilization by older adults; and factors that might facilitate or inhibit their use by older adults. This study involved three sequential steps consisting of: 1) an environmental scan to identify face-to-face peer support services in the province of Ontario; 2) subsequent interviews with peer support program contacts to learn more about their programs and identify elements that may enhance or impede participation by older adults; and 3) lastly, surveys of peer support facilitators and clients to learn more about who facilitates and attends these programs. Study 2, meanwhile, constituted a preliminary, in-depth, qualitative exploration of the needs of older adults living with cancer. Through a focus group and interviews the challenges and experiences of older adults living with cancer were examined, strategies and resources utilized to meet these challenges, as well as unmet needs were identified, and lastly, their awareness of support services, specifically peer support, was examined. Finally, Chapter Five summarizes the overall findings and provides recommendations for program planning and for future research.



Study 1: Examination of Current Ontario Cancer Peer Support Programs

Step 1: ***Environmental Scan***

To identify available peer support services/programs in Ontario

Step 2: ***Information from Program Directors***

Telephone interviews with 24 directors/providers of 30 programs identified in Step 1 to identify potential barriers to participation by older adults

Step 3: ***Profile of Facilitators & Clients***

Survey of 30 peer support programs (participating in Step 2) to:

- Profile program facilitators (n=39)
- Profile users of peer support programs (n=220)

Study 2: Older Adults' Living with Cancer Support Needs and Service Use

Inductive Exploration

- Focus group (n = 6) and interviews (n=20) with older adults living with cancer to explore needs and relevance of peer support

Figure 1: Project Flowchart

CHAPTER 2: Literature Review

2.1 Introduction

As stated in Chapter 1, this thesis is based on the premise that currently little is known about the supportive care needs of older adults with cancer, particularly with respect to peer support. Accordingly, this project explored the extent to which older adults are represented in peer support programs, as well as the challenges faced by older adults with cancer. Prior to embarking on these tasks, a search of the literature was conducted to determine the degree to which cancer peer support had been addressed with this population to date.

Several key words were used singly and in combination for this search, including: “peer support”, “supportive care”, “cancer”, “older adults”, “elderly”, “seniors”, “aging”, “support”, “social support”, “emotional support”, “information”, “utilization”, “barriers”, “needs”, “program”, “services”, “group support”, and “one-to-one”. The following databases were searched: Medline (1953 – present); Psych-Info (1840 – present); CancerLit (1963 – present); Social Services Abstracts (1980 – present); Sociological Abstracts (1963 – present); Nursing & Health Services (1982 – present); and CISTI Source (1994 – present). Reference lists from primary articles were subsequently examined for additional, possibly relevant information.

To lay the groundwork for the present study, this chapter begins by examining the relationship between aging and cancer. Next, supportive care is defined and presented as a framework for the delivery of cancer care services. The sections, which follow, entail a detailed description of face-to-face peer support including: underlying theory; modes of delivery; general barriers to participation; feasibility of use by older adults; and evidence for its efficacy and effectiveness.

2.2 Aging and Cancer

Over the next 30 years, the number of people over the age of 65 will increase from 13.2% to 24.5% of the Canadian population (Turcotte & Schellenberg, 2006). While the aging of society will have widespread implications within the Canadian health care system, it is expected to be of particular significance to cancer care since 60% of all cancers are diagnosed in individuals 65 years of age and over (Yancik & Reis, 2000). Moreover, for some common cancers, the proportion is even higher – 68% for lung, 72% for colorectal, and 67% for prostate (Pollack et al., 2005). Thus, as society ages, the total incidence of all types of cancer in Ontario is expected to rise from 53, 400 cases in 2002 to 91,000 in 2020 (Cancer Care Ontario, 2002). Taken together, these changing demographics are expected to have significant impact on the implementation and delivery of cancer care programs.

While an extremely heterogeneous group, nonetheless, older adults with cancer share similar characteristics distinguishing them from younger individuals with the disease. Compared to younger adults, cancer may present and progress in a different way (Repetto et al., 2003), treatment regimens may be tolerated differently, and the effects of treatment may be either muted or enhanced (Repetto & Balducci, 2002; Repetto et al., 2003). Furthermore, the diagnosis of cancer is more likely to occur when older individuals are already coping with other health problems (Yancik et al., 2001). Other challenges facing older adults with cancer may include: ageism, lower literacy levels, diminishing cognitive status, increasing frailty, lowering mobility, visual difficulties, and decreased access to social support (Ragan et al., 2003; Wymenga et al., 2001; Yancik, 1997).

Despite the number of older individuals living with cancer and the unique challenges faced by this group, there is a paucity of information in the literature pertaining to psychosocial support and management with this population. The few studies involving older adults with cancer have primarily focused on palliative care (Brockopp et al., 1996; Jordhoy et al., 2003; Ragan et al., 2003), screening (Jernigan et al., 2001; Mandelblatt et al., 1999; Mayo et al., 2001), or caregiver needs (Gilbar, 1999; Lowenstein & Gilbar, 2000; Teel & Press, 1999).

Elderly individuals with cancer are less likely to be offered the chance to participate in research (Fentiman et al., 1990; Yancik & Ries, 2000). Generally, when included in studies, older adults are grouped into one large category (age 65 and over) without consideration given to the considerable diversity within this population. Not only does aging proceed at a different rate for different individuals, there is a substantial variation in age-related decline, life style, work status, and physical health between a 65 year old and an 85 year old (Yancik, 1997).

While there is growing evidence that cancer in the elderly may not be like cancer in the young, little attention has been paid to older adults and their experience with this disease. Older adults remain underrepresented in studies and issues significant to this population (e.g., the consequence of co-morbidities) remain unexamined. Older adults present unique challenges to health service delivery in general and cancer care services in particular. Taken together with the expected rise in the number of older adults with cancer, these services must be examined within the context of aging. Before proceeding to look at support services and programs with respect to the aging process, it is important to understand both the current framework governing these services in Ontario along with their scope of availability.

2.3 Supportive Care

Individuals diagnosed with cancer face several challenges related to not only the physical presentation of the disease, but also to its social, economic, psychological, emotional, and spiritual impact. These challenges will differ from individual to individual and may vary over time throughout the course of the disease (Supportive Care Working Group, 2002). Supportive care services are believed to enhance an individual's abilities to meet a number of these challenges. Supportive care is defined as, " The provision of the necessary services for those living with or affected by cancer to meet their physical, psychosocial, informational and spiritual needs during the diagnostic, treatment, and follow-up phases encompassing issues of survivorship, palliation, and bereavement" (Fitch, 2000, p.40). Understandably, no single program or service can successfully meet all these needs throughout the cancer care continuum (from diagnosis, and treatment to follow-up phases).

While supportive care needs may vary as the disease unfolds, it is believed that all cancer patients require: 1) relevant and understandable information; 2) symptom management; 3) emotional support; and 4) effective communications with the health care team (Cancer Care Ontario, 2004). As conceived by Cancer Care Ontario (2004) and as illustrated in Figure 2.1, based on the literature, it appears that over half will require specific support interventions; one third will require expert psychosocial or rehabilitation, while about 10% will require ongoing professional psychosocial/spiritual intervention or complex symptom control.

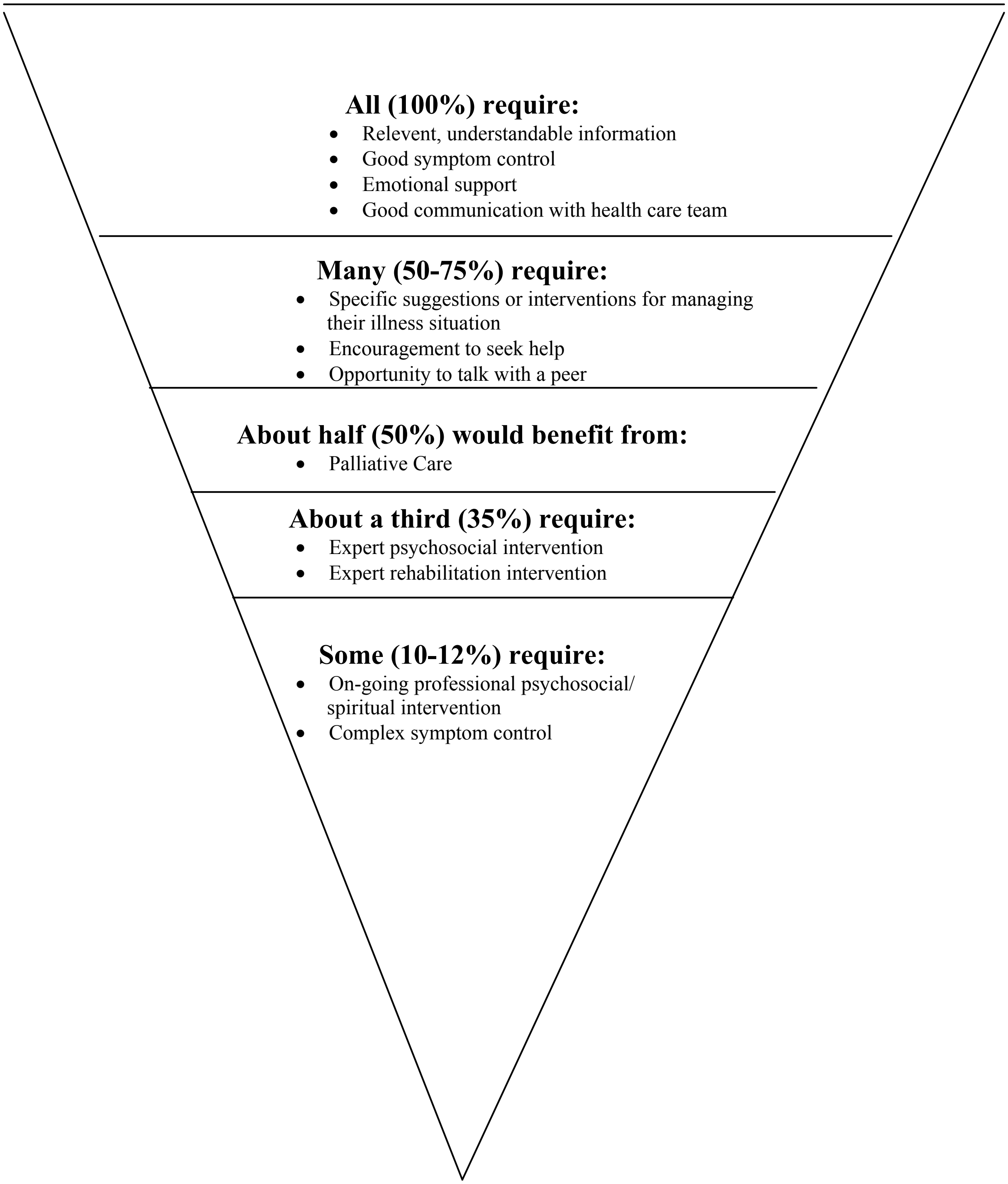


Figure 2.1: Requirements for Supportive Care – Taken from *Supportive Care. In GTA 2014 Cancer Report.*Cancer Care Ontario (2004, p.3)

Figure 2.2 presents a conceptual framework for both formal and informal supportive care interventions. As illustrated, the ultimate goal of supportive care is to enhance quality of life through interventions that meet the various needs of individuals with cancer throughout the care continuum. These interventions are provided through both informal (i.e., by family and friends) and formal mechanisms. Formal interventions are found in both the cancer care system and the community at large. Within the cancer care system, supportive care is delivered primarily by professionals either as an integral part of quality cancer treatment (e.g., empathetic patient care and teaching by oncology nurses), or through specialized interventions by oncology dieticians, psychologists, and social workers (Gray, Goel, Fitch, Franssen, & Labrecque, 2002). Outside the cancer care system, formal interventions can be found in many community settings many delivered by volunteers (e.g., patient transport, meals on wheels, home visitation, and peer support).

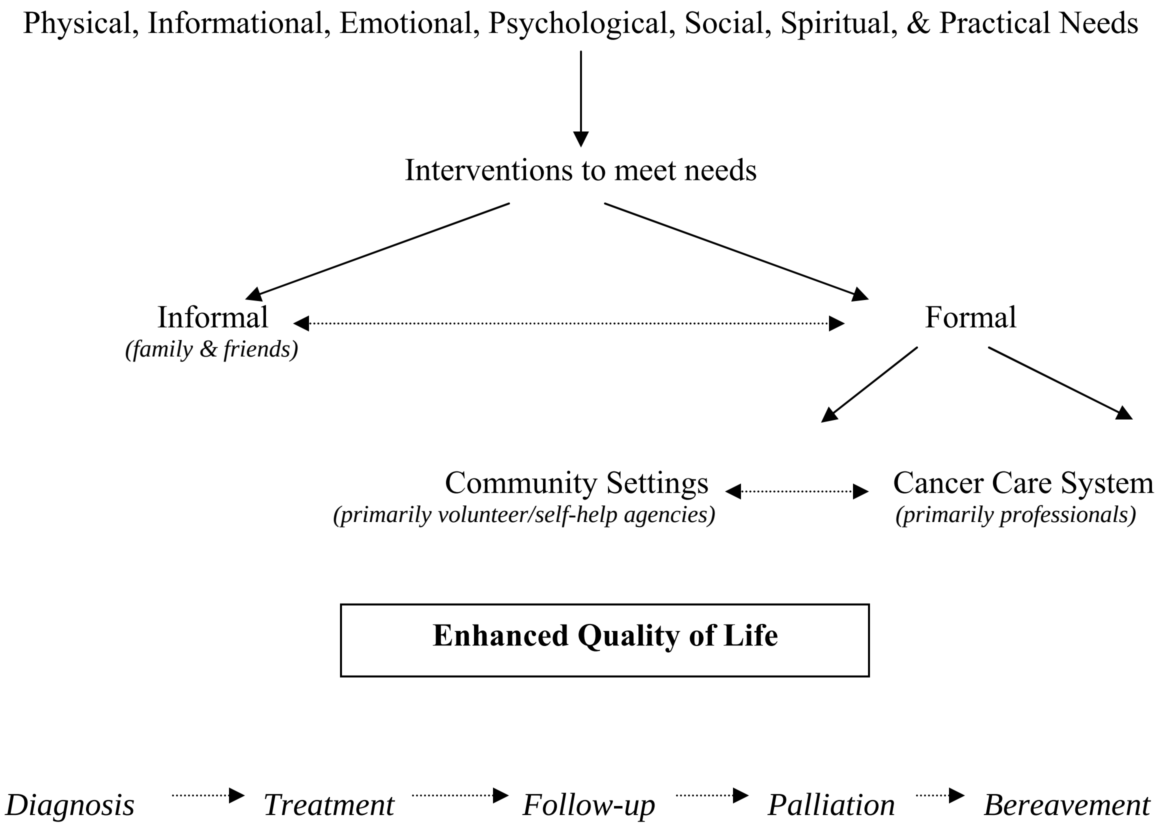


Figure 2.2: Supportive Care Interventions Schema

While supportive care services have received some attention in the literature, research has been primarily limited to examination of supportive care needs (Bilodeau & Degner, 1996; Bonevski et al., 2000; Foot & Sanson-Fisher, 1995; Galloway et al., 1997; Graydon et al., 1997) and the effectiveness of interventions (Ashbury, Cameron, Mercer, Fitch, & Nielsen, 1998; Billings, Joza, & Bielecky, 2003; Fawzy, 1999; Gustafson et al., 2001; Helgeson, Cohen, Schulz, & Yasko, 2000). Few studies have examined barriers to supportive care service utilization with identified barriers including lack of awareness (of available services) and limited professional referral (Eakin & Strycker, 2001; Fitch, 2000). Studies which have specifically looked at supportive care for older adults have been limited to examining interventions aimed at alleviating physical symptoms such as pain, weight loss, and cytotoxicity (Balducci & Carreca, 2003; De Cicco et al., 2002).

2.3.1 Cancer Supportive Care Services in Ontario

Cancer Care Ontario, an agency of the Provincial Government, is the principal governmental advisor on cancer care issues. Currently, Cancer Care Ontario brings together services within the cancer care system through the Regional Cancer Programs. Both medical treatment and supportive care services are offered in 12 Regional Cancer Centres within nine Cancer Care Ontario Regions. The bulk of medical services (including all radiotherapy) are available through the Regional Cancer Centres. However, services are not limited to these settings as surgery and chemotherapy are offered in many hospitals throughout the province. While no principal source listing available Cancer Centre based support services exists (Cancer Care Ontario, 2004), examination of the nine Regional Cancer Centres' websites indicates a variety of services are available including: assistance with nutrition management; pain and symptom management; counselling; social work; and pastoral care.

One comprehensive source, listing many of the available community based cancer services in the province, was found namely, the Canadian Cancer Society's (CCS) on-line Community Service Directory (Canadian Cancer Society, 2006). Using their postal code, interested individuals can easily search this directory for programs and services within their community. Over 4,000 cancer-related services in Canada are listed including:

- accommodations;
- advocacy;
- bereavement support;
- counselling;
- equipment and prosthesis;
- financial assistance;
- form completion;
- home health care;
- home services (friendly visits; Meals on Wheels);
- hospice;
- legal support;
- skills for looking your best;
- palliative care;
- nutrition;
- support groups; and
- transportation.

To illustrate the scope of available services, a list of community-based services, contained on the CCS directory for the Region of Waterloo, is shown in Appendix A. While these services have been categorized to meet physical, informational, emotional, psychological, social, spiritual, and practical needs, it is important to note that many of these services (e.g., HopeSpring) address multiple needs.

Although a wide range of formal supportive care services can be found in both community and cancer care settings in Ontario, current services are not well integrated resulting in gaps, duplication of services, and under-utilization (Cancer Care Ontario, 2004). Specifically, a recent study by the Canadian Cancer Society, Ontario Division (2003), which examined cancer patient and caregiver needs across the province identified several deficiencies in meeting needs related to: 1) dissemination of information; 2) emotional support; 3) support with daily living; 4) respite care; 5) financial needs; and 6) work related issues.

2.4 Peer Support Services

The diagnosis of cancer can be emotionally demanding (Koopman et al., 2001). Through the various stages of cancer care individuals are faced with emotional challenges. While various types of support exist to meet these emotional challenges, the availability of someone to discuss feelings, particularly negative ones, appears to be one of the most important (Helgeson & Cohen, 1996). Peer support appears to be a service able to assist some individuals in meeting these challenges. Prior to examining peer support services, a brief description of the social support theories underlying this intervention will be presented.

2.4.1 Social Support

Research has established empirical evidence for the association between social relationships and health (House, Landis & Umberson, 1988). In the case of cancer, the support of family and friends is generally considered to be associated with psychological well-being and, possibly, longer-term survival (Soler-Vila, Kasl, & Jones, 2003; Thoits, 1995). House, Umberson, & Landis (1988) note that the terms social support, social networks, and social integration are frequently used interchangeably for a wide array of phenomena pertaining to the effects of social relationships on health and well-being. At times of health crisis and distress, social networks provide instrumental (e.g., tangible assistance such as a ride to medical appointments), informational (e.g., where to find the wig boutique), social (e.g., visitation) and emotional support (e.g., listening and talking about problems and concerns) to those in need (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; House et al., 1988).

Several processes are identified in the literature by which social support is thought to influence well-being. Social support is believed to buffer the effects of stress by enhancing coping with and reappraisal of the stress (Lazarus, 1999; Thoits, 1995). The helper-therapy principle suggests that participation in a social network provides not only the opportunity to receive help but also to give assistance, which may enhance self-efficacy and self-esteem (Helgeson & Gottlieb, 2000; Reissman, 1965). Social networks provide opportunities for both upward and downward social comparisons. Upward social comparisons occur when an individual compares himself or herself to someone in a more advantageous position. In the case of a cancer diagnosis, this comparison may be to a survivor, who acts as a role model, offering the hope that 'cancer can be beaten'. Downward social comparison, meanwhile, occurs in the other direction – toward those less well off. In this instance, comparisons may enhance self-esteem through the realization that one is not as affected by cancer as others are (Festinger, 1954; Helgeson & Cohen, 1996; Lynch, 2000). Yankowich & Stam (2003) suggested that cancer "upsets the equilibrium between the individual's previous, current and future sense of self" (p. 734) forcing a re-evaluation of their life story. They suggested that cancer support groups provide an alternative social milieu in which individuals can understand the inherent identity-altering experience of cancer. Support groups provide cancer patients with an opportunity to talk about their illness with others undergoing similar transformations.

While tt has been long taken for granted that the size of social networks and the exchange of social support decreases with age, studies using large representative samples have indicated that there are few changes in social relationships across the lifespan (Antonucci, 2001). While the size of social networks may decrease, the number of close relationships and the amount of emotional support remains relatively stable until very old age (Antonucci, 2001). Age appears to be important for understanding the breadth of social resources available but not the depth of these relationships (Ajrouch, Blandon & Antonucci, 2005). With respect to gender, social networks among men and women differ in complex ways across the lifespan. In general, women have larger and more diverse social networks than men however; these network resources become more limited for women as they age (Ajrouch et al.). Older women appear to be particularly vulnerable to gaps in social support since they are more likely to experience widowhood (45% of Canadian women age 65 and over (Li, 2006)), illness, and financial strain (Antonucci, Lansford & Akiyama, 2002). Moreover, for many, their primary source of support (a spouse) may also need care (Helgeson & Gottlieb, 2000).

Research suggests that for some individuals with cancer their emotional support needs are not being met by their naturally occurring social environment. Individuals may feel alienated from their existing social network of family and friends, particularly if the network minimizes negative feelings or if the cancer has negatively affected social relationships. Family and friends may discourage the expression of feelings, minimize difficulties, or withdraw out of fear or discomfort (Helgeson & Cohen, 1996).

Peer support, defined in cancer as, “support from an individual who has previously experienced cancer” (Dunn, Steginga, Occhipinti, & Wilson, 1999, p.13) has emerged as a means to alleviate emotional support deficits. Peer support provides an opportunity to share feelings and experiences in a non-judgmental environment, assist others, increase empowerment and knowledge, foster a sense of community, and make social comparisons (Campbell et al., 2004; Helgeson & Gottlieb, 2000; Pilisuk, Wentzel, Barry, & Tennent, 1997; Ussher, Kirsten, Butow & Sandoval, 2006). As such, peer support is seen as an important aspect of a cancer supportive care network (Fitch, 2000).

Various approaches for delivering cancer peer support services are described in the literature including: telephone (Billings et al., 2003; Boudioni et al., 1999); Internet based services (Lieberman et al., 2003; Winefield, Coventry, Pradhan, Harvey, & Lambert, 2003); and face-to-face (Ashbury et al., 1998; Cameron, Ashbury, & Iverson, 1997; Helgeson et al., 2000; Pilisuk et al., 1997). All approaches are believed to enhance various informational and emotional support needs (Fernsler & Manchester, 1997; Fitch, 2000). Since only face-to-face support was examined during this study, the discussion below will be limited to this type of support.

2.4.2 Face-to-Face Peer Support Services

Face-to-face support can be delivered either individually (one-to-one) or in groups. Support groups are offered by a variety of organizations for a range of cancer types and age groups (Canadian Cancer Society, 2007; HopeSpring, 2007). Generally, participants meet together at a clinic, community hall, or cancer support organization (e.g., Canadian Cancer Society) once a week for approximately one to two hours (Canadian Cancer Society, 2007; HopeSpring, 2007). In contrast, one-to-one support services appears to take place primarily in the hospital, immediately after surgery, or in the home (Ashbury et al., 1998; Dunn et al., 1999).

One-to-one Support Services

Four articles were found that examined one-to-one peer support services with all examining services for women with breast cancer (Ashbury et al., 1998; Cameron et al., 1997; Dunn et al., 1999; Rankin, Williams, Davis, & Girgis, 2004). Not surprisingly, study participants were exclusively women.

All of the studies reported participant ages; however, comparison across studies was difficult, as each has reported the data differently. For instance, Ashbury et al. (1998) reported the percent of study sample within a defined age group (e.g., 29% are ≥ 65), Dunn et al. (1999) noted the average age of members of three focus groups (52, 47, and 61 years) and respondents to a survey (55 years), while Rankin et al., (2004), reported the average age (59 years) of study participants combining both those who attended peer support and the comparative group. Generally, study participants' ages appear to be younger than expected since 50-60% of new breast cancer diagnosis occur in women over the age of 65 – with 40% in women over the age of 70 (Brezden-Masley & Trudeau, 2005).

Only one article compared study participants to non-program users. Ashbury et al. (1998) compared a sample of the Canadian Cancer Society's Reach for Recovery program users (a service linking recently diagnosed women with breast cancer survivors) with non-users. Study participants consisted of 183 current clients (40% of program users) and 192 non-users identified through two provincial cancer registries. The sample of program users was found to be similar in marital and employment status, age, and income to non-users and differed in educational attainment (users were less highly educated) and treatment modalities (e.g., users were more likely to receive a mastectomy and undergo chemotherapy).

Group Support Services

Any program that brings together individuals with similar diagnosis or problems for the purpose of learning, sharing, and mutual support can be considered a support group (Johnson, 2000). Support groups generally take on one of three forms: psycho-educational groups directed by professionals (usually located in hospitals or clinics); community based, peer facilitated groups; or a hybrid where leadership and co-ordination are provided by both professionals, in a non-directive role, and volunteers (Edgar, Remmer, Rosberger & Rapkin, 1996). While there is an extensive literature examining directed psycho-educational group support (e.g., Bordeleau et al., 2003; Classen et al., 2001; Geiss-Davis et al., 2002; Goodwin et al., 2001), few studies have examined community-based, peer-facilitated or non-directive type of support.

Sixteen studies were found that examined group support services facilitated by peers. While some of the studies included professionally led education or exercise components (e.g., Helgeson, Cohen, Schulz, Yasko, 2000), all contained non-directive, peer facilitated discussion. Most of the studies were primarily concerned with either breast (Gray, Fitch, Davis, & Phillips, 1997a; Helgeson, et al., 2000, 2001; Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004; Pilisuk et al., 1997; Stevens & Duttlinger, 1998; Winefield, Coventry, Lewis, & Harvey, 2003) or prostate cancer (Coreil & Behal, 1999; Gray, Fitch, Davis, & Phillips, 1997b; Katz et al., 2002; McGovern, Heyman, & Resnick, 2002; Poole et al., 2001).

Participants. Thirteen studies (detailed in Appendix B) were found that examined users of community-based peer support groups. It is difficult to determine the extent to which study samples are representative of program users since sample selection procedures varied among the studies and none compared study participants with program users in general. Three studies examined participants at a single, ongoing community based program (Grande, Myers & Sutton, 2006; McGovern et al., 2002; Pilisuk et al., 1997); five studies examined participants from a variety of community programs (Coreil & Behal, 1999; Gray et al., 1997a, 1997b; Katz et al., 2002; Montazeri, 1996;); while another five studies surveyed a population of cancer patients to examine their peer support participation (Krizek et al., 1999; Michalec et al., 2004; Poole et al., 2001; Stevens & Duttlinger, 1997; Winefield, Coventry, Lewis & Harvey, 2003). Two studies, (Grey et al., 1997a, b) recruited small samples (12 and 24 participants respectively) to take part in qualitative focus groups. Moreover, response rates were not reported for two studies (Coreil & Behal, 1999; Katz et al., 2002). Generally, subjects were simply a 'snapshot' of whoever was present in the program at the time and volunteered to take part in the study.

Similar to the studies examining one-to-one support, sample ages were reported in several ways. In general, it appears that participants in studies examining breast cancer support groups (all female), as well as those with predominantly female subjects were younger than expected. Mean ages in these studies ranged from 46 (Stevens & Duttlinger) to 63 years (Pilisuk et al., 1997) with one study reporting more than half the participants were under 50 (Gray et al., 1997b). In comparison, participants in studies examining prostate cancer support groups appeared to be age appropriate with over 50%

of the men attending 38 ‘Man-to-Man’ support groups reported to be between 71 and 80 years of age (Coreil & Behal, 1999).

Seven studies compared the ages of peer support users and non-users (Grande et al., 2006; Katz et al., 2002; Krizek et al., 1999; Michalec et al., 2004; Poole et al., 2001; Stevens & Duttlinger; 1997; Winefield, Coventry, Lewis & Harvey, 2003). Non-user participants were recruited from cancer registries (Grande et al. & Michalec et al.), a long-term national study (Katz et al.), or treatment settings (Krisek et al.; Poole et al., Stevens & Duttlinger; Winefiled, Coventry, Lewis & Harvey). With one exception (Winefield et al.), studies with predominately female samples found significant differences in the average age of users compared to non-users (Grande et al., & Michalec et al.). While Winefield, Coventry, Lewis & Harvey found no significant difference; their sample was restricted to women under the age of 70. In contrast, of two studies with primarily male samples, one found either no age difference between users and non-users (Katz et al.), while the other found that users were significantly older than non-users (Poole et al.). In the only study to examine peer support utilization by age and gender, Krizek et al. found that women with breast cancer who attended peer support were significantly younger than those who did not attend. No age difference between users and non-users was found for men with prostate cancer.

With respect to length of time since diagnosis, it appears support group participants tended to be longer-term cancer survivors. For instance, average length of time since diagnosis was reported by Katz et al., (2002), Poole et al. (2001) and Pilisuk et al. (1997) as 42, 30 and 40 months respectively. Similarly, Montazeri (1996) reported that 42% of participants were 1-5 years post diagnosis (with 39% over 5 years), while

Coreil & Behal (1999) reported 41% of participants were 3-5 years post diagnosis. Support group participants examined by Grande et al. (2006) were even further along in their cancer journey with a median time of 8 years since diagnosis.

The studies which specifically examined ethnicity, education, and income level of participants found that participants were generally white (over 90%), with some post-secondary education, and higher socioeconomic status (Coreil & Behal, 1999; Krizek et al., 1999; Pilisuk et al., 1997). However, a survey of 958 women with breast cancer identified from the Eastern North Carolina Tumor Registry, found no significant difference in peer support group participation between white and black women (Michalec et al., 2004). Michalec et al. (2004) attributed previous findings (indicating a racial difference in participation) to hospital-based sampling techniques, arguing that African American women may be more likely to participate in less formalized, community based support groups, which are generally not included in research studies.

Attendance Patterns. The three studies that examined patterns of attendance relied on retrospective estimates from current (Coreil & Behal, 1999; Krizek et al., 1999) or current and former participants (Pilisuk et al., 1997) – perhaps because, as Krisek et al. found, attendance records were not available. Two studies examined frequency of support group attendance. In the first study, attendance data was obtained from a retrospective survey of participants from 38 'Man to Man' prostate cancer support groups in Florida. Men attended these groups on average once per month with the majority of groups meeting on a monthly basis (Coreil & Behal, 1999). In contrast, women attending a YMCA support program in California (with a group discussion and exercise component) participated, on average, three times a month (Pilisuk et al., 1997). This program was offered five times a week, each time at a different location. Thus, it is difficult to separate frequency of attendance from program characteristics such as program availability and content.

With respect to length of attendance, overall, findings suggest that while some participants may attend a group for up to 10 years or longer (Pilisuk et al., 1997), most generally stay with a group for less than three years (Coreil & Behal, 1999; Krisek et al., 1999; Pilisuk et al., 1997. No significant difference in length of attendance was noted between male and female participants (Krizek et al., 1999).

Barriers to Participation. Few studies have examined barriers to participation in face-to-face peer support programs. Eakin & Strycker (2001) noted the most commonly reported barriers include lack of awareness and lack of referral. Already having adequate support is also frequently cited by individuals as reasons for not attending (Eaking & Strycker). Other reported barriers include, time and day of meeting, location of meeting, and feeling too tired or ill to attend (Pilisuk et al., 1997).

While older adult participation in peer support remains unexamined, other potential barriers to participation may include: mobility issues, access to transportation, fatigue, and frailty. Importantly, peer support is based on the premise that individuals will share feelings and experiences with 'like others'. If, as indicated in the literature, group members tend to be younger, this may present a deterrent to older adult participants.

Facilitators. Only one study profiled peer group facilitators (Coreil & Behal, 1999). Of the 41 facilitators who responded to the 'Man-to-Man' support group survey, 90% were prostate cancer survivors, 49% were over the age of 71, and 46% had completed the ‘Man-to Man’ Facilitator Training Program. Most of the facilitators were Anglo-American (85%), which reflected the ethnicity of participants (89%). Almost all (93%) had post-secondary education with the majority being retired physicians, other health providers, or managers.

Program Characteristics. Only three articles reported on characteristics of the support programs themselves, such as group size, frequency of meetings etc. (Coreil & Behal, 1999; Pilisuk et al., 1997; Montazeri, 1996). Number of participants per group varied widely. For instance, Montazeri reported participation ranged from 10-20 individuals per group, while Coreil & Behal reported groups ranged in size from less than 20 to over 60 individuals. Monthly meetings appeared to be the most common (Coreil & Behal; Montazeri) with session lasting between 1-2 hours (Coreil & Behal). Two articles reported on program content. Coriel & Behal, noted that the typical prostate group meeting consisted of time for personal sharing as well as a speaker/question and answer component. In contrast, Pilisuk et al., reported on a program, which combined a pool-based exercise element with a support group meeting involving both education and sharing components. Several of the groups were affiliated with a larger NGO such as the American Cancer Society (Coreil & Behal).

2.4.3 Efficacy & Effectiveness of Peer Support Programs

In the previous sections, studies concerning both one-to-one and group-based peer support interventions were reviewed to establish a profile of the ‘typical’ program client. This section examines available evidence on the efficacy and effectiveness of peer support services. Efficacy addresses the question, “Does the intervention produce an effect under controlled conditions?” whereas, effectiveness asks the question, “Does the intervention produce desired outcomes in the real world?". Thirteen studies were found that examined outcomes in face-to-face, peer facilitated support programs (three controlled interventions and 10 evaluation studies). Study details (design, peer support type, cancer site, samples, measures, and findings) are summarized in Appendix C.

Results from the three efficacy studies showed little benefit from peer support participation. Helgeson et al. (2000), Helgeson, Cohen & Schulz (2001) and Jacobs et al. (1983) found no impact on quality of life, anxiety, depression, interpersonal problems, or physical well-being. Helgeson, Cohen and Shulz (2001) determined that participation in an education group was more effective than peer discussion groups on health and well-being. It is important to note however, that the peer support intervention in Helgeson et al.'s study eliminated the educational component. As Dunn et al. (2003) observed, peer support rarely develops with such restrictions as most programs contain an educational component (for instance, they may use the peer-facilitated discussion to learn about effective ways of coping). Additionally, all of the studies were based on limited, 8-week peer support interventions, which may not be enough time to affect change.

While the findings from the 10 effectiveness (or outcome evaluation) studies were generally positive, most did not use a pre/post design – relying on retrospective reports of perceived benefits – and findings are suspect. Participants reported feeling less anxious and isolated, more reassured, as well as better able to communicate with their physician (Ashbury et al., 1998). Peer support appears to help individuals by enhancing the ability to cope, providing information, improving outlook, and reducing feelings of isolation (Cameron et al., 1997; Coreil & Behal, 1999; Grande, Myers & Sutton, 2006; Gray et al., 1997a, 1997b; Stevens & Duttlinger; 1998). The principal benefit from peer support appears to be a sense of connection which comes from sharing information and experiences (Gray et al., 1997b; Montazeri, 1996).

Unfortunately, none of these studies included a ‘process evaluation’ (examination of program delivery). While many studies reported high participant satisfaction, ‘client satisfaction’ surveys are problematic as such findings are vulnerable to response bias and rarely include input from dropouts. Moreover, such surveys do not generate much useful information about how a program can be improved or why clients may be dissatisfied (Myers, 1999).

Efficacy and evaluation studies investigating the effects of cancer support group participation to date have several methodological limitations. None of the studies have specified the criteria used to identify support groups, reported participation levels, or commented on the features of the group that were particularly salient. Samples have been primarily restricted to women with breast cancer. Importantly, studies have failed to control for stage of disease, treatment modalities, and a host of other important variables that can impact program adherence and outcomes. Many of the instruments used to measure outcomes were developed specifically for the studies without reference to the tool’s reliability or validity (c.f., Ashbury et al., 1998 and Helgeson et al., 2000). Comparison among the studies is difficult, as most have measured different outcomes.

Most studies have taken a “black box” approach to examining efficacy or effectiveness, that is, a simple input-output formulation (Lipsey & Pollard, 1989, p. 281). The program is regarded as a single entity rather than a complex amalgam of discrete components which may independently or interdependently influencing outcomes (Sidani, 1998). In contrast, a theory-driven approach addresses what works for whom and under which conditions of program delivery (Davidson, 2004). Characteristics of users, deliverers, as well as the nature of the intervention, and the settings in which the program operates can all affect outcomes (Sidani & Braden, 1998). For instance, program attendance should be examined to determine if there is a relationship between program adherence and outcomes while participant characteristics should be looked at to establish if the program is more or less beneficial to some subset of clients. To date, none of the examined studies has utilized this approach, perhaps explaining why relationships between program attendance and outcomes, as well as the effects of program settings and content have not been examined. Additionally, it remains to be established whether facilitator characteristics affects participation rates and/or outcomes.

2.4.5 Summary and Implications

Examination of the published literature in the field of cancer peer support suggests that these services may not be reaching all segments of the affected population. In fact, the majority of individuals with cancer do not use peer support services (Eakin & Strycker, 2001; Krizek et al., 1999). It appears most face-to-face peer support participants are younger women with breast cancer who are several years post cancer diagnosis. Generally, both men and women utilizing these services are white, better educated, and from higher socio-economic status. With few exceptions (namely, prostate support groups) participants of studies in this area tend to be younger and over-represented by breast cancer patients. Furthermore, it is unclear whether these study participants are representative of peer support users in general. Few of the studies compared sample characteristics to program user's profiles perhaps because this information is not systematically collected or examined by programs (Campbell et al., 2004). Importantly, little is known about who uses peer support as no ‘survey’ of users has been conducted.

Not all individuals may benefit from participation in peer support. Studies rarely address the issue of which clients/user users benefit the most from various interventions. Characteristics of dropouts are rarely examined, participation rates not linked to outcomes, and other important variables (such as type of cancer, stage of disease, and treatment modalities) are not empirically examined or controlled for. Such data is essential for identifying who benefits from these programs and tailoring the intervention to maximize benefits.

While it appears that a substantial number and variety of peer support services are currently offered, it was difficult to establish precisely what is available. As previously noted, little attention has been given to older adults’ use of these services. Age-related changes such as decreased hearing and vision, as well as lower literacy rates, declining mobility, and frailty may adversely effect older adult participation. Presently, it is unclear whether such barriers account for older adults’ limited participation as their extent of actual use has not been examined.

2.5 Conclusions

As the number of older adults in Canada continues to grow and more individuals develop cancer, greater pressure may be placed on support services. Program providers will be required to stretch further already limited resources. It will become imperative that providers tailor program delivery to effective interventions and target services to individuals most in need and most likely to benefit.

Older adults present unique challenges to health service delivery in general. Although older adults are a very heterogeneous group, as a whole they are frailer, have more co-morbidity, lower literacy levels, and are more socially isolated than younger cancer patients. Little is known about the effects of these challenges regarding utility of peer support services. Clearly, more work in this area is warranted to identify supportive care needs of older adults particularly with respect to their use of cancer peer support services.

CHAPTER 3: Study 1 Examination of Ontario Cancer Peer Support Programs

3.1 Introduction and Objectives

As stated in Chapter 1, this thesis is based on the premise that little is known about the role of peer support services in the lives of older adults living with cancer. A review of the literature, presented in Chapter 2, supports this premise. Available information suggests that supportive care services may be reaching primarily younger adults. At present, it is not clear whether this situation is due to program recruitment strategies (i.e., not attracting older adults), delivery strategies (i.e., not meeting the needs and expectations of seniors), preferences of older adults for other sources of support, barriers to accessing support services, or a combination of these factors.

Over the course of the cancer care continuum, peer support services may address a wide variety of issues, including: survivorship, palliation, and bereavement. While examining service delivery across the entire continuum would be informative, there were several reasons for restricting the present study to services aimed at survivorship (diagnosis, treatment, and follow-up). Bereavement services, by their nature, are aimed at family members and significant others rather than the individual with cancer. With respect to including palliative care services, meanwhile, the needs and expectations of individuals at this point on the care continuum may vary significantly from individuals at other points. Moreover, recruiting individuals at the palliative stage would present significant challenges and, unlike services aimed at survivorship, palliative care services have received significant attention in the literature. Accordingly, the present study was restricted to face-to-face (one-to-one and group) peer support programs, aimed at issues of cancer survivorship for adults, and, for practicality, operating within the province of Ontario. More specific inclusion study criteria are presented below.

Study 1 aimed to gain a better understanding of the extent to which older adults are represented in face-to-face cancer peer support programs. In order to achieve this objective, it was necessary to:

1. determine the type and scope of community based face-to-face peer support services available in Ontario;
2. profile current users to determine the extent to which older adults utilize these services; and
3. identify potential factors that may facilitate or inhibit participation by older adults.

The following sections describe the study methods beginning with specification of data collection procedures, sample recruitment, and data analysis, followed by findings and discussion. Prior to detailing study methods, ethical considerations will be addressed.

3.2 Ethics

Ethics approval for this study was obtained from the Office of Research Ethics at the University of Waterloo. Voluntary informed consent was obtained from all participants. Letters of information and consent tailored to each audience are described in subsequent sections.

3.3 Methods

As illustrated in Figure 1.1, this study comprised three sequential steps:

1. an environmental scan of available community based peer support programs in Ontario potentially open to older adults with cancer;

2. telephone interviews with key contacts from a convenience sample of peer support programs; and
3. subsequent surveys of participants and facilitators from these programs.

3.3.1 Data Sources:

Step 1: Environmental Scan

Environmental scanning is a business management concept described by Brown & Wiener (1985) as, “a kind of radar to scan the world systematically and signal the new, the unexpected, the major and the minor” (p. 9). While a Pubmed search revealed few studies utilizing the term, “environmental scan” a Google search indicated that it was widely employed in the health care sector. In this context, the term ‘environmental scan’ seemed to be synonymous with an overview of available services – a kind of map that provides information on “who’s doing what” (Barker et al., 2005; Battye & McTaggart, 2002). Two recent examples of environmental scans in the health care sector include *Addiction Treatment Indicators in Canada: An Environmental Scan* (Thomas, 2005), and an *Environmental Scan of Métis Health Information, Initiatives and Programs* (Lamouche, 2002). It appears that environmental scans are published primarily in the form of government and non-government organization (NGO) reports.

Several resources were utilized to identify face-to-face cancer peer support programs in Ontario, including: the Canadian Cancer Society’s on-line directory of support services; community resource guides; cancer treatment centre websites; and Internet search engines (e.g., Google). Generally, these resources provided the following information: program type (group versus one-to-one); affiliation; target audience (gender, type of cancer, etc.); contact telephone number; and meeting location and times. The following criteria were used to select programs for inclusion in the scan:

- community based;
- conducted in English;
- administered by a volunteer agency;
- open to adults over the age of 65 (i.e., programs for children with cancer were excluded);
- targeting individuals with cancers commonly occurring in older adults (e.g., prostate, colorectal but not testicular carcinoma);
- using a peer based model of support; and
- addressing issues of survivorship (rather than bereavement or palliative care).

Step 2: Interviews with Key Contacts

A purposeful sample of key contacts (program directors/providers) from programs identified during the environmental scan was selected to participate in interviews. First, however, programs were categorized by region, as defined by the Ontario Division of the Canadian Cancer Society. This Canadian Cancer Society regional breakdown was chosen for expediency as it divides the province into eight geographically diverse areas namely; Northwestern (Thunder Bay & area); Ontario North East (Sudbury, Sault Ste. Marie, North Bay & area); Ontario East (Ottawa, Kingston & area); Central Lakelands (Barrie, Simcoe & area); South Central (Newmarket, Halton-Peel, Mississagua); Toronto (metro Toronto); Central West (Hamilton, Niagara, Waterloo Region); and Southwest (London, Windsor & area). In order to capture a diversity of programs within each region, three factors were considered:

- program affiliation (both Canadian Cancer Society and non-Canadian Cancer Society programs were included);
- cancer type (where possible, programs were chosen to represent a variety of cancer types affecting older adults); and
- geographic diversity (programs were chosen from a range of communities within each region).

Step 3: Survey of Program Facilitators and Users

If programs did not routinely collect background information on their facilitators and participants, key contacts who participated in Step 2, were subsequently asked to distribute surveys to their program facilitators and clients. The surveys were designed to provide a 'snapshot' of facilitators and users. Facilitators and clients attending the next regularly scheduled meeting of the support group (following the key contact interview) were eligible to participate. Only clients with a history of cancer were included (i.e., caregivers and partners were not asked to complete the surveys).

3.3.2 Procedures

Environmental Scan

The environmental scan began with a search of the Canadian Cancer Society's on-line directory of community support services. Using a list of postal codes for the province of Ontario and search limitations available in the directory (e.g., searched by terms such as '*support (emotional)*' and '*education*' but not '*hair donation*' or '*equipment*'), an exhaustive search of this database was conducted and an initial pool of support services was compiled. This pool was expanded further through a search of community resource guides (such as the Supportive Care for Cancer Community Resource Guide prepared by the Toronto Sunnybrook Regional Cancer Centre), Cancer Treatment Centre websites, and the Internet, until no further programs were identified.

Telephone Interviews

Initial contact was made with key contacts (generally a Program Director or Facilitator) via telephone. Programs were screened to determine if they were currently operating and met the inclusion criteria outlined above. A brief explanation of the purpose of the study was provided. A letter of information outlining the details of the study (shown in Appendix D) was then forwarded via fax or e-mail to eligible contacts who expressed an initial interest in participating. A follow-up phone call was made approximately one week later to verify continued willingness to participate and establish a mutually convenient time for the 30 - 45 minute phone interview. The interview protocol was first piloted through two face-to-face interviews with a program director and a facilitator, respectively. Based on their feedback, a question pertaining to limits placed on the discussion was added to the interview scripts.

During the interviews, detailed notes were taken for later analysis. At the end of the interview, program contacts were asked to assist with the distribution of the client and facilitator surveys. Those willing to assist were also engaged in a discussion of survey distribution and return strategies. Thank you letters (Appendix E) were mailed within one week to all participating program contacts.

Facilitator and Client Surveys

Program contacts, agreeing to participate in Step 3, were mailed a package containing:

1. a letter explaining the procedures for distributing questionnaires and noting attendance for both clients and facilitators (Appendix F);

2. facilitator questionnaires (Appendix G) and letter of information (Appendix H);
3. client questionnaires (Appendix I) and accompanying letter of information (Appendix J); along with
4. a stamped return envelope (to return questionnaires).

Directors were asked to distribute these at the next meeting of the support group. To ensure client and facilitator anonymity and confidentiality, an envelope (with a return address for the study) was provided with each questionnaire. Participants could then either a) complete the questionnaires during the group meeting and return them, sealed, to program contacts or b) take them home and return them directly to the researcher.

3.3.3 Instruments

Telephone Interview Protocol

Interviews with key program contacts were conducted using the protocol shown in Appendix K. This protocol was designed to obtain a better understanding of available programs, as well as features of program recruitment and delivery that might facilitate or impede participation by older adults. Program contacts were asked to generally describe their program, with respect to: structure (e.g., components, setting, time of sessions); accessibility (e.g., parking availability, proximity of public transit); promotion strategies (e.g., advertising activities); facilitators (e.g., age, gender, qualifications); and clientele (e.g., age, gender, cancer type). Program contacts were also queried about the extent to which they agreed with the statement, "*Most individuals with cancer are over the age of 65*" (on a scale of 1, strongly agree to 5, strongly disagree) and asked to comment on why they felt older adults were/were not using their services. Finally, they were asked to provide personal background information in order to describe the sample.

Facilitator Surveys

Print surveys for facilitators (shown in Appendix G) included close-ended questions on: age, gender, education level, work history, history of cancer diagnosis (if any), length of time as a facilitator etc., together with open-ended questions on motivations for becoming a facilitator and perceived benefits. Additionally, facilitators were asked to what extent (on a scale of 1, strongly agree to 5, strongly disagree) they agreed with the following statements: 1) *"People who have had cancer themselves make the best support program facilitators";* 2) *"Facilitators who are similar in age and gender to their participants can better understand their concerns";* and 3) *"Most individuals with cancer are over the age of 65".* These attitudinal ratings were specifically developed for the present study.

Client Surveys

Print surveys were also developed for peer support clientele (see Appendix I). Clients were asked to provide some background information (e.g., their age, gender, level of education), as well as their cancer diagnosis, other health problems, and work history. In addition, clients were asked about program attendance patterns (e.g., when they joined, length of attendance, reasons for coming); barriers to participation (e.g., difficulties encountered, transportation availability); as well as a few questions developed for the study to gauge their level of social support and attitudes towards seeking assistance. It should be noted that additional questions (16 f, g, and h) were added to the survey halfway through the study to examine preferences for particular facilitator characteristics, primarily similarities with participants with respect to age, gender, and cancer diagnosis.

3.3.4 Analysis

The telephone interviews and survey questionnaires yielded both quantitative and qualitative data. Quantitative data, analyzed using SPSS Version 14.0, comprised descriptive statistics (frequencies), as well as comparative non-parametric chi-square (χ^2) for categorical variables (e.g., gender & cancer type) and Mann-Whitney U tests for continuous variables (e.g., age & length of time attending program). In all cases, P-values were set at .05. Analysis of the qualitative data consisted primarily of a "content analysis" since the discussion and questions were highly structured and focused.

3.4 Results

This section begins with the findings from the environmental scan followed by a description of programs and key contacts participating in Step 2. Next, characteristics of the facilitator and clients who completed questionnaires are presented. Findings emerging from the "content" analysis of the interviews and open-ended survey questions are presented to elucidate and substantiate quantitative results.

3.4.1 Step 1: Environmental Scan

The environmental scan yielded a total of 177 programs across Ontario meeting the study criteria. Programs are presented in Appendix L stratified by region and type. The vast majority of programs were group based (n = 165; 93%) versus one-to-one (n=12; 7%). Judging by their name, about half of the programs (n=83; 47%) appeared to be directed toward individuals with breast or prostate cancer. While programs were found throughout the province, not surprisingly, many were concentrated in and around major metropolitan areas (GTA, London, Windsor, Ottawa etc.)

Few programs appeared to be targeted to minority populations – to the extent this could be determined by the program name. Only one program was advertised as being offered in a language other than English or French (i.e., a group support program in Toronto conducted in Cantonese). Additionally, Wellspring offers a group support program for gay men and their partners as well as a group for Aboriginal Canadians.

3.4.2 Step 2: Key Contact Interviews

As originally proposed, we were aiming for detailed information on 30 programs. As shown in Table 3.1, a total of 29 key contacts were approached. Of these, one individual represented a program (an ostomy group) which had no upcoming regularly scheduled meetings and, therefore, the program did not meet criteria. Four others declined to participate citing illness (n=1) and lack of interest (n=3). Three contacts, however, reported on more than one peer support program. Thus, the 24 participating program contacts represented a purposeful sample (variety of program affiliations, cancer types, diversity of geographic areas) of 30 different support groups.

Table 3.1: Regional Distribution of Participating Programs.

Provincial Region	Programs Approached n	Step 1: Program Contacts Interviewed n (%)	Step 2: Participated in Facilitator & Client Surveys n (%)
Northwestern	2	1 (4)	1 (3)
Ontario North East	3	2 (8)	2 (7)
Ontario East	4	4 (16)	4 (13)
Central Lakelands	3	2 (8)*	4 (13)
South Central	4	4 (16)	4 (14)
Toronto	5	3 (13)	3 (10)
Central West	4	4 (16)*	7 (23)
South Western	4	4 (16)*	5 (17)
Total	**29**	**24**	**30**

* Contacts reported on more than one program

As originally proposed, the intention was to limit the study strictly to non-professional, "peer facilitated" programs. However, as the study progressed it became apparent that this was impractical. For instance, while most of the Canadian Cancer Society programs were peer facilitated, non-peer facilitators were employed when Canadian Cancer Society Units could not obtain peer volunteers. In other instances, programs employed paid, professional facilitators who were also cancer survivors. This lack of consistency made it extremely difficult to distinguish between a "professional" versus a "peer" leader, thus this criterion was dropped.

The original intention was also to include programs representing a greater diversity of cancer types. The environmental scan, however, showed that a significant proportion (47%) of Ontario programs targeted persons with breast or prostate cancer. Only two community-based programs targeting individuals with colo-rectal cancer were identified, both of which were included in the study. While the Ostomy Association offers a number of support groups throughout the province, several are institution based (i.e., taking place in hospitals or other health settings), others met infrequently, and only one of the two groups approached responded to the initial telephone call. The Brain Tumour Foundation was also approached to participate, however; only one program was obtained from this source. Unfortunately, their Executive Director resigned two weeks after initial contact and no other individual from this organization felt qualified to act as a contact person. Finally, it was discovered that nearly all of the cancer-specific programs (targeted to sites other than prostate and breast) are provided by large self-help organizations such as Wellspring, Wellwood, and Hearth Place. All of these organizations declined to participate in the study citing a desire to "protect" or "not burden" their clients.

Similarly, it was not possible to include a sample of one-to-one programs. As previously noted, few such programs were identified in the scan. For one of the largest providers of community-based peer support programs, namely the Canadian Cancer Society, this type of support is not provided in person but rather through their *CancerConnection* telephone service. Moreover, all identified face-to-face, one-to-one programs were offered by Wellspring, Hearth Place, Wellwood, or HopeSpring. Although HopeSpring agreed to participate with respect to their group programs, this organization declined with respect to their one-to-one services. The HopeSpring Program

Director reported that their one-to-one clients were “too vulnerable” and generally “in crisis” and she did not wish to burden these individuals further.

Description of Program Contacts

Program contacts were a diverse group of paid employees (n=15) and volunteer program co-ordinators (n = 14) some of whom also functioned as group facilitators. Program contacts were primarily female (71%), ranging widely in age from 40 to 81 years (mean = 61.8 ± 11.3 years). While varied, most came from the ‘helping professions’ (i.e., nurses, social workers, teachers etc.) or previous/current employment in the volunteer sector. Contacts had been in their current positions from 2 to 15 years (mean = 6.8 ± 3.46 years).

Description of Programs

A breakdown of program characteristics is provided in Table 3.2. The majority of programs contacted (70%) were associated with large national organizations such as the Canadian Cancer Society, Breast Cancer Alliance, and the Canadian Prostate Cancer Network. These organizations provided a variety of assistance including: supplying meeting rooms, providing and training facilitators, advertising, and distributing monthly newsletters to participants. As well, these organizations provided educational materials (e.g., pamphlets, books, videos) and speakers. Only one group charged a nominal ($20.00/yr) fee for attendance; the rest covered program costs through their affiliated national organization or donations.

Table 3.2: Program Characteristics

Characteristic (N=30)	**n (%)**
Part of larger organization	
Yes	21 (70.0)
No	5 (30.0)
Fee to attend	
Yes	1 (3.3)
No	29 (96.7)
Number of Facilitators per program	
Mean ± SD	2.7 ± 2.9
Range	1-14
Facilitators Volunteers	
Yes	25 (83.3)
No, paid staff	5 (16.7)
Advertise Program	
Yes	30 (100.0)
Parking on site	
Yes	29 (96.7)
No	1 (3.3)
Public Transit Nearby	
Yes	19 (63.3)
No	11 (36.7)
Time of Day	
Evening	29 (96.7)
Afternoon	1 (3.3)
Length of group	
1 ½ hours	7 (23.3)
2 hours	23 (76.7)
Type of Cancer	
Breast	9 (30.0)
Prostate	9 (30.0)
Colon	2 (6.7)
Other	2 (6.7)
Mixed	8 (26.7)
Components	
Sharing only	14 (46.7)
Sharing & education	12 (40.0)
Sharing & occasional education	4 (13.3)
***Estimated* Number of Clients Attending**	
Mean ± SD	14.2 ± 12.6
Range	3 - 70
Median	12.0

Staffing. On average, most groups had three facilitators, ranging widely from 1 to 14. Generally, only 1-2 individuals facilitated a meeting at a time. All of the programs with large numbers of facilitators (n = 6, 10 & 14) were prostate focused. In these instances, one or two men at a time facilitated a meeting (rotating through a roster). Most (83%) were unpaid volunteers. Most groups (77%) were lead by 'trained' facilitators with training generally consisting of attendance at a one to two day workshop provided primarily by Canadian Cancer Society or Willow – a breast cancer support organization located in Toronto. Although a greater proportion of Canadian Cancer Society affiliated programs than non-Canadian Cancer Society programs (92% versus 65%) had trained facilitators, this difference was not statistically significant. While a few of the programs (n = 4) selected or interviewed potential facilitators, most reported that facilitators, "*kinda fell into place*". Essentially, there was general agreement as to the attributes needed by a facilitator. As summed up by one director such qualities included, "*compassion and good listening/hearing skills, and an individual who can be supportive, ability to handle dominant and withdrawn members, and keep the group moving*". One area of disagreement among program directors concerned the issue of whether the facilitator should be a cancer survivor. While some believed that this was "*not necessarily important*" others noted, "*It's really important that a facilitator be a survivor – that's who they want to talk to. I'm amazed at the number of people who ask that question when they phone up*".

Advertising and Promotion. All groups advertised their service. The two most common strategies for program advertisement were through the 'community events' sections in local newspapers (70%) and distribution of pamphlets (93%) in doctors offices, cancer clinics, community centers, and pharmacies. Some of the programs had developed other innovative ways to advertise their services. For instance, two breast cancer groups produced ‘pink bags’ that were distributed in the local hospital to women post surgery. These bags contained information related to treatment for breast cancer and the availability of breast prosthesis and wigs, along with a pamphlet promoting their program. One prostate group, meanwhile, had developed a working relationship with the urology group at a tertiary care hospital. This support group was given access to a small meeting room near the urology clinic and a support group facilitator was present at all times during urology clinics hours. Many newly diagnosed men were immediately referred to the group by the urologists.

Locations. All 30 programs convened in well lit, wheelchair accessible locations (e.g., churches, community centres), situated in areas of the community described as “*safe*” by program directors. As one director noted, “*When we have chosen venues for our meeting we have always had a safe environment in mind. Women are ill and vulnerable and we’ve had to think about the area being well lit and wheelchair accessible*.” Meeting rooms were invariably reported as ‘*easy to find*’ and 76% of the groups had either a formal reception desk or an informal ‘greeter’ to welcome new participants. Free parking was available for all but two sites and in both these instances, cost for parking was minimal (i.e., maximum $5.00). Access to public transit was close for 63% of groups, and all of those without public transit access were located in small towns with no public transit system.

Format. The majority of programs were ongoing. Only four (13%) were of fixed duration (all of them 10 weeks in length). About half the programs did not meet for the summer (56.7%); although, those targeting individuals with breast cancer were significantly more likely to continue meeting over the summer ($p < 0.05$). As these program contacts reported, "*Cancer doesn't take a holiday so we don't either*".

Only one group met during the afternoon (from 2-4 pm); the remainder met during the evening. Sessions ranged from 1.5 to 2 hours in length with the majority (77%) lasting two hours. Breast and prostate cancer were the most common focus (30% of the groups, respectively). Half of the groups emphasized emotional support through discussion (talking and sharing of experiences), while 40% gave equal weight to an information or education component (usually a guest speaker with expert knowledge). A further 13% of the groups occasionally included an education component.

While most of the programs targeting breast cancer were primarily a 'sharing' format (n=7) over 'sharing and education' (n = 2), the reverse was found for prostate programs where all eight were 'sharing and education'. The majority of the groups (83%) reported having "rules of conduct", which consisted primarily of "no doctor bashing" and discouraging participants from offering 'medical advice' or comparing treatment regimens.

Several program contacts for prostate cancer support reported that the 'sharing' portion was less well received than the educational component. As one contact noted, "*It's tough to pry it free and make them talk about it. Most are putting on their coats and going home after the speaker*". However, all program contacts did not share this belief as one noted, "*I'm surprised by how many men in their 60's and 70's are very willing to go there and share their experiences including some potentially sensitive issues*" while another stated, "*Some meetings are sharing only. Usually get only 8 to 10 guys but, they* *have sometimes been our most successful meetings*". It is important to note that when initially asked if they have a 'sharing' component, two prostate program contacts replied '*no*'. When probed further (i.e., asked if they have time for 'testimonials'); however, the answer became, "*Oh yes, the guys get up and talk about their experiences all the time*". Humour appeared to be an important characteristic of many of the prostate groups. Several of the program contacts mentioned, "*laughing at it all*" and *"joking around with each other*" as an important aspect of their meetings.

Estimated Participation Rates and Description of Clientele. Few program contacts could provide detailed demographic profiles of their clientele since, as noted below, routinely collected client information was often limited to client's names and contact information. The description that follows, therefore, is based on 'estimates' by program directors.

Average program attendance, as *estimated* by program contacts, ranged from 3 to 70 individuals per program (mean 14.2 ± 12.6, median 12.0). Only two programs reported being filled to capacity and none had a waitlist. While some of the groups included a support person, most were restricted to individuals with cancer (80%). Program contacts described their clientele as primarily female (33% of groups were exclusively female with a further 13% predominantly female), with most (60%) having either breast or prostate cancer. Contacts estimated that 2/3 of their clients were under the age of 60. One third of contacts did not know their clients' cancer status (i.e., whether they were in treatment, finished treatment etc.).

There was general agreement that the presence of long-term survivors in a group was an asset to the program. These individuals represented a 'beacon of hope' for those newly diagnosed. One contact noted, "[the] *most important comment is from new women who say, "it's amazing to see all you people alive*", while another (who was also a cancer survivor) reported, "*When I walked into that room* [where the prostate support group was being held] *and saw all those old guys sitting around laughing and scratching, for the first time I knew I was going to be all right".*

Program contacts made several salient comments with respect to their clients. They acknowledged walking " *a fine line between being available to them* [clients] *and fostering their own self-sufficiency*" as well as the limits of their program, "*community is a mess and sometimes volunteers say the wrong things but people are running on empty and need someone to listen*".

Evaluation Activities. None of the programs had conducted any formal evaluation studies (such as needs assessment, process, or outcome). Only six of the programs (20%) had, collected participant feedback – all via client satisfaction surveys that had been developed and distributed by the program directors/facilitators. None collected this feedback within the last two years. Several program contacts however, said that they receive considerable informal feedback as typified by comments such as, "*Feedback comes in funny ways. They'll talk to me at the end of the group, call me up*" and "*I get most of my feedback in the parking lot after the meeting. They let me know what they thought of the speaker and comment on other things going on in the meetings*." Client feedback was invariable described as "*positive*". As one director noted, "*98% come back so we must be doing something right*".

All eight of the prostate groups utilized client registration forms. These forms were generally limited to basic demographic information (usually name, address, e-mail, phone number, and, in one instance, type of treatment and Gleeson score), used chiefly as ‘mailing lists’ for the group’s newsletters. The remainder of the groups simply collected names and telephone numbers primarily to contact clients when meetings were unexpectedly cancelled (i.e., due to poor weather).

All of the Canadian Cancer Society affiliated programs (43%) were required by the Canadian Cancer Society to record the total attendance at each session – which is reported monthly to the local Unit. Unit Managers, in turn, submit this information monthly to Division. Attendance records were not retained (by either Canadian Cancer Society facilitators or local Unit Managers). With respect to non-Canadian Cancer Society affiliated programs, attendance was collected by only two (both prostate focused). For the remainder, (50% of the programs), contacts said that they were aware of “who comes and who doesn’t”.

None of the programs had a clear definition of a program ‘absentee’. Slightly over half of the programs (53%) contacted members who had missed sessions (usually through a telephone call from the facilitator or a group member). As one contact (who was also a facilitator) noted, “*I keep an eye on how many people are showing up. If I haven’t seen someone for a few meetings we* [the facilitator or a fellow group member] *will call them*”. The remainder relied on monthly newsletters or bulk emails to “*keep participants informed*”.

Contacts also noted that it was difficult to define a ‘dropout’ due to the ongoing nature of their programs. One contact noted that, *“As people get well they want to go back to work but, they still want to stay on the list. I leave it open ended with no pressure to come. You never know when they may need us again.”* Not surprisingly only twenty percent of programs contacted dropouts and all did so informally – similar to absentees, dropouts were "called" after repeated absences.

Directors' Beliefs about Older Adults and Cancer. When asked directly why their programs appeared to serve few older adults, several contacts replied, "*I don't know*". Others reported that they were seeing younger people because "*cancer is being diagnosed earlier*" and that, *"it's younger people who seek out help*". Some felt that older adults with cancer were being "*supported by family*" or "*perhaps turn to friends*" and that "*driving at night*" might discourage older adults (particularly women) from participating. A number of program contacts believed that older adults (principally older women) were more stoic and less likely to question their situation as noted in comments such as, "*they're not looking for information*", "*many older adults were raised not to ask questions*", "*they think, 'I know I'm going to die and if it's breast cancer, so be it'*", and "*older adults just deal with it and go on with life*". Several program contacts believed that the issues facing cancer patients/survivors differed between the generations noting, "*there's a lot of anger with younger women*" and "*for younger women there is the concern about children and partners*".

Figure 3.1 shows the percentage of program contacts who agreed with the statement, "*Most individuals with cancer are over the age of 65*". As can be seen, 67% moderately or strongly disagreed with the statement. Spontaneous responses to this statement were also revealing as illustrated by the following: *"that's not true", "we see so many young people"* and *"we're getting more and more younger guys coming out, guys in their 40's"*.

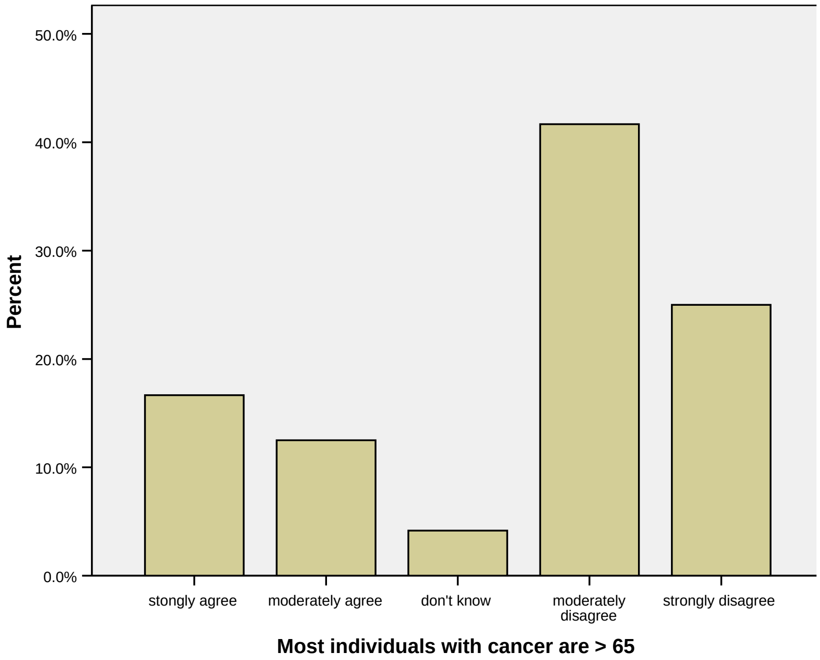


Figure 3.1: Program Directors' Beliefs

3.4.3 Facilitator and Client Surveys

Facilitator Characteristics

Contacts distributed a total of 43 facilitator surveys to the 30 programs. Thirty-nine surveys were returned for a response rate of 91%. As shown in Table 3.3, the majority of facilitators were female (75%), volunteers (83%), well educated (87% had at least some college/university). Eighty-five percent were born in Canada. Male facilitators were significantly older than the females ($p < .05$), with half of the male facilitators aged 65 and above (compared with 17% of female facilitators). Sixty-seven percent had been facilitating for at least three years.

The majority (77%) had been diagnosed with cancer, primarily breast (57%). Many of these (77%) were long-term cancer survivors (on average 9 yrs post diagnosis). Four were currently in active treatment – all for treatment of a recurrence. All of the 10 male facilitators had been diagnosed with cancer, eight of whom facilitated prostate focused groups.

Table 3.3: Facilitator Characteristics

Characteristic (N=39)	**n (%)**
Sex	
Female	29 (74.5)
Male	10 (25.6)
Age (yrs)*	
All	61.0 ± 11.4; 25 - 84
Female	58.8 ± 11.2; 25 – 73
Male	68.5 ± 8.8; 56 – 84
Education Level	
Did not complete high school	1 (2.6)
Completed high school	4 (10.5)
Some college/university	16 (42.1)
College/university graduate	17 (44.7)
Missing	1
Employment	
Full time	8 (21.1)
Part time	7 (18.4)
Unemployed/retired/unable to work	23 (60.5)
Missing	1
Type of Occupation	
Management	3 (25.0)
Social Work/Counselling	3 (25.0)
Nursing	1 (8.3)
Other	5 (41.6)
Missing	3
Length of time facilitating	
< 1yr	6 (15.4)
1-2 yrs	7 (17.9)
3-5 yrs	11 (28.2)
over 5 yrs	15 (38.5)
Facilitate more than one group	8 (20.5)
Cancer diagnosis	30 (76.9)
Type of Cancer	
Prostate	8 (26.7)
Breast	17 (56.7)
Colorectal	1 (3.3)
Other	4 (13.3)
How long ago (yrs)	8.9 ± 4.5; 2 – 18
Where in cancer experience	
Diagnosed undergoing treatment	4 (13.8)
Completed treatment	22 (75.9)
Recurrence	3 (10.3)
Missing	1

$^{*}p < 0.05$

Motivations and Beliefs

Many said they became a facilitator because they were asked by either their facilitator or the unit manager. While less frequently cited, altruistic reasons (e.g., a need to "*give back*") also appeared to be an important motivator for some of these facilitators. As one facilitator noted, *"They* [the support group] *were there when I needed them so, now it's my turn".*

When asked what they gained from the experience, facilitators identified several positive aspects to their role. Chiefly, they reported a sense of "*satisfaction*" from "*helping others*", particularly if they had not experienced the same connection during their own cancer journey. The opportunity to "*meet*" and "*connect*" with others was also identified. Importantly, many facilitators viewed themselves as a 'beacon of hope' for others with cancer. As one breast support group facilitator noted, "*by showing a positive attitude myself in spite of having extensive metastasis I give others a sense of hope*". A prostate group facilitator expressed similar thoughts when he noted, "*I have given so many men peace of mind at the start. They come and tell me so*". Additional benefits included, "*learning about the latest treatment", "physical, mental, emotional, & spiritual aspects of living the cancer journey"*, and "*how different people cope with cancer".*

Most facilitators (74%) moderately or strongly agreed with the statement that individuals who have had cancer themselves make the best support program facilitators, while less than half (45%) believed that facilitators should be similar in age and gender to participants. Experience as a facilitator was viewed by 76% as just as important as training, while 76% believed non-professionals could be as effective as professional facilitators.

As shown in Figure 3.2, the percentage of facilitators who agreed with the statement, "*Most individuals with cancer are over the age of 65*". A greater proportion of facilitators (92%) moderately or strongly disagreed compared with key contacts (67%). When compared by gender, 97% of all female respondents (both program contacts and facilitators) strongly or moderately disagreed compared with 77% of male (Z = -1.96, *p* = < .05)

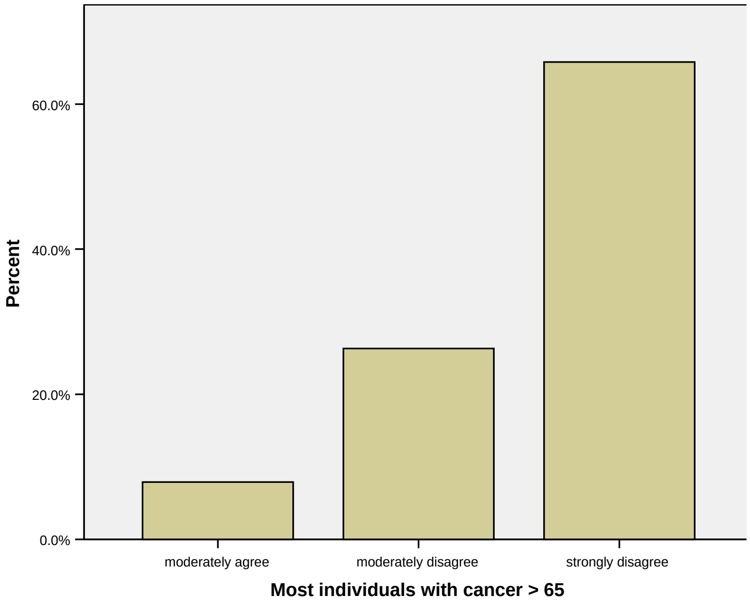


Figure 3.2: Facilitators' Beliefs

Client Characteristics

Program contacts reported distributing a total of 320 questionnaires (shown in Appendix I) to clients attending the 30 support groups. Questionnaires were returned for 220 individuals for an overall response rate of 69%. Response rates varied from 10% to

100% across the groups, averaging 74% per group. No significant difference in response rates were found between prostate cancer (75%) and breast cancer (77%) focused groups.

Program contacts were also asked to report the attendance for the session in which questionnaires were distributed. Average attendance for this session (across the 30 groups) was 11 participants (range of 2 to 37) – somewhat less than estimated by program directors. Median attendance was 9.5 clients with 75% of groups having 14 or fewer attendees. The three groups with the largest attendance rates were all prostate cancer groups. Participant characteristics, overall and by gender, are presented in Table 3.4.

Table 3.4: Client Characteristics Overall and by Gender

Peer Support Client Characteristics (N=220)	Total Sample N (%)	Males n (%)	Females n (%)
Gender	219	117 (53.4)	102 (46.6)
Missing	1		
Age (yrs)*			
Mean ± SD	63.7 ± 10.66	67.7 ± 8.19	58.9 ± 11.25
Range	25 – 91	44 – 82	25 – 91
Median	64.0	68.0	58.5
Missing	4	2	2
Education			
Did not complete high school	29 (13.6)	17 (14.8)	12 (12.4)
Completed high school	54 (25.4)	29 (25.2)	24 (24.7)
Some college/university	49 (23.0)	22 (19.1)	27 (27.8)
College/university graduate	81 (38.0)	47 (40.9)	34 (35.1)
Missing	7	2	5
Employment			
Full time	52 (23.9)	29 (25.0)	23 (22.8)
Part time	20 (9.2)	8 (6.9)	12 (11.9)
Unemployed/retired/unable to work	146 (67.0)	79 (68.1)	66 (65.3)
Missing	2	1	1
Other health problems			
Yes	127 (58.5)	62 (53.9)	64 (63.4)
Missing	3	2	1
Type of cancer			
Breast	81 (37.2)	n/a	81 (79.4)
Prostate	93 (42.7)	93 (80.9)	n/a
Colon	19 (8.7)	11 (9.4)	8 (7.8)
Lung	1 (0.5)	1 (0.9)	0 (0.0)
Other	22 (10.1)	8 (7.0)	13 (12.7)
More than one	2 (0.9)	2 (1.7)	0 (0.0)
Missing	2	2	0
Where in cancer journey			
Newly diagnosed	16 (7.4)	13 (11.5)	3 (2.9)
Undergoing treatment	32 (14.8)	18 (15.9)	13 (12.7)
Completed treatment	158 (73.1)	80 (70.8)	78 (76.5)
Recurrence	10 (4.6)	2 (1.8)	8 (7.8)
Missing	4	4	0
How long diagnosed (mo.) **			
Mean (SD)	62.2 (57.4)	55.3 (57.8)	69.8 (56.5)
Median	48.0	40.0	60.0
Range	1 – 396	1 – 396	3 – 228
Missing	2	2	0

Significant gender differences: $^{*}p< 0.001$; $^{**}p < 0.05$, $^{***}p< 0.01$

Peer Support Participant Characteristics (N=220)	**Total Sample N (%)**	**Males n (%)**	**Females n (%)**
Heard about program from†			
Friend	81 (37.0)	42 (36.2)	39 (38.2)
Fellow patient	21 (9.5)	13 (11.2)	7 (6.9)
Family	12 (5.5)	8 (6.9)	4 (3.9)
Family Doctor	16 (7.3)	10 (8.6)	6 (5.9)
Specialist/oncologist **	22 (10.0)	16 (13.8)	6 (5.9)
Nurse	22 (10.0)	11 (9.5)	10 (9.8)
Pamphlet*	33 (15.1)	7 (6.0)	26 (25.5)
Newspaper	23 (10.5)	12 (10.3)	11 (10.8)
Other	34 (15.5)	20 (17.2)	14 (13.7)
How long attending program (mo.)**			
Mean ± SD	40.8 ± 40.41	32.5 ± 30.9	50.4 ± 47.6
Range	1 – 224	1-120	1-224
25 percentile	8.0	5.8	11.3
50 percentile	30.0	24.0	36.0
75 percentile	60.0	51.0	72.0
Missing	5	3	2
Where in cancer journey when began attending program***			
Newly diagnosed	91 (42.7)	60 (52.6)	31 (31.6)
Undergoing treatment	51 (23.9)	20 (17.5)	30 (30.6)
Completed treatment	60 (28.2)	27 (23.7)	33 (33.7)
Recurrence	11 (5.2)	7 (6.1)	4 (4.1)
Missing	7	3	4
Time travelling to program ***			
30 minutes or less	149 (70.0)	70 (60.3)	79 (81.4)
Over 30 minutes	64 (30.0)	46 (39.7)	18 (18.6)
Missing	7	1	5

Significant gender differences: $^{*}p < 0.001$; $^{**}p < 0.05$, $^{***}p < 0.01$
† Some participants indicated more than one source

The average age of respondents was 64 years (±10.67). Participants were generally well educated; 61% had at least some college/university education. The majority (67%) were currently not working – 78% were retired while 14% were unable to work due to illness. Most (84%) lived with someone, primarily a spouse (78%). Most participants were born in Canada (70%), with 46% of immigrant clients coming from English speaking countries.

Prostate (43%) and breast (37%) cancer were the two most common diagnoses. Almost three quarters of participants had completed their cancer treatment. Many were long-term cancer survivors (on average 5 years post diagnosis, range 1-396 months). The majority (58%) reported other health problems in addition to cancer.

Female participants were significantly younger than male (Z = -6.23, $p < .001$) and had been diagnosed with cancer for a longer time (Z = -2.27, $p < .05$). Male and female participants were similar with respect to educational attainment, employment status, number of health problems, and medication usage.

Table 3.5 shows participant characteristics by age group. In total, 49% of clients were aged 65 and over however, only 14% of participants were women in this age group. Participants aged 65 and over were more likely to be male ($\chi^2 = 25.81$, $p < .001$), have prostate cancer ($\chi^2 = 28.12$, $p < .001$), and to report other health problems ($\chi^2 = 5.87$, $p = < .05$) than those under age 65. While a greater number of older adults reported having a health problem other than cancer, none of these differences was significant. Medication usage varied significantly between the two groups (Z = -2.27, $p < .05$) with older adults taking an average of 3.1 medications per day (± 2.04, range = 1 to 13) compared with 2.4 per day (± 1.69, range 1 to 7) for younger participants. Both groups (older versus younger) had been diagnosed a similar length of time. Fewer older adults had at least some post secondary education compared with younger participants (56% versus 65%); however, this difference was not significant.

Table 3.5: Client Characteristics by Age Group

Client Characteristics (n=216)	< 65 years of age n (%)	≥ 65 years of age n (%)
Gender *		
Total	111 (51.4)	105 (48.6)
Female	70 (63.1)	30 (28.6)
Male	41 (36.9)	75 (71.4)
Age (yrs)		
Mean ± SD	55.5 ± 7.63	72.3 ± 5.25)
Range	25-64	65-91
Missing = 4		
Education		
Did not complete high school	13 (12.0)	15 (14.9)
Completed high school	23 (21.3)	30 (29.7)
Some college/university	25 (23.1)	23 (22.8)
College/university graduate	47 (43.5)	33 (32.7)
Missing	3	4
Employment *		
Full time	41 (37.3)	10 (9.6)
Part time	13 (11.8)	6 (5.8)
Unemployed/retired/unable to work	56 (50.9)	88 (84.6)
Missing	1	1
Other health problems**		
Yes	55 (50.5)	69 (66.3)
No	54 (49.5)	35 (33.7)
Missing	2	1
Type of cancer *		
Breast	56 (50.5)	23 (22.3)
Prostate	32 (28.8)	61 (59.2)
Other	23 (20.7)	19 (18.5)
Missing	0	2
How long diagnosed (mo.)		
Mean (SD)	59.3 (54.40)	64.6 (58.60)
Range	1-228	1-396
Missing		2
Where in cancer journey		
Newly diagnosed	10 (9.1)	6 (5.9)
Undergoing treatment	13 (11.8)	17 (16.7)
Completed treatment	81 (73.6)	75 (73.5)
Recurrence	6 (5.5)	4 (3.9)
Missing	1	3

Significant age group difference $^{*}p < .001$; $^{**}p < .05$

Participant Characteristics (n=216)	**< 65 years of age n (%)**	**≥ 65 years of age n (%)**
Heard about program from†		
Friend	35 (31.5)	45 (43.3)
Fellow patient	9 (8.1)	11 (10.6)
Family	6 (5.4)	6 (5.8)
Family Doctor	7 (6.3)	9 (8.7)
Specialist/oncologist	14 (12.6)	8 (7.7)
Nurse	11 (9.9)	10 (9.6)
Pamphlet**	23 (20.7)	9 (8.7)
Newspaper	11 (9.9)	11 (10.6)
Other	20 (18.0)	14 (13.5)
How long attending program (mo.) **		
Mean ± SD	37.7 ± 41.48	43.0 ± 37.93
Range	1-168	1-224
25 percentile	3.0	12.0
50 percentile	20.0	36.0
75 percentile	63.0	60.0
Missing	2	3
Where in cancer journey when began attending program		
Newly diagnosed	46 (43.0)	44 (43.1)
Diagnosed undergoing treatment	24 (22.4)	26 (25.5)
Completed treatment	31 (29.0)	27 (26.5)
Recurrence	6 (5.6)	5 (4.9)
Missing	4	3
Time travelling to program**		
15 minutes or less	60 (56.1)	46 (44.7)
15 to 30 minutes	22 (20.6)	20 (19.4)
Over 30 minutes	25 (23.3)	37 (35.9)
Missing	4	2

Significant age group difference $^{*}p < .001$; $^{**}p < .05$
† Some participants indicated more than one source

Support Group Participation

On average, clients had been attending these groups for 3 and one half years (range from 1 month to over 18 years). Participants heard about the program from a variety of sources. Ninety-four percent of participants drove a car with 80% driving themselves to meetings. Half of the participants traveled 15 minutes or less to the program and most (90%) never or rarely worried about transportation costs.

Women attend longer (2.6 versus 4.1 years on average, z = -2.47, $p < .05$), while men were more likely to join a support group program earlier in their cancer journey (χ^2 = 11.52, $p < .01$). Men also spent more time traveling to meetings (χ^2 = 11.18, $p < .001$). Men and women differed slightly in how they learned about their support group with women more likely to learn about a program from pamphlets (χ^2 = 15.99, $p < .001$) and men from an oncologist/specialist (χ^2 = 3.74, $p = .05$).

Older and younger participants were similar with respect to where they were in their cancer experience. As shown in Table 3.5, compared to younger participants, older clients (age ≥ 65) had participated longer (z = -2.011, $p < .05$) and spent more time traveling to the program (χ^2 = 3.98, $p < .05$). They were less likely to hear about the program from a pamphlet (χ^2 = 6.17, $p = < .05$) than younger participants.

Few participants reported any initial reservations or concern regarding participation. Those who did acknowledge such concerns (n=21) specified privacy issues (e.g., "*wasn't sure who all I wanted to know about me*"), possible adverse effects (e.g., "*it may be depressing with a group all with breast cancer*"), anxiety about "*meeting new people*", "*talking in front of people*" and engaging in group activities (e.g., "*I didn't know how I would deal with a group setting*"). Possible embarrassment (e.g., "*I felt my questions would be too simplistic*" and "*embarrassed about the possibility of breaking down*") as well as uncertainty about "*how helpful it would be*" were also mentioned. Despite these reservations, several participants noted that their concerns quickly dissipated, for example, "*once I was there everything seemed to be okay*".

Respondents revealed several reasons for attending the support group including: enhancing coping skills; a need for information (particularly first hand knowledge from others who had been there) as well as emotional support. While a need for information was the most prominent reason mentioned by male respondents, the need to "*share experiences*", "*discuss common problems*" and "*learn more about dealing with*" cancer and its treatment were also frequently cited.

Participants' Beliefs

As shown in Appendix M, most respondents (80%) believed that support group participants who were similar to them in age and gender could better understand their concerns, There was strong consensus that people who have had cancer make the best facilitators (86% agreed), while two-thirds believed that non-professional facilitators can do as good a job as professional (65%). A majority of participants strongly or moderately agreed that they don't like to impose on others (70%), don't like to complain (78%), and shouldn't dwell on illness (72%). Almost all (95%) believe that others with cancer make the best support person. In answer to the question, "*do you have someone to count on when you need to talk*", 93% of participants responded 'yes'. Spouses, children, siblings, and friends were the most commonly reported sources of support. Men and women differed significantly on three of the eight statements. Men were more likely to prefer support group participants ($z = -2.28$, $p < .05$) and facilitators who were similar in age and gender ($z = -2.72$, $p < .01$) while more women do not like to impose on others ($z = -2.78$, $p < .01$)

When examined by age, almost all of the older adults had some social support with 96% reporting they had "*someone count on*". Compared with younger participants, fewer older adults than expected disagreed with the statements, “I don’t like to complain” ($z = -2.32$, $p < .05$) and “I don’t like to dwell on illness” ($z = -2.23$, $p < .05$). Both older and younger participants generally agreed that people who have had cancer make the best support person and group leader and that participants as well as facilitators should be similar to them in age and gender. Participant beliefs by age group are presented in Appendix N.

3.5 Discussion

Findings from each phase of this study – environmental scan; interviews with key contacts; and the survey of program facilitators and clients – are discussed below. Study limitations are addressed as they pertain to each phase.

3.5.1 Environmental Scan

Electronic searches of databases (such as the Canadian Cancer Society on-line support directory) are not error free and, although significant effort was made to verify the findings of this search, some Ontario cancer peer support programs may have been missed.

Results from the environmental scan indicate that while there are numerous programs throughout the province, services aimed at individuals with breast and prostate cancers appear to dominate and thus, individuals with other types of cancer may be under serviced with respect to peer support. Specifically, only two programs (other than those associated with the Ostomy Association) were found for individuals with colo-rectal cancer despite being the second most prevalent type of cancer in both men and women (National Cancer Institute of Canadian, 2005). While a potential source of support, Ostomy Association groups are not limited to individuals with cancer; other conditions such as Crohn's disease, ulcerative colitis, and trauma may also result in an ostomy. Moreover, not all individuals with colorectal cancer have an ostomy. These ostomy groups, therefore, may not be meeting the unique needs of many individuals with colo-rectal cancer.

3.5.2 Key Contact Interviews

The main purpose of this study was to gain a better understanding of peer support services in the Ontario context particularly as they relate to older adults. This is the first study to examine a broad range of community based, group peer support programs targeting adults who are cancer patients or survivors. Although 165 group peer-support programs in Ontario were identified (through the scan), it was not feasible to interview contacts from all programs and only 18% were examined. Although a larger more diverse sample of groups than previously examined was studied, a major limitation to this study is the generalizability of findings due to reliance on a convenience sample of program contacts. In particular, programs in Northern Ontario were not well represented in this sample due to the difficulty contacting programs in this region.

The typical peer support group appeared to be ongoing (rather than session limited). Most programs were free of charge, and met during the evening for about two hours in locations with free parking and/or close access to public transit. Programs made a conscious effort to find suitable, safe locations. Thus, with the exception of evening meeting times, accessibility does not appear to be a deterrent to participation by older adults. In fact, older clients surveyed spent more time traveling to these programs than their younger counterparts. It is possible that older women may be particularly reluctant to attend meetings at night, although this remains to be determined. It is known that older women are less likely to drive at night than older men (Hakamies-Blomqvist & Wahlstrom, 1998) and therefore, may be less inclined to drive to evening meetings.

While lack of awareness has been cited as a reason for under-utilization of peer support services (Eakin & Strycker, 2001), the programs surveyed in this study utilized a variety of strategies to recruit clients. ‘Word of mouth’ appeared to be an important mechanism through which support groups attracted clients, with over half of participants learning about the program from friends, fellow patients, or family members. It is unclear from this study whether these friends/family members/fellow patients were individuals with previous experience with a peer support program or were aware of the support group from other recruitment strategies employed by programs. Younger clients were significantly more likely than older to hear about a program through a pamphlet. While it is possible that the contents of these promotional tools appeal more to younger individuals and/or are more frequently distributed to this group, the reason for this difference remains to be determined.

The findings of this present study indicate that about one quarter of participants identified health care professionals as a source of referral. The greater likelihood of men than women hearing about the support program from a cancer specialist indicates that urologists may be referring to these services with greater frequency than other specialists; however, this assumption cannot be verified through this study as participants were not asked to identify which type of specialists informed them about the program. Further, the close relationship between one rather large prostate support group and a team of urologists may have influenced the findings. Interestingly, although nurses have rated psychosocial interventions as important aspects of patient care (Frost, Brueggen, &

Mangan, 1997), only one in ten support group participants in the present study identified nurses as a source of referral.

Most programs utilized aggregate attendance or, if noting individual turnout, did not keep track of this information. Hardly any collected client information beyond names and addresses and the few programs that obtained client feedback relied solely on the sporadic administration of client satisfaction surveys. The systematic collection of client information data allows programs to determine if they are reaching their target audience, examine how drop-outs might differ from adherents, track utilization, and look at changes in client profiles. Moreover, it would allow larger organizations such as the Canadian Cancer Society to compare clients, facilitators, and program participation across programs. When coupled with outcome measures, this information may allow programs to determine which type of client benefits the most from their intervention (Myers, 1999; Sidani & Braden, 1998). It is unfortunate that the programs studied did not use such a systematic approach, although they may not perceive a need to do so.

3.5.3 Facilitator and Client Surveys

There were several limitations with both facilitator and client participant samples. Although response rates for these two groups (93% and 69%) were good (Babbie, 2001), the data are limited to those who chose to respond. Moreover, surveys were distributed at a single meeting of the groups and results represent only a ‘snapshot’ of participants. While this is one of the first studies to examine support group facilitators – and the only to examine facilitators from non-prostate groups – results are based on a sample of 39 respondents, only 10 of whom were men. With respect to the client survey, this is one of the largest and most diverse samples of peer support group clients to be examined to date.

For comparison, previous studies have been based on samples of 131 women attending breast cancer support (Pilsuk, 1997); 62 men and women with a variety of cancer types (Grande et al., 2006); and 27 women with breast cancer (Stevens & Duttlinger, 1997). While Coreil & Behal (1999) examined a sample of 405 peer support clients, all were men with prostate cancer.

The majority of male facilitators in the present study were over the age of 65 – reflective of the age of cancer patients in general. In contrast, most female facilitators were under 65. Facilitators appeared to see themselves as a ‘beacon of hope’ and received significant interpersonal gains from their role. Similar to previous findings (Coreil & Behal, 1999), facilitators surveyed in the present study were a well educated group of cancer survivor volunteers, aged 60 and over. In contrast to the findings of Coreil & Behal, facilitators here were predominantly female, from the helping professions or volunteer sector rather than managerial/professional background and a greater percent had received training (77% vs. 46%). Since Coreil & Behal examined only prostate support groups, their predominance of older male facilitators is not unexpected.

Cancer support group participants have been described as generally highly educated, English speaking, and predominantly individuals with breast or prostate cancer (Coreil & Behal, 1999; Grande et al., 2006; Krisek et al., 1999), similar to the sample in this study. In contrast to previous findings, which have indicated that women are more likely to attend support programs, the present sample of program users contained slightly more men – predominantly individuals with prostate cancer (Edgar et al., 2003; Grande, Myers & Sutton, 2006; Krisek et al., 1999). This difference may be due to the substantial representation of programs directed at prostate cancer (27% of the sample) and the generally large size of these groups. Moreover, the previous studies cited above have examined groups offered through only one organization and users may not be representative of a broader selection of peer support clients.

This study found that fewer older adults than would be expected were participating in the support groups surveyed. While 60% of cancer is diagnosed in individuals who are over the age of 65 (Yanick & Reis, 2000), this population accounted for less than 50% of support group users in the present study. Persons over age 65 comprised less than one third of female participants compared with almost two thirds of male. One possible explanation for this finding may be the earlier median age of onset of breast as compared to prostate cancer (61 years versus 68 years; Reis et al, 2006). However, it is doubtful that age of onset alone explains this difference as previous research has found that women attending breast support groups were generally younger than non-attendees (Krizek et al., 1999). An additional explanation may be that women find it easier to obtain the 'mutual sharing' aspect of participation in their natural support system. However, other factors such as ageism may also be at work.

Coreil & Behal (1999) and Krisek et al. (1999) found that support group clients generally attended programs for less than 3 years and less than 18 months, respectively. In contrast, users in this study had participated for much longer (average length of attendance was 3 ½ years; with 25% having attended for 5 years or longer). This propensity of some participants toward ongoing, long-term attendance raises several questions that could not be answered by this study, primarily, why do they continue to attend these programs long after the diagnosis of cancer and completion of treatment?

Are these individuals attending to 'give back to others'? Possibly they are part of the estimated 35 to 50% of cancer patients experiencing clinically significant psychosocial distress (Stark et al., 2002; Zabora et al., 2001), many of whom Schofield et al., (2006) note may not be receiving needed interventions. If so, is participation in a peer support group helping to alleviate these difficulties? The lengthy association would suggest perhaps not.

Contrary to findings by Krizek et al.(1999), women in this study attended support programs significantly longer than men. It would seem probable that male participants are coping with a number of issues and would require long-term support since prostate cancer impacts quality of life in several areas – sexual and urinary dysfunction, social and physical well-being (Eton & Lepore, 2002) – and treatment frequently exacerbates symptoms such as impotence and urinary incontinence (Saranchuk et al., 2005). Whether men leave these programs earlier than women because their needs were met or because the program is no longer meeting their needs is unclear.

Men and women also differed at the point at which they began attending the program with men more likely to attend when newly diagnosed. Since a primary role of prostate support groups is to educate men about a sometimes bewildering array of treatment options (Calabrese, 1995) this is not surprising. Unlike previous studies (Krisek et al.) findings in this study suggest that men attend to '*share experiences*' and '*discuss common problems*'. There does appear however, to be a different taxonomy at work within men's groups, for instance the frequent use of the term 'testimonial' to describe their sharing experiences.

Lieberman (1979) contends that individuals who join support groups are those able to use social support from several sources. In contrast, Borkman (1984) suggests that such services attract individuals who lack support in their natural system. Still another view suggests that support groups offer a substantially different type of support from that available in an individual's daily life – the sharing of first hand knowledge with those intimately associated with the mutual problem or concern (Rogers, Bauman & Metzger, 1984). This study appears to support both the premise that peer support group users are able to mobilize social support from a variety of sources, but are still looking for the unique type source of support such groups may provide. Almost all participants, including older adults, reported having "*someone to count on*" indicating they had a readily available support system. At the same time, participants consistently noted that they attended these programs in order to "*share experiences*". It is unclear from this study why older adults, particularly older women, are less likely to use peer support groups than their younger counterparts although several possible explanations are presented below.

Findings concerning the belief statements were particularly interesting. Almost three quarters of the older adult users surveyed moderately or strongly preferred a facilitator similar to them in age and gender. Correspondingly, over 80% favored fellow participants similar in age and gender. These findings are consistent with the 'peers helping peers' nature of the groups examined where experience with the key issue is a fundamental requirement for leadership and participation (Thaxton, Emshoff & Guessous, 2005). Older women may not be seeing themselves reflected in support groups and therefore, might not view these services as a 'peer' experience.

Program contacts seemed to believe that there was a lower need for their services among older adults with cancer. They appeared to view this group as ‘stoic’, accepting of the diagnosis, unquestioning, less emotional, having fewer issues and able to find adequate support from family and friends. Generally, they seemed unconcerned about the under representation of older adult participants.

Surprisingly, few facilitators or program contacts were aware that most individuals with cancer are over the age of 65. However, compared to female facilitators, male facilitators (who happened to be older themselves and generally worked with older clients) were less likely to disagree with the statement. Whether this misconception stems from the clientele served (i.e., male facilitators/program contacts see more older men than female contacts/facilitator see older women) or is indicative of a larger societal view regarding the nature of cancer remains to be determined.

Programs may not be targeting services to a cohort of older adult women due to these assumptions and beliefs. The idea that all older adults with cancer “*just deal with it*” is not born out by research. Older adults experience higher rates of depression than their younger counterparts (Rao & Cohen, 2004) and one third report worries about recurrence, secondary cancers, and concerns that symptoms they are experiencing may be from cancer (Deimling et al., 2006). To date, little work has been undertaken examining the supportive care needs of older adults. A preliminary examination of these needs, from the perspective of older adults living with cancer was the focus of the second study, which is presented in the next Chapter.

CHAPTER 4: Older Adults' Support Care Needs and Use of Services

4.1. Introduction and Objectives

Older adults, aged 65 and over, constitute 60% of all incident cancer (Yanick & Reis, 2000); for many of the more common cancers, the proportion of older adults is even higher. For instance, 72% of colorectal, 68% of lung, and 67% of prostate cancer is initially diagnosed in this age group (Pollack et al., 2005). Furthermore, unlike younger individuals with the disease, older adults with cancer are more likely to face a variety of unique challenges including but not limited to: other health problems, ageism, lower literacy levels, decreased mobility, diminishing cognitive status, and increasing frailty (Repeto et al., 2003; Wymenga et al., 2001; Yancik, 1997).

Despite a well-documented high incidence of cancer in this population, little is known about the supportive care needs of older adults. As noted in the literature review presented in Chapter 2, no studies to date have examined older adults support related needs or utilization of supportive care services. Moreover, as found in Study 1, fewer peer support participants than expected were older adults. While older adults (age ≥ 65) comprise the majority of individuals with cancer, only 49% of peer support participants were from this age group. Older women in particular appeared to be underrepresented in these services, comprising only 14% of participants. The purpose of this study therefore, was to explore key issues with this population in order to embark on a better understanding of the supportive care needs of older adults living with cancer. The specific objectives of this study were to:

1. examine the challenges and experiences faced by older adults' since being diagnosed with cancer;
2. identify strategies and resources used to deal with these challenges;
3. identify unmet support related needs; and
4. examine older adults' awareness of support service, particularly peer support, as well as their experiences, if any, with these services.

This chapter begins with a description of study methods including strategies for sample recruitment, data collection, and analysis. Results are presented following the rationale for data analysis. The chapter concludes with a discussion of study limitations and findings. It is important to note that this study was exploratory and was not designed to be an exhaustive examination of the challenges facing a broad selection of older adults. Rather, it was intended to generate preliminary understanding, as well as lay the groundwork for further exploration. Thus, a qualitative, inductive approach using in-depth focus group and interview methods was used.

4.2 Methods

4.2.1 Participant Recruitment

A convenience sample of older adults (≥ 65 years of age) residing in the province of Ontario was recruited to participate in focus groups or telephone interviews for those unwilling or unable to travel to focus groups. Older adults were eligible for participation if they had been diagnosed with breast, prostate, or colon cancer (within the last 5 years), and were English speaking. These three cancer sites were chosen so that the potential sample pool would be larger and both genders would be represented. Although recruitment took place throughout Ontario, efforts were primarily concentrated in

Kitchener-Waterloo-Cambridge and surrounding communities for convenience. The university's Office of Research Ethics approved all recruitment procedures and voluntary informed consent was obtained from all participants. Letters of information and consent tailored to each audience are discussed in subsequent sections.

Recruitment was conducted using several strategies. First, advertisements were placed in the February 2006 issue of the *Canadian Association of Retired Persons Magazine for the 50+* (*CARP 50+)* distributed to members living in Ontario. This issue was circulated to members by the middle of January. As well, ads were placed in several local, community newspapers (*Waterloo Chronicle, KW The Record, Cambridge Times* and *Kitchener-Waterloo-Cambridge Pennysaver)* during one week early in January 2006. A sample advertisement is shown in Appendix O. Subsequently, posters (Appendix P) were displayed in six 'seniors' apartment buildings/retirement complexes and five Seniors' Community Centres in the Kitchener-Waterloo-Cambridge area. Verbal recruitment also took place in these venues, with venue contacts drawing attention to the study posters during meetings and group activities. In two of these venues, the researcher also attended meetings of the Residents' Board to deliver a recruitment speech (script shown in Appendix Q) and answer questions. Finally, a copy of the study recruitment poster was e-mailed to the Ontario Division of the Canadian Cancer Society and subsequently distributed to Unit Managers for display in Canadian Cancer Society offices throughout the province. Participants were offered a modest honorarium ($20.00) for focus group participation to cover travel costs.

Those interested in the study were asked to call a toll-free telephone number and leave a message. Calls not answered directly by the researcher were returned within 24 hours. During the initial call, potential participants were screened for eligibility, given a description of the study, and details of their commitment (Appendix R). Individuals agreeing to attend a focus group were then provided with the time and place. Mutually convenient times for the one-to-one telephone interview were established at this point.

4.2.2 Procedures

This study comprised both focus groups and interview methods. Initially, 12 to 13 focus groups were planned to take place throughout the province; however, due to problems with recruitment (outlined below in section 4.4.1) only one focus group took place. The following section outlines the procedures for the focus group and interviews including participant consent and collection of background information.

Focus Groups

Focus groups are the method of choice for exploring the meaning of a given phenomenon with individuals who have the most intimate knowledge of the subject. While other qualitative methods can also be used (e.g., case studies or one-on-one interviews), focus groups have the advantage of soliciting discussion and debate from several individuals who share common characteristics or interest in the topic. The dynamic nature of focus groups can stimulate new ideas and uncover aspects of the topic that may not have been anticipated (Krueger, 2000; Myers, 1999). Focus group discussions are intended to encourage different perspectives and provide the opportunity for members to reconsider their initial opinions or impressions in light of comments made by others (Krueger, 1994; Myers, 1999). Normally, focus groups consist of between 6 and 12 participants (Krueger, 2000; Myers, 1999). Very small groups limit the range of experiences and increase pressure on each person to contribute to the discussion. As group size increases, however, each person has less opportunity to contribute to the discussion in a typical 60 to 90 minute session.

Appendix S contains the protocol and scripts for the one focus group, which followed the procedures outlined by Morgan, Krueger, King, & Scannell (1998) and Myers (1999). The focus group took place in a meeting room of a local community centre and lasted for one hour. The author facilitated the group, while a fellow graduate student (also trained in focus group methods) acted as the recorder. Prior to beginning the discussion, consent for participation and audio taping was obtained from all group members (refer to Appendix S). At the end of the session, participants were asked to complete a short background questionnaire (see Appendix T) in order to describe the sample.

During the session, the recorder used a seating plan to record non-verbal gestures of participants, as well as the initial comments of each speaker (which were later inserted anonymously into the transcripts to distinguish speakers). Immediately following the session, the facilitator and the recorder debriefed. The debriefing process is essentially a post session examination in which the two observers share their immediate impressions of the session (Morgen et al., 1998; Myers, 1999). Key areas addressed included whether certain participants contributed more to the discussion or stood out in terms of their opinions or experiences, as well as the main areas of agreement and disagreement among participants. All data sources (audiotape, seating chart, recorder's notes, consent forms, etc) were labelled and dated.

Telephone Interviews

Similar to focus groups, interviews can be used for an in-depth examination with individuals who have personal experience with the phenomenon (Trochim, 2001). While there is less opportunity for interaction and debate than in focus groups, telephone interviews allow participation by individuals who may be at a geographic distance from one another and the researcher, as well as those less willing to leave their home .

The researcher telephoned participants at a mutually agreed upon time and, prior to proceeding, verbally obtained consent to participate in and audiotape the interviews. The tape recorder was then turned on and the consent protocol was repeated for verification. The semi-structured interviews then proceeded using the protocol shown in Appendix U. To ensure that the findings accurately reflected the discussion, the researcher summarized the findings at the end of each interview, asked participants to verify the summation, and invited additional comments. Finally, participants answered a short background questionnaire (see Appendix T).

4.2.3 Data Analysis

The audiotape discussions (both focus group and interview) were transcribed verbatim by a professional transcriber. The transcriptions were imported into QRS N6 software (QRS International, 2005) to assist with the organization and coding of the qualitative data. Transcripts of the focus group and interviews were examined separately before looking at differences and similarities across sessions. Analysis progressed through three types of coding (i.e., identification of patterns in the data) namely: descriptive, topic, and analytical (Morse & Richards, 2002). Descriptive coding provides context for the data - descriptions of the respondent (e.g., age, gender) and the setting, as well as the encompassing context (e.g., question being answered, mood). While it can be descriptive, topic coding should be more than merely sorting and labelling the data since interpretation begins here. It entails identifying categories in the data and is very analytic since topic coding involves determining were data belong – into a new category or one previously identified. Meanwhile, analytic coding moves the interpretive process forward through further reflection, which leads to developing links between categories, new concepts, and comparisons within the data (Morse & Richards, 2002).

It is important to note that data collected through structured interviews and focus groups differ from other forms of qualitative research where the intention is to develop a ‘grounded theory’. Thus, findings that emerged are more in keeping with “patterns” or “issues arising” and “main points” versus more generalized, broad “themes” (Luborsky, 1994). Once an initial list of recurring patterns (across focus group and interviews) was determined, it was narrowed to a more manageable number by eliminating less salient categories and combining those closely related. The discussions were then revisited to make certain that there was sufficient data to support each pattern. Finally, the data were searched for ‘negative cases’ (Morse & Richards, 2002), that is, an effort was made to find different instances which could disprove initial findings and to ascertain whether findings would hold up under further scrutiny.

Investigators never begin an inductive research project as a ‘blank slate’ rather; sensitizing concepts are the starting point for any qualitative research. Sensitizing concepts are ideas, notions, or questions that guide inductive data collection and analysis (Patton, 1990). In this study, these concepts originated in the investigator’s nursing experience, as well as findings from Study 1. Namely, a priori, it was thought that few older adults, particularly older women would have participated in peer support services.

Focus groups and interviews followed similar scripts (see Appendices R & T) and the results were highly comparable; therefore, information from all sources was integrated for analysis and presentation. Reference will be made to noteworthy differences from the two data sources as they arise. The results section will begin with a description of sample recruitment challenges and participant characteristics, followed by focus group and interview dynamics. Findings are organized with respect to the topics or areas explored in both the focus group and interviews (refer to Appendices N & P for scripts).

4.3 Results

4.3.1 Sample Recruitment

Significant difficulty was encountered recruiting participants for this study. The first wave of recruitment began in January 2006 with the placement of ads in the *CARP 50+* magazine and local newspapers. Despite previous success recruiting seniors (although individuals without a cancer diagnosis) for cancer-related research through such advertisements (c.f. Freidman, 2006), only two individuals responded to the ads in the magazine (one from Toronto and from Ottawa). A further two individuals (both from the K-W area) responded to the newspapers ads (one of whom responded in April after returning from Florida – a relative had kept the ad for him). Thus, by the beginning of March only three individuals had been recruited for the study (one for a focus group and two for interviews).

By the middle of March, five more individuals responded to the second wave of recruitment activities (posters in local community centres and senior's housing) and the focus group was held. While a further six individuals were later recruited from these venues, three preferred interviews over focus groups (two were avoiding crowds due to cancer treatment and one lacked transportation). The remainder of participants were recruited in response to the posters in local Canadian Cancer Society offices (n=11); one person was referred by a focus group participant. Since these individuals were either located in various communities (e.g., Thunder Bay, Peterborough, St. Mary's, Toronto, Fergus) or reluctant to participate in focus groups, interviews were undertaken.

Although all individuals who responded to the ads or posters subsequently participated in the study, recruiting 26 older adult participants required five months of effort by several individuals (the researcher, as well as contacts in community centres, retirement residences, and the Canadian Cancer Society) across a variety of settings. Moreover, for eight of the 26 participants, inclusion criteria were relaxed. Seven participants had been diagnosed with cancer more than five years and the focus group included one individual with oral cancer. Her contribution was welcomed due to difficulty recruiting participants as well as her role as driver for another focus group member. Recruitment avenues, number of participants garnered from each, and the type of participation (focus group versus interview) are presented in Table 4.1.

Table 4.1: Responses to Each Recruitment Strategy and Type of Participation.

Recruitment Avenue	Number of responses	Number participating in focus group	Number participating in interviews
CARP magazine & newspaper advertisements	4	1	3
Posters in Community Centres	7	4	3
Posters in retirement complexes/senior's buildings	4	1	3
Referral	1	0	1
Canadian Cancer Society	10	0	10
Total	**26**	**6**	**20**

4.3.2 Sample Characteristics

In total, 14 older women and 12 older men participated in the focus group and interviews (n=26). Participants ranged in age from 65 to 86 (average 73.2 ± 6.6 years). All were retired, most were living with a spouse (69%), and 73% had at least some college or university education. Age, education level, employment status, and living arrangements did not differ significantly according to gender. However, as shown in Table 4.2, 50% of the female participants (versus 25% of men) were under the age of 70.

The total sample (focus group and interview participants combined) was split among individuals with breast (n=9), prostate (n=9) and colon (n=7) cancer. Three individuals in the focus group had colon cancer; (n=3); the other members had prostate (n=1), breast (n=1), and oral (n=1) cancer. Median time since cancer diagnosis was 48 months (range 2 to 156). While the men had been diagnosed slightly longer (63 versus 50 months), this difference was not significant. With respect to other chronic health problems, nearly everyone (92%) reported other conditions, primarily heart disease (46%), high blood pressure (46%), and arthritis (58%).

Table 4.2: Participant Characteristics

Participant Characteristics (N=26)	Total Sample N (%)	Males n (%)	Females n (%)
Gender		12 (46.2)	14 (53.8)
Age (yrs)			
65-69	10 (38.5)	3 (25.0)	7 (50.0)
70-74	6 (23.1)	2 (16.7)	4 (28.6)
75-79	6 (23.1)	4 (33.3)	2 (14.3)
80-84	3 (11.5)	2 (16.7)	1 (7.1)
85+	1 (3.8)	1 (8.3)	0 (0.0)
Mean ± SD	73.2 ± 6.6	75.8 ± 7.0	70.9 ± 5.4
Range	65 to 86	65 to 86	65 to 81
Education			
Did not complete high school	4 (15.4)	2 (16.7)	2 (14.3)
Completed high school	3 (11.5)	1 (8.3)	2 (14.3)
Some college/university	7 (26.9)	3 (25.0)	4 (28.6)
College/university graduate	12 (46.2)	6 (50.0)	6 (42.9)
Employment			
Retired	26 (100.0)	12 (100.0)	14 (100.0)
Worry about transportation			
Rarely	2 (7.7)	2 (16.7)	2 (14.3)
Sometimes	5 (19.2)	3 (25.0)	0 (0.0)
Never	19 (73.1)	7 (58.3)	12 (85.7)
Other health problems			
Yes	24 (92.3)	10 (83.3)	14 (100.0)
Talking medication			
Yes	24 (92.3)	10 (83.3)	14 (100.0)
No	2 (7.7)	2 (16.7)	0 (0.0)
How many medications per day			
Mean ± SD	3.3 ± 1.9	4.0 ± 1.6	2.9 ± 2.0
Range	1 to 6	2 to 6	1 to 6
Type of cancer			
Breast	9 (34.6)	0 (0.0)	9 (64.3)
Prostate	9 (34.6)	9 (75.0)	0 (0.0)
Colon	7 (26.9)	3 (25.0)	4 (28.6)
Other	1 (3.8)	0 (0.0)	1 (7.1)
Where in cancer journey			
Newly diagnosed			
Undergoing treatment	2 (7.7)	1 (8.3)	1 (7.1)
Completed treatment	2 (7.7)	1 (8.3)	1 (7.1)
Recurrence	18 (69.2)	9 (75.0)	9 (64.3)
Palliative	3 (11.5)	0 (0.0)	3 (21.4)
	1 (3.8)	1 (8.3)	0 (0.0)

Participant Characteristics (N=26)	**Total Sample N (%)**	**Males n (%)**	**Females n (%)**
How long diagnosed (mo.)			
Mean ± SD	56.0 ± 44.0	63.3 ± 44.5	49.7 (44.2)
Range	2 to 156	13 to 156	2 to 140
Median	47.5	55.0	34.0
Live alone			
Yes	8 (30.8)	2 (16.7)	6 (42.9)
No, with spouse	18 (69.2)	10 (83.3)	8 (57.1)

Sample Beliefs

As shown in Appendix V, most participants strongly or moderately agreed that they did not like to impose on others (77%), complain (73%), or dwell on their illness (85%). More than 90% of the total sample believed another individual with cancer made the best support person, while 77% felt this individual should be similar to them in age and gender. Similarly, 92% of respondents reported having ‘someone to count on’. No significant gender differences emerged.

It should be noted however, that during the interviews several of the respondents qualified their answers with a number of salient, spontaneous comments. For instance, some individuals noted, “*sometimes you do have to impose”* (to get needed assistance). Others differentiated between complaining and advocating noting, “*I do like to stand up and be heard”* and *“I do a lot of complaining on behalf of seniors”*. With respect to “dwelling on an illness”, several participants suggested there was a difference between being unable to ‘move on’ and engaging in proper vigilance as illustrated by comments such as, “*It should not become the only part of their identity but if they have a serious illness then they need to acknowledge it to others and themselves”, “Well, maybe not making it their life focus...but at the same point it’s important”, “some if they don’t dwell on their illness they’re not going to get help”, “you’ve got to get on with life, you just* *can't dwell on stuff"*, and *"they shouldn't ignore it, but they shouldn't let it take over their lives but they should also do something about it"*.

4.3.3 Focus Group and Interviews Dynamics

The discussion portion of the focus group lasted 65 minutes while the 20 interviews averaged 36 minutes (range 20-91). The atmosphere during the focus group and interviews was positive and open. Specifically, the dynamics of the focus group were very good with all participants contributing and no one individual or cancer type dominating. Participants appeared to voice their opinions without restraint and were listened to with respect by their peers. Similarly, interview participants openly discussed sensitive issues such as impotence, incontinence, loss of family, and the ability of friends and family to cope with the cancer diagnosis.

4.3.4 Challenges or problems experienced

Guiding questions:

1. ***What kinds of challenges or problems have you experienced?***
2. ***What were the main challenges?***

Most participants reported facing a variety of challenges while dealing with the diagnosis of cancer. Four challenges were particularly germane namely: physical sequelae of treatment, becoming informed about their cancer, interacting with medical services, and staying positive in the face of fear and uncertainty. At the same time, a few participants reported little or no difficulty. This apparent ease in dealing with their cancer diagnosis seemed to be related to experiencing few sequelae coupled with a good prognosis as illustrated by the following comments:

> James-FG-C[a] : *I think I came through this fairly easily.*
>
> Jim-I-P: *I considered it pretty minor. When you look around and you see some of the cancers that are around in the internal organs and I mean they're like death sentences almost.*

In two instances, past experience with cancer either a previous personal diagnosis, *"I dealt with it* [leukemia] *really and the same with the breast cancer"* (Marg-I-B), or diagnosis in others close to them, *"My two sons had cancer* [bowel and melanoma] *with much more difficult courses"* (Terry-I-C) seemed to mediate some individual's perception of challenges.

Physical sequelae

Participants commented on a variety of physical sequelae to cancer and its treatment. While some reflected on past challenges such as fatigue and nausea during treatment, post surgical infections, and dental abscesses, many spoke more insistently about present or ongoing issues such as incontinence, lymphodema, diarrhoea, and impotence. Individuals with prostate cancer, in particular, emphasized the challenges of physical sequelae as exemplified by these comments:

> Jim-I-P: *You can't control your water so that was I think what bothered me more than all the other things.*
>
> Bob-I-P: *I've been pretty incontinent since then and that's really demoralizing, disgusting, and everything else.*

---

[a] Participants are indicated by pseudonym, session type (I-interview, FG-focus group) and cancer type (C-colo-rectal, P-prostate, B-breast, O-other).

However, ongoing physical difficulties were not limited to individuals with prostate cancer as evident by the following comment:

> Lila-I-C: *I have very bad diarrhoea and I've had it for months and I'm desperate with it and they say well you know this is one of the things you probably, when they cut out the cancer they cut out rather much of the bowel and I have a short bowel syndrome.*

Becoming Informed

Respondents were remarkably well informed with respect to their cancer and its treatment. All participants spoke knowingly and accurately about technical medical terms such as Gleeson's staging, chemotherapeutic agents, and various treatment regimens. In fact, several noted that they were sometimes overwhelmed with information, as exemplified by this exchange during the focus group:

> *I had a thing like this* [pointing to a large brown envelope] *with all the information from the cancer support, some of which said you know possible side effects with a list this long* [holding hands wide apart] (James). *Yeah, you look at it. Oh my!* (Maureen) *Yeah, I could fall over dead from that one* (Verna) – general laughter and nodding of heads within the group.

Surprisingly, a few respondents reported health care professionals had not informed them about major sequelae such as lymphodema post lumpectomy/mastectomy and impotence post radical prostatectomy:

> Maureen-FG-B: *They don't tell you enough…they don't tell you when they take your lymph nodes out about lymphodema.*
>
> Bonnie-I-B: *The only thing they didn't tell me about…they didn't talk about lymphodema.*
>
> Joe-I-P: *They never told me my sexual activities would be completely gone…and the doctor especially who I talk to he had surgery done himself but he never told me exactly what all the implications would be after the surgery and I was a little upset about that.*

Interacting with medical services

When discussing their experiences, several participants noted difficulties with medical services. These difficulties began during treatment with some participants encountering unacceptable wait times for treatment, inconsistent physician care, lack of personal contact with health care personnel, as well as seemingly unsympathetic health care workers as exemplified by the following comments:

> Maureen-FG-B: *When I first got diagnosed my surgery was in May. I was diagnosed with cancer a few weeks before that an then I had to wait until late October, mid to late October for radiation…and it bothered me that I waited all that time…it was do something now, do something.*
>
> Pat-FG-C: *Getting a doctor. It was while that big shuffle was going on at* [the cancer centre] *and each time in I had a different doctor.*
>
> Peggy-I-B: *Still to this day I have not met the nurse they assigned me for the radiation oncologist. I'd spoken to her on the phone a couple of times but I've never met her.*
>
> Peggy-I-B: *One* [nurse] *actually, one time asked me how I was, but I'm fine, that was it. I can walk all the way down the hall following her* [nurse] *until she takes me to whatever room she's going to put me in and she won't say a word. You get into the room and she'll say, you can change into this gown there. You know, whatever happened to, "How are you today?" that really bothers me.*

Difficulties were not confined to the treatment phase. As one participant noted, subsequently obtaining funding for specialized equipment was a challenge:

> Peggy-I-B: *I got a letter back from the Minister of Health saying well yes you are covered* [for a lymphodema sleeve] *if you are over 65, well they sure kept that quiet so I sent the thing* [bill] *to OHIP and OHIP said no, because she's* [therapist fitting sleeve] *not one of the people who's registered with OHIP. So I bundled the whole thing up and sent it back to the Minister and said I think you're extremely badly advised.*

Meanwhile, two participants were simply lost by the system:

> Jean-I-C: *I went back in to see them* [cancer centre] *because I said my doctor doesn't know what I'm talking about so they went to look up my records and couldn't find them. They searched and searched for two days and couldn't find them and I thought well isn't this cute, so the next thing they phoned me and said well we've got them and we're faxing them over to your doctor so then I phoned the doctor's office, "oh I don't know, I don't see them in the file" – here we go again. You know, things like that really, really bother me.*
>
> Maureen-FG-B: *They* [cancer centre] *lost me for the follow-up*

The most common complaint or concern appeared to be obtaining follow-up care from their primary care physicians, as exemplified by these comments from both focus group and interview participants:

> Maureen--FG-B: *when he* [oncologist] *left, when he left about six months ago they put my papers and all my stuff over to my own current GP…and he never checks up on anything, I had to beg to get my mammogram.*
>
> Verne-FG-O: *This doctor* [primary care physician] *has never had my shoes or clothes off in two years. How does he know what's going on between my cancer and my other problems?*
>
> Pat-FG-C: *Well, my general practitioner has a little sign, "I accept only three symptoms per visit" – Mine takes only two (Maureen-FG-C) – I've heard of one symptom per visit (Walter-FG-P)* (general shaking of heads by participants).
>
> Lila-I-C: *I can never get my doctor's office on the phone. I have to drive down there to make an appointment.*

Staying positive

Across cancer types and gender, shock and fear were the most commonly reported reactions to the diagnosis of cancer as summed up by these statements:

> Frank-I-P: *Well, fear, I was never sick in my life, I'm a veteran of WWII and I was 4 ½ years in active service and never gotta scratch of any kind, I was never sick in my life until this happened so it was a shock to me and you know to be told you have cancer and right away the first thing you think of is death and how long I got and all that stuff*

> Jean-I-C: *Well for the first month, well even before the chemo I mean I was just a basket case you know. Every time I turned around I was crying you know. I was such a shock you know.*

Several participants noted that staying positive in the face of the fear and shock was the biggest challenge they faced:

> Bonnie-I-B: *Just making myself stay positive*

As noted by this exchange during the focus group, participants reported that staying positive was how some people coped:

I think if you look on the positive side you know and hope that thing will go OK (Pat- C). There's not much else you can do (James-C). No. (Maureen-B) (general agreement and nodding of heads)

4.3.5 Strategies for dealing with challenges

Guiding questions:

1. ***How did you deal with these?***
2. ***Has anyone or anything been helpful to you in dealing with these challenges? Who? What? How did they help?***

Participants used a variety of strategies and resources to deal with difficulties including seeking informational and emotional support, as well as advocating for enhanced or timely treatment.

Information Seeking

All of the respondents engaged in information seeking utilizing a variety of resources to increase there knowledge. They sought information on the cancer diagnosis itself, various treatment regimens, chemotherapeutic agents, and support services. Generally, participants combined sources of information and used them as an adjunct to information provided by physicians as typified by this comment, "*Well, my doctors obviously, my GP* *specifically, and the guys at the prostate cancer group that I was able to call and talk to them*" (Frank-I-P).

The internet emerged as a vital source of information for many participants as noted by this exchange during the focus group:

> *You can get some good information off the* [internet] (James-C) *– That's another source*(Pat-C) *– I went into the* [internet] *and I looked up John Hopkins and got some fantastic information on there what not to do, what to do and that has been a real helpful*(Maureen-B) *– Yeah, that's a whole new access* (John-C) *– Yeah, real good* (Walter-P).

One person lacking computer skills was still able to mobilize this resource through others as noted, *"I'm not computer literate but my niece was able to get a large folder on taxotere which was a relatively new chemotherapy substance"(Walter-FG-P).*

While the Internet was the most often mentioned information source, participants did not limit themselves to this resource. Other sources of information mentioned were: books, *"I've been reading all this stuff and on the Internet and breast books and I bought Susan Love's breast book"* (Bonnie-I-B); hospital newsletters, *"We get the John's Hopkins newsletter"* (Joe-I-P); magazines, *"There are several magazines that have been published by prostate cancer survivors"* (Walter-FG-P); and booklets from the cancer centre, *"They give you a booklet here"* (Peggy-I-B). Support groups were also mentioned as a source of information however, primarily by men with prostate cancer.

Participants were also cognizant of the limitations of these resources with several noting that care needed to be exercised in choosing information resources:

> Ray-I-P: *with very, very, careful selection, I mean I underline very careful on the Internet and there was only abut three places that I went to on that which was American Cancer Society, the Canadian Cancer Society, and the Princess Margaret Hospital, and the one, the Mayo Clinic, and those are the ones that I used for information as to answer my questions.*

> Peggy-I-B: *They* [cancer treatment centre] *give you a booklet here which is very nice, but its out of date. Half the stuff out there is out of date and I mentioned that to them. They said something about if you're not having chemotherapy you will not having a CAT Scan so how come you're having a CAT Scan, "Oh well, that book's out of date". See that's a bit stupid too, I mean why bother to give somebody information that's no good?*

One participant commented on a lack of good Canadian websites: *"There's not a good cancer site in this country at all, not in this province. The Canadian Cancer Society thing just says give money…you can go onto the Ontario Cancer Society and they'll, they list research projects and stuff if you want to get involved (Peggy-I-B).* While no other participant explicitly corroborated this comment, several frequently mentioned visiting American sites such as the American Cancer Society, Johns Hopkins, Mayo Clinic, Imaginis.com, and breastcancer.org rather than comparable Canadian websites.

Mobilizing Emotional Support

Similar to information seeking behaviour, participants mobilized several resources for emotional support including family, friends, and fellow cancer patients/survivors. Most participants turned initially and primarily to family as indicated by these comments:

> Beryl-I-C: *well first of all my children were the biggest help.*
>
> Kate-I-B: *I think my husband and my sons as well. They were all very supportive about it and we talked very openly about it as well so I think that helps.*

Friends also emerged as an important source of emotional support. In some cases, the experience of cancer enhanced these existing relationships, while, for others, it presented an opportunity to meet new individuals, as noted by the following comments:

> Kate-I-B: I became very close to her mom and you know it was just so many good things there, so I guess that line from Tennyson's poem, I am part of all that I have met, really rings true, because if you've been blessed with some caring friends before this comes then they are still with you…although I think it is really true that you, that through cancer you do meet some very nice people too.

> Peggy-I-B: *One of the women that I volunteer with has become a friend, she was diagnosed after I was and she has had chemo and the whole thing.*

Most of the participants recounted an important 'peer' relationship with a fellow cancer patient/survivor. For women, this peer was generally, although not exclusively, someone within their natural support system such as a close friend, fellow member of a golf, bridge club, or flower arranging club, or a relative as typified by these statements:

> Bonnie-I-B: *One of the ways I did that* [stayed positive] *was by different people and our golf club actually that I knew were diagnosed with breast cancer and so even without, at that time I didn't know there was such a thing* [peer support] *but I was doing it anyway*.
>
> Verne-FG-B: *I talked to the people when I went for my radiation. They have all sorts of support there and being there* [treatment residence] *for six weeks, that's the best support you can get really.*

In contrast, men generally formed these relationships through a support group.

> Ray-I-P: *They [Man 2 Man] got me through a deep, deep anxiety and out of a depression and kept me out of it*
>
> John-I-P: *I found out that first time I walked in [Man 2 Man meeting] there was 40 guys in there that all had some form of prostate cancer treatment and all alive, well, laughing away, having a hell of a good time which kind of set a new standard for me at that point.*

Taking charge

Several of the participants found themselves in the position of advocating for treatment. For example, one participant was not willing to wait over six weeks for radiation treatment and couriered a letter to the Minister of Health. She had a call within 24 hours and an appointment for radiation the next week. Another refused to combine biopsy surgery with a lumpectomy telling the surgeon, *"well I guess I'll have to go somewhere else because I am not going through surgery without knowing what's wrong with me"* (Beryl-I-B). Several others reported being actively involved in discussions of treatment options with physicians questioning the choice of chemotherapeutic agent, "[The doctor] *said once the radiation was finished he would put me on tamoxifen and I asked why that and not arimidex"* (Peggy-I-B).. Even the one participant who noted that he *"just left it up to the doctor"* (Henry-I-P) was well informed about treatment options having searched the internet about treatment for his prostate cancer prior to seeing the physician. Moreover, he was actively monitoring treatment efficacy by 'watching his PSA'.

For a number of participants advocating for care did not stop with the completion of treatment. One participant noted that she returned several times to her family physician, each time asking for a mammogram, until the test was booked. Another believed that persistence was necessary when approaching physicians, as exemplified by the following:

Pat-FG-C: P*ersist and insist and once you get into the routine of a certain blood test about every three or four months, then they* [family physician] *know*.

One participant in the focus group speculated that the need to advocate might stem from an inherent ageism within the health care system, as noted by the following statement (which was greeted by a general nodding of heads):

> Pat-FG-Breast: "What I find about age. I have a gut feeling from what I've been going through in my life that as you get to a certain age you are less and less looked after by the medical profession, okay what's your problem, okay, this is a twitch, goodbye"

4.3.6 Unmet needs

Even though participants talked in general terms throughout the discussions about unmet needs and frustrations in meeting challenges, when asked directly if they "could use more assistance" all but one participant responded "no". This individual (John-I-P), noted that he could have used the services of the prostate support group sooner. While others were less specific, it was apparent through various comments throughout the discussions that many individuals continued to need ongoing information and emotional support and that the transition from “patient” to “survivor” had been particularly difficult:

> Pat-I-B: *Dismissed is a good word, I mean you’re finished. My last radiation was _ here’s your next appointment with Dr ._ and goodbye and that’s it.*
>
> Maureen-FG-B: *But I think you’re in a different position, you’re an ongoing patient so to speak, I’m over four years know almost starting my fifth year and they think okay you’re doing fine, that’s it.*
>
> Marg-I-C: *Yeah, the supports disappear* [after finishing treatment].

4.3.7 The Meaning of Support

Guiding questions:

1. ***What does support mean to you?***
2. ***How about emotional support?***
3. ***Where would you look for emotional support?***

The meaning of support differed among participants and seemed to reflect their cancer experience. For some, particularly those currently in treatment, support meant tangible help in some aspect of their daily lives:

> Lila-I-B: *Oh, just to be here to help in some way. Like this girl who gives me a bath, oh boy do I bless her.*
>
> Jean-I-C: *Well sometimes support is in a sense mechanical like the way the Cancer Society will transport you within the city or form one community to another.*

For others support meant help with finances:

> Walter-FG-P: *I wonder when you speak of support, about financial aspects, I think we’re very fortunate or at least I feel very fortunate when I see the cost on my prescriptions of the medications that I’m now receiving for $2.00.*

Many respondents noted that support comes in many forms, as exemplified by this comment:

> Mary-I-C: *People to talk to, I would think, people to be there for you. I had a neighbour that every month on the Friday night when I finished chemo brought in supper.*

For most, however, support meant someone to talk to and share with – primarily a peer – as exemplified by these comments:

> Lynn-I-B: *A group of people with the same information, talking to each other.*
>
> John-I-P: *Well my definition of support is that I can go somewhere and find somebody who can give me answers to specific questions based on their experience.*

When asked specifically about emotional support, participants had difficulty defining emotional support preferring to give examples of instances where they received this type of support, for instance this exchange during the focus group:

> *When I found out about mine I was talking to somebody on the computer and it ended up we were chatting back and forth but it was neat because you were telling somebody you know* (James-FG-C) --- *what's that old saying, misery loves company* (Maureen-FG-B) — *that's about it, that's exactly what it is (James-FG-C).*

along with these comments during interviews:

> Reg-I-P: *I had three guys that when I was down there would frequently take me over to a window, look outside and say what did you see there or what do you see, in this case it was more in the summer, not in the winter, there was bright sunshine and everything was green and pretty and flowers, and they'd say what the hell are you in such a negative mood about. Everything else is wonderful around here, smarten up and very, very helpful to keep you from becoming emotionally a basket case.*
>
> Marg-I-B: *My friends have been bringing all kinds of angels (laughing). I've got angels all over the place. I have angels in my pocket even. – (along with the angels have they brought you emotional support as well?) - yeah, yeah, yeah, and hugs everywhere.*

> Joe-I-P: *I'm not emotional about this. I probably talk about it at home with my wife more than these other guys* [support group members] *and she just listens (laughing) so I probably get as much emotional support at home as I do anywhere else*

These examples seem to illustrate that emotional support means sharing, being there, and providing assurance to the older adult participants.

Respondents reported that they looked primarily to family (spouse, children) for emotional support:

> Verne-FG-O: *My husband and he was worse than me, he soaked it all up until the point he was not handling it well and I was fine, but he was there.*
>
> Lynn-I-B: *Yeah, I think my husband and my sons as well. They were very supportive about it and we talked very openly about it as well so I think that helps.*
>
> James-FG-C: *My wife was very supportive as were the kids.*

However, for many older adults, particularly those who no longer had a partner, friends and neighbours emerged as an important source of emotional support:

> Lila-I-C: *Well, I seem to have friends who have as many problems as I do. It's a good thing we stick together.*
>
> Jean-I-B: *I have a very good friend that lives in ____ and we've been friends for over 50 years so they used to live in ____ and you know so she's been very good.*

Interestingly, respondents living in retirement complexes seemed to have a strong mutual support system among their neighbours, as noted by these comments:

> Lila-I-C: *I have a wonderful neighbour who will just pop in and say do you want me to get your mail.*
>
> Jean-I-B: *you'd be more isolated if you were living in a house somewhere else or in a condo somewhere else because you don't usually get to know your neighbours. Only next door or something, but here* [retirement complex] *you know everybody.*

> Beryl-I-C: *I have two* [friends] *that live here, are very supportive.*
>
> John-I-C: *I had a good friend here in the building and he had had the same thing and we talked about those experiences you know, but we made jokes about it too so,* (laugh).

4.3.8 Awareness and Use of Cancer Support Services

Guiding Questions:

1. ***Would you consider speaking to someone who has had cancer but you don't know about your cancer experience?***
2. ***Have you ever heard of programs such as (insert formal peer support program in their area)***
3. ***What have you heard?***
4. ***Have you considered participating?***
5. ***What have been your experiences with these programs? Would you recommend it to others?***

Most participants had heard about a local peer support service and several were participating or had participated in these services, particularly the male respondents. For instance, four out of six focus group participants (67%) were aware of local support groups and 17 of the 20 interviewees (85%). Three respondents reported that while they were now aware of these programs (several years after their diagnosis) they had not been aware of the services at the time of diagnosis and treatment.

While none of the focus group participants were attending a peer support group at the time of the study, nearly half (45%) of the interview participants were. Fewer women (21%) than men (50%) were attending peer support, although this difference was not significant. A further four participants (one focus group [male] and three interview [all female]) had attended peer support in the past. Taken together, 50% of participants had attended peer support at some point. When analysed by cancer type, 33% of participants with breast, 56% of prostate, and 14% of colon cancer were currently attending peer support. Interestingly, two of the female participants who did not attend a peer support group, accessed analogous services through their own natural support system. Each was a friend of a peer support facilitator and received regular one-to-one sessions.

Almost all respondents had favourable views of support groups with several noting that they had played a significant role in their cancer journey as shown in the following comments:

> Jane-I-B: *The ladies at [support group] made it all [recovery] possible.*
>
> Roy-I-P: *I got lucky because I got hooked up with a support group called Man-to-Man…so I found that exceptionally helpful.*

A lack of need appeared to be the most common reason cited for not using these groups as noted by the following:

> John-I-P: *Well personally I don't think I need it but I think we have a good friend here…she's had radiation treatment. I would think for a person like her, yes, she's such a nice person, that it would be good to have a support group. Yeah this is for a different type of cancer you know and we had a son-in-law who died at age 41, he died of cancer, so I think yeah for some people it might be a good idea to go to a support group. No personally I'm cancer free.*
>
> Terry-I-C: *Never even thought of doing it* [attending a support group] *to be quite honest…probably because I didn't feel I needed extra support. Now Alan my son still goes to a cancer support group.*

Only two participants commented that talking to strangers or in a group were factors potentially inhibiting participation:

> *Beryl: I'm not certain I could talk to a stranger.*
>
> Pat-I-B: *I'm not really good at sitting around kind of discussing feelings person. I'm a do'er. I'm ok on one-to-one but not in a group.*

4.3.9 Suggestions for the Canadian Cancer Society

Guiding question:

1. ***In your opinion, what can the Canadian Cancer Society or other community agencies do to assist older adults, such as yourself, living with cancer?***

All of the respondents were aware of the Canadian Cancer Society and many spoke highly of Canadian Cancer Society services they had received such as transportation to treatment centres ("*It was wonderful to have that service*, Jean – I – C), CancerConnection, and the peer support groups. In fact, 42% were Canadian Cancer Society volunteers. Apart from, as previously noted, improving the website, only one other recommendation was offered. Specifically, it was suggested that retirement communities would be a good location for promoting Canadian Cancer Society services and increasing cancer awareness, *"Sometimes I think they should come and talk. This* [retirement complex] *is a good place for them to come and talk*" (Jean-I-B). One further salient observation merits comment. A few participants noted that they had been unaware of support services such as CancerConnection and local peer support groups until sometime after their diagnosis and treatment. One participant, who was almost two years post diagnosis for breast cancer, had been unaware of CancerConnection until very recently. A second participant noted that several individuals with cancer in her community were unaware of the Transportation service. These participants believed that the Canadian Cancer Society did not effectively promote its services.

4.5 Discussion

All studies have inherent limitations. Perhaps the most important issue in the present study was the reliance on a convenience sample, which limits the generalization of findings. Only three cancer types were included in the study (breast, prostate, and colon), and although these three types represent a significant proportion of the cancer population in Ontario, experiences of older adults with other kinds of cancer may differ. Second, the sample consisted of a small homogeneous group of English speaking, educated older adults who use community centres, volunteer at their local Canadian Cancer Society, use the internet, and were interested enough to participate. Importantly, they appeared quite capable of mobilizing need resources. Thus, the present study fails to capture the experiences of less well educated as well as more marginalized older adults (e.g., ethno-cultural minorities, lower socio-economic levels) with poorer access to cancer resources.

Similar to older adult respondents in Study 1, most participants in this study had someone to count on and did not like to impose, complain, or dwell on illness. Over 90% believed that individuals with cancer make the best support person. Given that half the sample had not attended peer support, it appears that a significant proportion of non-peer support users also held this belief.

Additionally, 50% of the female participants were under the aged of 70 (i.e., relatively young older women). There are significant variations in life style, work status and health between young and older seniors (Yancik, 1997) and older individuals (age 80+) may face different issue when coping with a diagnosis of cancer.

While efforts were made to include older adults from several regions in Ontario, respondents were primarily from the Kitchener-Cambridge area. Older adults in other regions (particularly northern communities) may not experience issues germane to this area (e.g., high turn over of physicians at the regional cancer centre). Moreover, seniors living in rural and remote communities may experience additional challenges receiving cancer care and support.

Finally, while the use of the telephone interviews allowed for a wider participation, it was not possible to observe non-verbal cues such as body language to assess participant's responses. In other words, the dynamic give and take of a focus group was not present.

Notwithstanding, this is one of the first studies to examine supportive care needs with a sample of older adults with various types of cancer. The greatest challenge encountered doing this research however, was recruiting participants. Significant time, effort, and a variety of venues were required to recruit 26 older adults. It is unclear whether this is a result of ineffective recruitment methods or whether older adults with cancer were generally unwilling to participate. With respect to recruitment methods, two issues are apparent. First, advertisements were small and placed in the classified sections of the publications, thus it may not have been noticed. Second, although the use of posters has been successful in the past, (e.g., Freidman, 2006), previous work by Adams et al. (1997) indicates that posters are generally one of the least successful recruitment strategies to use with an older adult population. Although, Freidman, targeted older adults who were cancer free, it is of interest that she obtained a highly educated group of volunteers.

The sample of older adults examined in this study noted challenges that were similar to those reported by other, general cancer patients. Previous findings have highlighted problems with psychological concerns (including fear of recurrence), sexuality, obtaining information (Steginga et al., 2000), as well as physical, role and social functioning (Aranda et al., 2004). While this sample noted problems with physical functioning, sexuality, emotional distress, and obtaining information however, few difficulties with role or social functioning were mentioned.

Participants were aware of and utilized a variety of strategies and resources to meet these challenges, particularly concerning informational and emotional needs. For older adults in this study, the internet appeared to play a significant role in providing needed information either directly or with the help of younger family members. Online searching for health information is the third most popular Internet activity by regular home users, after email and general browsing (Statistics Canada, 2004). Health related information is readily accessible on the internet with an estimated 100,000 medical websites available (Kolata, 2000). However, less than one quarter of Canadians in their early 60's, and one in 10 over the age of 75 use the internet (Silver, 2001). Moreover, although functional health literacy is often low in older adults (Baker, Gazmarian, Sudano, & Patterson, 2000) cancer information found on the web is frequently written at a high reading level (Friedman et al., 2006). Participants in this study were generally highly educated - typical of older adult Internet users (Silver, 2001). Taken together, it appears that the Internet is not readily accessible by all older adults and participants in this study may be an exceptional group of older adults.

Support groups appeared to play a more significant role for the older adult males than females, particularly with respect to providing information. Treatment for prostate cancer is an area where there is considerable ambiguity surrounding optimal medical management (Chodak, 1998) and men with prostate cancer appear to have a high need for informational support (Steginga et al., 2001). Not surprisingly, one of the primary functions of prostate peer support groups is to provide members with information and it appears that several participants utilized this resource.

Participants in this study reported facing several challenges with respect to receiving needed health care services. It is unclear from this study whether ageism was a factor. Ageism is defined as "a prejudice toward, stereotyping of, and/or discrimination against any person or persons directly and solely as a function of their having attained a chronological age which the social group defines as *old*" (American Psychological Association, 2007). Ageism is an insidious prejudice that can adversely affect the quality of care given to older individuals. Older adults are less likely to receive preventive care and to be tested or screened for diseases than younger people (Alliance for Aging Research, 2006). Older adults' reports that they are limited by their primary care physician to one complaint per visit along with accounts that they must actively advocate for what appears to be routine follow-up is a troubling sign with additional implications for seniors' health beyond cancer care. Specifically, it raises concerns about the ability of marginalized older adults (e.g., due to language, literacy and/or cognitive deficits), who may have fewer resources than the older adults represented in this study, to obtain adequate health care.

While participants acknowledged few unmet needs, one area of concern appeared to be in the transition from ‘patient’ to ‘survivor’. Hewitt et al., (2005) have noted that many cancer survivors become lost during this changeover and have recommended several strategies to assist with this transition including formal written care plans (Hewitt et al.). Whether such a care plan would assist cancer survivors remains to be determined however; participants in this study indicated they would have appreciated a seamless transition.

It is apparent that older adults in this study were able to differentiate among the various types of support services. They spoke of a variety of services that met physical, psychosocial, informational, and spiritual needs (Fitch, 2000). Moreover, few participants reported difficulties accessing these services.

It was difficult to gain a clear understanding of older adults’ awareness and use of peer support services primarily because of sample bias. Due to the difficulty of recruiting participants from the general population, recruitment took place through Canadian Cancer Society offices and participants from this venue might know about supportive care services in general and peer support in particular. In fact, a significant proportion of respondents were peer support participants (either currently or in the past). It is important to note however, that some participants regretted not being aware of these services earlier.

Support groups are believed to provide a unique sense of community, unconditional acceptance, and information (Ussher et al., 2006). Coreil et al. (2004) found that support group relationships involve a mutual exchange based on the shared experience of cancer. The older adults in this study who participated in peer support appear to confirm these findings. They reported positive, accepting experiences that increased their knowledge and understanding of cancer and enhanced their ability to cope. Moreover, few participants were negatively pre-disposed to peer support participation with only two reporting a reluctance to speak with strangers or join a group.

Previous studies have found that support group participants reported feeling isolated from their natural support system because their family and friends feel frightened and helpless (Davison et al., 2000) or don’t know what to say (Yaskowich & Stam, 2003). In contrast, the older adults in this study reported good support from family and friends. In fact, many of the participants were able to find a “peer relationship” within their own circle of acquaintances, which, in some instances, may account for their non-utilization of peer support.

CHAPTER 5: Summary and Recommendations

5.1 Summary

While the need for psychosocial support is well documented for cancer patients in general, this issue has not been widely examined in older adults. As described in Chapter Two, research to date has been primarily conducted with younger women with breast cancer. It is unclear whether study volunteers are representative of peer support users in general since few studies compared characteristics of study samples to program users. It is also unclear whether older adults with cancer need or want such services. Although preliminary, this is one of the first studies to look at a broad selection of peer support programs and specifically address the supportive care needs of older adults living with cancer. This final chapter presents a brief summary of the main findings in relation to existing literature, followed by implications for practice, directions for future research and overall conclusions.

Two separate studies were conducted during this project. Study 1 comprised three sequential steps: 1) an environmental scan to identify available peer support groups in Ontario; 2) interviews with 24 key contacts from a purposeful sample (based on type and geography) of 30 of these groups; and 3) surveys of facilitators (n= 39) and clients (n=220) from these groups. Study 2, meanwhile, consisted of an in-depth, qualitative exploration from the perspective of older adults living with cancer. Through a focus group (n=6) and interviews (n=20) the experiences and challenges of older adults living with cancer were examined, including resources used to meet these challenges and awareness of support services, specifically peer support.

The environmental scan yielded a total of 177, predominantly grouped based (93%), cancer peer support programs. While programs were available throughout the province, services were concentrated in urban areas and directed primarily at English speaking individuals with breast and prostate cancer. Few groups were directed specifically at colon cancer – although it is the third leading cause of cancer for both men and women in Canada (Canadian Cancer Society/National Cancer Institute of Canada, 2006). Moreover, few participants of the support groups surveyed reported having this type of cancer. It remains unclear why only a limited number of groups are directed at colon cancer and why so few individuals with this type of cancer utilize peer support.

Of the 30 groups examined during the key contact interviews, breast and prostate cancer were the most common focus (60%). The majority of programs were ongoing (87%) and all but one met during the evening. Few structural barriers were identified which could account for the possible under-utilization of these services by older adults. For instance, all programs were held in well-lit, accessible locations – although evening meeting times may be an issue for older adults. Program directors were primarily female (71%), two-thirds of whom were unaware that the majority of individuals with cancer were over the age of 65.

The present study affirmed the previous conjecture that few cancer peer support programs systematically collect client information (Campbell et al., 2004). All the programs recorded aggregate, but not individual, attendance data. Only one of the programs (a prostate group) collected client information beyond names and addresses. However, this information was limited to Gleeson score and type of treatment. Only one-fifth of the programs solicited participant feedback via client satisfaction surveys. While only 18% of identified programs were examined, they were remarkably similar in their data collection practices. There is no reason to believe that other peer support group programs would differ substantially in this respect.

Since program directors were generally unaware of who was using their services, surveys were distributed to provide a snapshot of facilitators and clients at the next session. Survey findings indicated that group facilitators were primarily female (75%), most of whom had personally experienced cancer (77%). Male facilitators were older (p <.05) and most likely to lead the prostate groups. Over 90% of facilitators were unaware most individuals with cancer are over the age of 65. Many of the facilitators had been asked by program directors to take on this role. From this role, they gained, chiefly, a sense of '*satisfaction*' from *'helping others'*.

The 220 clients who completed the surveys on the day in question ranged in age from 25 to 91 years and many were long-term cancer survivors (average five years post diagnosis). Overall, less than half the clients were aged 65 or older. Clients over age 65 were predominately men (86%) with prostate cancer (59%).Confirming previous research, support group participants in this study were predominantly well-educated, English speaking (Coreil & Behal, 1999; Krizek et al., 1999; Pilisuk et al., 1997) and longer-term survivors (Coreil & Behal, 1999; Grande et al., 2006; Katz et al., 2002; Montazeri, 1996; Poole et al., 2001; Pilisuk et al, 1997). In contrast to previous findings (Edgar et al., 2003; Grande et al., 2006; Krisek et al., 1999), a greater proportion of men than women were identified as peer support participants. Prostate cancer groups are numerous and well attended suggesting that older men with prostate cancer may not be reluctant to seek out support.

The sample of older adults with cancer in Study 2 was primarily recruited through the Canadian Cancer Society. Thus, it was unsurprising that 46% had participated in peer support. The 14 women and 12 men who participated in the focus group and interviews ranged in age from 65 to 86 years and had primarily breast (n=9), prostate (n=9), or colon (n=7) cancer. The sample reported several challenges in dealing with cancer, including impaired physical and sexual functioning, emotional distress, and obtaining information.

In keeping with Antonucci's (2001) findings that individuals experience few changes in social relationships across the lifespan, the older adults interviewed here reported strong social networks with ties to family, friends, and neighbours. All were able to mobilize their network to meet support related needs. Interestingly, several of those interviewed had actually expanded their networks (e.g., formed new relationships with other cancer survivors).

Similar to Crooks (2001) our study found evidence of ageism. Several older adults reported difficulties receiving necessary follow-up care by family physicians feeling that, because they were older, their concerns were not taken seriously. Although the older women in Crooks' study who encountered similar difficulties fired their family doctors and sought out someone who would listen to their concerns, none of our sample exercised this option. The current shortage of family physicians means that older adults may be required to advocate for their own care, which is especially challenging for people who are less educated and/or frail (unlike the present sample).

The findings also confirmed prior assertions that older adults have difficulty obtaining cancer information, particularly after they return to their primary care provider (Sinding, Wiernikowski & Aaronson, 2005). Breakdowns in communication (e.g., transfer of patient records) are a significant problem for health care providers (both within cancer care centres and between and primary care providers). Relatively few providers have access to information systems that would facilitate information transfer (Hewitt et al., 2006). While several systems are under investigation (c.f. Blobel, 2000), they have yet to reach widespread implementation. In the interim, both cancer care specialists and primary care providers need to be cognizant of the flow of information regarding patients, particularly concerning older patients who may be dealing with multiple health challenges.

As described in Chapter 2, several theories have been proposed to explain the mechanisms of cancer support groups. These include: the helper-therapy theory (Reissman, 1965) whereby the opportunity to receive and give help enhances empowerment; social comparison theory (Festinger, 1954) where the experience of comparing oneself to others with cancer is thought to normalize illness, provide positive role models, improve self-esteem and encourage healthy behaviours (Davison, et al 2000); and the narrative theory where support groups provide a mutually supportive environment for individuals to re-evaluate their sense of self (Yankowich & Stam, 2006). While it was not the intention of this project to explore the mechanisms of support groups, findings from both studies appear to indicate that these explanations are not mutually exclusive.

Based on the present findings, implications for practice and further research are discussed below. The recommendations are intended to assist organizations to improve services and gain a better understanding of their programs, particularly their clients. It is important to note, however, that many of these recommendations pertain to larger organizations, such as the Canadian Cancer Society and HopeSpring, which are more likely than small grassroots programs to have the resources necessary for implementation.

5.2 Practice Recommendations

1. **Organizations, which provide peer support, should raise awareness of the connection between cancer and aging among program personnel.**

   Facilitators and program directors alike were, generally, unaware that most individuals with cancer are over the age of 65. Whether this belief contributes to the fewer than expected number of older adult participants remains to be determined however, it points to a potential ageism bias.

   Addressing the connection between cancer and aging in initial or continued education/training of faciliators may be one way to enhance understanding of this relationship. Little research attention has been paid to cancer support group facilitators, in particular to their training, support and ongoing educational needs (Price, Butow & Kirsten, 2006). To my knowledge, training programs offered to facilitators (e.g., by the Canadian Cancer Society or Willows) have not been empirically examined. While internal reports may exist, no published data with respect to the core curriculums of training programs and/or their effectiveness in preparing individuals for their role as facilitator could be found. The call by Price et al. for more research to provide an evidence base for facilitator training is particularly salient given the present finding that few facilitators were aware that most people with cancer are over the age of 65.

2. **Organizations should develop and implement standardized procedures to systematically collect client and facilitator information from all peer support groups.**

As noted, few programs collected sufficient information to develop user and facilitator profiles. Although only 30 of the 165 group-based programs available were looked at, those examined were consistent in their record keeping practices with few collecting information beyond names and addresses. Clearly, programs know little about who is using and delivering their services – a situation that is problematic for both programs and researchers. The systematic collection of client data would allow programs to determine if they are reaching their target audience and develop client profiles (e.g., characteristics of long-term users). In particular, such information would allow programs to determine whether the apparent under representation of older women might be a result of difficulties attracting or retaining these individuals, or both. Facilitator data, meanwhile, would enhance understanding of who delivers programs and allow for the examination of the connections, if any, between facilitator and client characteristics, user retention, and outcomes. Moreover, without such information researchers are unable to determine whether their samples are representative of peer support group users and facilitators.

For organizations that offer multiple programs, standardized tools and procedures to collect and report information on all registering clients (such as age, gender, cancer type, date of diagnosis, treatment history, etc) and facilitators (e.g., age, gender, type of training, presence/absence of cancer diagnosis, etc.) would allow them to compare client and facilitator profiles across provinces and regions. It will then be possible to determine if client profiles change over time, as the population continues to age and cancer treatment evolves. Ultimately, the demographic and cancer related information provided by a client profile will assist programs in targeting and promoting their services.

It is important to note that the Canadian Cancer Society currently uses a standardized protocol and tool to collect client information in their one-to-one telephone support program (personal communication, Dr. S. Campbell, Centre for Behavioural Research and Program Evaluation). With modification, this protocol and tool may also be applicable to their group support programs. Modelled on prior tools used by the Canadian Cancer Society and templates in Myers (1999), Appendix W presents a template that programs can use as a starting point (adapting as necessary to their own needs).

Programs should also routinely collect individual attendance data, in addition to aggregate usage (Myers, 1999). Routine collection of individual attendance data would allow programs to track participation rates, examine characteristics of frequent and long-term users, profile dropouts, etc. (Myers, 1999). Moreover, individual participation rates are necessary for outcome evaluation given that participants who attend more often should, in theory, benefit more from any given program. In addition, programs will need to develop a client-information system in order to link various data databases (e.g., client characteristics and usage patterns) by confidential and unique identifiers (Myers, 1999).

3. **Programs should consider other strategies for obtaining client feedback**

   While easy to develop, client satisfaction surveys have limited utility. Problems include: response bias (most individuals report being satisfied with a service); limited representation (dropouts are rarely surveyed); and difficulty with interpretation since forced-choice response formats (e.g., 1, extremely satisfied to 5, extremely dissatisfied) provide little information about why clients are satisfied/dissatisfied (Myers, 1999). More in-depth and useful feedback can be obtained through other methods such as focus groups and client exit interviews. Focus groups can be used to examine client expectations and issues of concern. Such groups should be conducted by a neutral moderator (rather than the program facilitator) following standard guidelines (c.f., Kruger & Casey, 2000; Myers, 1999). Programs should also consider developing and implementing a standardized protocol for contacting absentees or drop-outs to determine the reasons why they did not continue in the program (Myers, 1999).

5.3 Future Research Directions

The findings in this project indicated that, similar to others with cancer, older adults seek information about their disease, emotional support to cope with the diagnosis, and mutual sharing. What remains unclear is whether or not older adults view peer support as the best mechanism to assist them in meeting the many challenges presented by a cancer diagnosis. While one-half of the older adult participants in Study 2 had or were participating in peer support, these findings must be interpreted with caution as they stem from a non-representative, highly select sample. Further, it was apparent that few services were directed towards and utilized by individuals with colon cancer. Although this project identified possible under utilization it did not determine if there was an existing demand for group peer support by older adults and/or individuals with colon cancer. This has particular significance for program planners and researchers since, prior to the implementation of a new program or the expansion of an existing one, the level of need (i.e., the extent to which the service is necessary for an individual to achieve optimum health) and demand (i.e., the extent to which individuals desire to participate) for the service should be determined.

If future research can substantiate the need and demand for peer support services for these populations, the next step is to determine why programs may not be attracting and/or retaining such individuals. Organizations might then consider recruiting older women as peer group facilitators and examining whether this increases participation by this group. Our subjects expressed a marked preference for facilitators who were similar in age and gender to themselves.

Additionally, programs should review their promotional materials to ensure that they are appropriate for a broad range of potential clients. Although program promotional materials were not examined during this project, findings that fewer older participants, compared with younger, heard about group peer support programs through pamphlets may indicate that ageism is a factor in the production and/or distribution of these materials. In particular, the materials themselves should be examined for readability, comprehension, appeal, and content (e.g., inclusion of only issues pertinent to younger individuals, and those with prostate and breast cancer rather than a broad range of cancer types). As well, the distribution of materials should be scrutinized for potential ageism and other forms of bias (e.g., pamphlets circulated only to younger individuals and those with breast and prostate cancer, not circulated to places frequented by older adults such as seniors centres, etc.).

Efficacy and effectiveness research in the area of peer support has been hampered by a lack of appropriate tools. With respect to peer support outcomes, as Gottlieb (2005) noted, members are rarely consulted about the outcomes that matter to them. Additional research needs to be conducted to develop outcome measures that are based on relevant social support theory and include older adults with cancer (i.e., utilize an inductive approach to tool development). Such measures would enable comparisons of meaningful outcomes across programs (i.e., examine relative effectiveness), and when coupled with information on client, facilitator, and program characteristics, better enable programs to determine what works for whom and under what circumstances (Sidani & Braden, 1998).

It was apparent from the findings of this project that many peer support clients are longer-term cancer survivors. Their continued presence in peer support programs requires further investigation. Are these individuals attending programs to ‘give back’ and act as a ‘beacon of hope’ for other individuals with cancer or do they have a continuing need for support? Over the past several years, some attention has also been paid to examining various aspects of quality of life in cancer survivors (Ayanian & Jacobsen; 2006). However, many of these studies have relied on cancer patient specific instruments such as the European Organization for Research and Treatment of Cancer (Ringdal & Ringdal, 1993) and Functional Assessment of Cancer Therapy (Cella et al., 1993). These scales may not be appropriate for survivors (i.e., anyone post active treatment), as they are designed to capture the immediate effects of diagnosis and treatment rather than issues related to re-integration and long-term sequelae. The issue of measurement of cancer survivor quality of life requires further investigation.

Finally, it is important to comment on the experience of conducting research with a population of older adults with cancer. While participants in Study 2 were extremely supportive of the project, sample recruitment was quite challenging. Future researchers will need to be creative in their approaches to recruiting and involving older adults with cancer in research. One possible recruitment venue may be Family Health Teams. Family Health Teams (FHT) consist of doctors, nurses, nurse practitioners and other health care professionals. Currently, there are 152 FHT located throughout the province of Ontario (Government of Ontario, 2007). These organizations use health information technology in an integrated manner and may provide a rich environment for collaborative research. Moreover, since family physicians are the primary health care providers for individuals no longer in active cancer treatment thus, FHT may be a good avenue to potentially recruit individuals from several points on the cancer care continuum.

Cancer registries represent another avenue to recruit a large, representative cohort of older adult cancer survivors. These databases can be used to identify and contact a large sample of cancer survivors to participate in research studies. While these registries contain crucial data on cancer type, stage, and time of diagnosis, it is important to note that significant time (e.g., fostering buy-in and developing collaborative research strategies) and expense might be incurred utilizing this resource.

5.4 Conclusions

As society ages and more individuals are diagnosed with cancer, the number of cancer survivors will continue to grow. Due to advances in treatment, cancer has been identified as chronic illness for many individuals (Pollack et al., 2005). Countless cancer survivors continue to deal with the physical and psycho-social morbidity associated with cancer diagnosis and treatment (Rowland et al., 2006). Peer support has been advanced as a mechanism to assist cancer survivors to meet several of these challenges. Although preliminary, current findings indicate that group peer support services may not be reaching a broad spectrum of cancer survivors, in particular older women and individuals with colon cancer. Further evaluation and research is necessary to confirm these findings, as well as determine the supportive care needs of older adults and the best strategies for meeting these needs.

Appendix A: Supportive Care Category & Available Community Services Waterloo Region

Category	Definition[1]	Community Services[2]
Physical	Needs for physical comfort and freedom from pain, optimum nutrition, ability to carry out ADL's	• UW Well Fit
Informational	Needs for information to reduce confusion, anxiety and fear; to inform the person's or family's decision-making; and to assist in skill acquisition	• Breast cancer action and support of Waterloo Region • Hope Springs (numerous programs) • Canadian Cancer Society Waterloo Region • Reach to Recovery • Circle of Friends • KW Brain Tumour Support Group • Leukemia Support Group • Light of Hope • Living with Cancer • New Voice Club • Prostate Cancer Support Group • CancerConnection
Emotional	Needs for sense of comfort, belonging, understanding, and reassurance in times of stress	• Breast cancer action and support of Waterloo Region • Hope Springs (numerous programs) • Reach to Recovery • Cansurmount • Circle of Friends • KW Brain Tumour Support Group • Leukemia Support Group • Light of Hope • Living with Cancer

Sources: [1]Canadian Strategy for Cancer Control (2002); [2] Cancer Service Directory: www.cancer.ca (2006)

Need Category	**Definition**[1]	**Community Services**[2]
Emotional		- Lookgoodfeelbetter - Waterloo Region Bereaved Families of Ontario - Prostate Cancer Support Group - CancerConnection - New Voice Club
Psychological	Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem	No community services listed
Social	Needs related to family relationships, community acceptance and involvement in relationships	- Breast cancer action and support of Waterloo Region - Hope Springs (numerous programs) - Reach to Recovery - Cansurmount - Circle of Friends - KW Brain Tumour Support Group - Leukemia Support Group - Light of Hope - Living with Cancer - New Voice Club - Prostate Cancer Support Group - CancerConnection - Lookgoodfeelbetter - Just Between Friends

Sources: [1]Canadian Strategy for Cancer Control (2002); [2] Cancer Service Directory: www.cancer.ca (2006)

Need Category	Definition[1]	Community Services[2]
Spiritual	Needs related to the meaning and purpose of life	No community services listed
Practical	Needs for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person (e.g., homemaking services, financial assistance)	• CCS wig loan service • Red Cross • Home Support Services Cambridge • Meals on Wheels • Raise Home Support for the Elderly • CCS Waterloo Region (Transportation) • Seniors for Seniors

Sources: [1]Canadian Strategy for Cancer Control (2002); [2] Cancer Service Directory: www.cancer.ca (2006)

Appendix B: Characteristics of Support Group Users and Non-users

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other Reported Characteristics of Users	Comparison with non-users
Coreil & Behal 1999	Survey questionnaire of 38 Man-to-Man prostate support groups	N= 405 users Prostate	92% > 61 years; 50% > 70 years	Male	89% anglo American 72% at least some college or university 58% 3-10 years post diagnosis 65% attend about once per month	n/a
Grande, Myers & Sutton 2006	Survey comparing users in a community cancer support group with a random sample of non-users obtained from a cancer registry	N = 62 users; 44 non-users Breast Female genital Male genital Colorectal Hematological Melanomas Lung	Mean age of support group users = 61 yrs	Support group users: 83.9% female	56% married/cohabitating 76% unemployed or retired	Significant difference in cancer type, gender & age: users more likely to be younger, female, have breast cancer. No significant difference in employment or marital status, income, years since diagnosis, functional status, global health

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other Reported Characteristics of Users	Comparison with Non-users
Gray, Fitch, Davis & Phillips (1997a)	Semi-structured interviews with men involved in prostate support groups	N= 12 Prostate	Between 45 & 80 yrs	Male	None reported	n/a
Gray, Fitch, Davis 7 Phillips (1997b)	Semi-structured interviews with women involved in breast cancer support groups	N=24 Breast	33 to 73 yrs with 63% under the age of 50	Female	None reported	n/a
Katz et al., (2002)	Survey questionnaire of men attending prostate cancer support group and a comparison group of men enrolled in a long-term national prostate cancer study	N= 96 users; 1,996 non-users Prostate	users: 84% > 60 yrs	Male	90% white 85% living with a spouse 93% have at least some college education	No significant difference in age, ethnicity, or time since diagnosis. Users more likely to have higher income, educational attainment, and Gleason score.

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other Reported Characteristics of Users	Comparison with Non-users
Krizek et al., (1999)	Telephone interviews with 130 women with breast cancer and 87 men with prostate cancer	N= 51 users (41 women & 10 men); 166 non-users (89 women & 77 men) Breast & Prostate	Mean age of users = 60 years	Male & Female	Users/non-users not distinguished	Users were significantly younger than non-users. However, when compared by gender significance held only for women.
McGovern et al., (2002)	Survey of prostate support group participants matched with non-participants	N = 14 users; 41 non-users Prostate	Mean age of sample (users and non-users) = 67 years	Male	Users/non-users not distinguished	n/a

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other reported Characteristics of Users	Comparison with Non-users
Michalec et al., 2004	Telephone interviews with breast cancer survivors identified through a state tumour registry	958 women (users & non-users) Breast	Mean age of sample (users & non-users) = 63 years	Female	Users/non-users not distinguished	No significant difference in support group participation by race; users more likely to have graduate education; more likely to be professional women; significant negative relationship between age and participation
Montazeri (1996)	Interviews with users of 6 cancer support groups	N= 31 users Breast Lymphoma Lung Other	Mean age = 56	Males – 13% Females – 87%	58% married; 87% middle & affluent classes; 36% breast cancer; 42% 1-5 years post diagnosis & 39% > 5 years; 64% post treatment	n/a

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other Reported Characteristics of Users	Comparison with Non-users
Pilisuk et al., (1997)	Survey of women attending a breast cancer support group	N = 131 Breast	Mean age = 57	Female	61% had at least some college education; 87% white; 63% married	n/a
Poole et al., (2001)	Survey of 234 men with prostate cancer	N = 142 users; 92 non-users Prostate	Mean age of users = 69 Mean age of non-users: 66 ($p < 0.05$)	Male	84% married 77% college/ university education 80% retired 94% Caucasian	Significant differences on employment status (more non-users worked full time), time since diagnosis (users longer since diagnosis) & type of treatment (non-users more likely to have received radiation Users cited other patients more often as source of support; non-users medical staff

Author	Methods	Sample Size/ Cancer Type	Users' Age	Users' Gender	Other Reported Characteristics of Users	Comparison with Non-users
Stevens & Duttlinger (1997)	Survey of established users of support groups, new users, and non-users	N = 27 users; 11 non-users Breast	Mean age of established users = 46 yrs Mean age of new users = 46 yrs Mean age of non-users = 48 yrs	Female	None reported for users alone	Users, new users, and non-users did not differ on age, ethnicity, marital status, income, stage of cancer, treatment received, or duration of treatment
Winefield, Coventry, Lewis, & Harvey (2003)	Interviews	N = 20 users; 73 non-users Breast	32% of study sample (users & non-users) > 60 yrs. 39% < 50 yrs	Female	None reported for users alone	Users, possible users, and non-users did not vary on age, household composition, marital status, employment, or physical or mental health. Users more likely to live outside a metropolitan area, have some post-secondary education.

Appendix C: Summary of Studies Examining Efficacy and Effectiveness of Face-to-Face Peer Support

Author	Study Design/ Methods	Intervention	Cancer Site	Sample	Outcome Measures	Findings
Helgeson, Cohen, Schulz, Yasko (2000)	Efficacy: RCT	Participants randomized into: one of three 8 week interventions: 1) group peer support only; 2) Weekly group education session only; or 3) Peer support & education	Breast	312 women aged 27 to 75 (mean age 48) recruited from oncologists offices	Measures developed/ adapted for study: social support scale negative interaction scale body image scale personal control over illness illness ambiguity scale Existing measures: Rosenburg's Self-Esteem Scale SF-36	Peer support was helpful for women who lacked support from their partners or physicians but harmful for those who had high levels of support (lower scores on the physical health component score of the SF-36)
Helgeson, Cohen, Schulz (2001)	Efficacy: Three year follow-up of Helgeson et al., 2000	See above	Breast	225 women aged 27 to 75 (mean age 48)	Only SF -36 used as an outcome measure at follow-up	Did not detect any benefit from peer support – however short term negative effects disappeared (see Helgeson et al. 2000)

Author	Study Design/ Methods	Intervention	Cancer Site	Sample	Outcome Measures	Findings
Jacobs et al. (1983)	Efficacy: RCT	Participants randomized into one of 4 groups: 1) education receiving a 27-page booklet and newsletters; 2) education control; 3) peer support group meeting 1 ½ hours per week for 8 weeks; or 4) peer support control	Hodgkin's	45 men 36 women all under age 40 recruited from Stanford medical centre	Existing measures: Cancer patient Behavior scale Measures developed/ adapted for study: Knowledge of Hodgekin's disease questionnaire	No significant difference between the peer support group participants and peer support control. The education group had significant reductions in anxiety, treatment problems and improvement in, knowledge, depression, and life disruption compared to education controls.
Ashbury, Cameron, Mercer, Fitch & Neilson (1998)	Effectiveness: Case comparison/ Telephone interviews and focus groups	Existing one-to-one peer support program: *Reach to Recover* (RtoR)	Breast	367 Women 175 RtoR users & 192 comparison non-users Mean/median age not reported	Developed for the study – included items from Functional living index, Functional assessment of Cancer Therapy Scale, Functional Social Support Questionnaire	76% satisfied RtoR users had greater 'functional social support' and better relationship with physician than non-users

Author	Study Design/ Methods	Intervention	Cancer Site	Sample	Outcome Measures	Findings
Cameron, Ashbury, Iverson (1997)	Effectivenes: Cross-sectional/ Telephone interviews	Existing one-to-one peer support programs:	Breast	14 women ages not reported	Content of interview scripts not reported	Peer support described as helpful
Coreil & Behal (1999)	Effectivenes: Cross-sectional/ survey	Existing group peer support program: 38 *Man to Man*	Prostate	405 men 90% over age 61	Developed for study: demographic information, perceived benefit; satisfaction with participation	High levels of satisfaction Involvement improved outlook and increased knowledge

Author	Study Design/ Methods	Intervention	Cancer Site	Sample	Outcome Measures	Findings
Grande, Myers & Sutton (2006)	Effectivenes: Case/ comparison survey	Existing community cancer support group	Breast Female genital Male genital Colorectal Hemato-logical Melanomas Lung Other	63 support group users and a random sample of 43 non-users obtained from a cancer registry	Existing measures: EORTC QLQ-C30; Revised Illness Perception Questionnaire; Brief Cope; Hospital Anxiety and depression scale ; Multidimensional scale of perceived social support; Developed for study: Beliefs about support group participation; others views of participation; and perceived difficulty of joining group	Users held more positive beliefs about benefits of participation, perceived less difficulty in joining, felt great personal control over their cancer, and used more adaptive coping. Users received less support from ‘a special person’, and felt more distress and anxiety than non-users.

Author	Study Design/ Methods	Intervention	Cancer Site	Sample	Instruments/ Measures	Findings
Gray, Fitch, Davis, Phillips (1997a)	Effectiveness: semi-structured interviews	Existing community peer support groups	Prostate	12 men aged 45 to 80	In-depth open ended interviews focusing on experience of the benefits and limitations	Information, emotional support, and decreased social isolation core benefits Benefits extended to family members
Gray, Fitch, Davis, Phillips (1997b)	Effectiveness: semi-structured interviews	Existing community peer support groups	Breast	24 women Range: 33 to 73 15 women under age 50	In-depth open ended interviews exploring reasons for involvement; impact on users; importance of group; perceptions of group	Core benefit is the sense of bonding Share information, get hope, share experience Helped to cope with disease
Katz et al., (2002)	Effectiveness: Case/ Comparison Survey questionnaire	Existing community support groups	Prostate	96 users: 84% > 60 yrs 1,966 Non-users from a national cancer registry: 87% > 60 years	Existing measures: SF-36 UCLA Prostate Cancer Index	Users more likely to have higher income and educational attainment, and higher Gleason score. Sexual function higher, and sexual & bladder bother lower in users

Author	Study Design/ Methods	Support Type	Cancer Site	Sample	Instruments/ Measures	Findings
McGovern et al., (2002)	Effectiveness: Case comparison/ Interviews	Group	Prostate	14 prostate support group participants matched with 41 non-participants	Mini-mental adjustment to Cancer Scale SF-36	Support group users endorsed a coping style of low helplessness/ hopelessness and high fighting spirit compared with non-users. No difference reported on overall health.
Montazeri (1996)	Effectiveness: Cross sectional Structured interviews	Six community based cancer support groups	Mixed unspecified	4 men 27 women mean age 55.5	22-item questionnaire developed for study:	Allowed sharing of experiences
Stevens & Duttlinger (1998)	Effectiveness: Case comparison Interviews	Face-to-face group	Breast	38 women aged 25 to 65 years Average age: Established group members: 46.1 years New members: 45.7 Non-members: 48.6	Medical Questionnaire Personality Assessment Inventory	Compared to new members and non-members established members evinced the least anxiety, depression, stress, non-support, and aggression

Appendix D: Study 1 Program Contact Letter of Information & Consent

January 20, 2006

Dear Program Contact:

As I mentioned in our recent telephone conversation, I am forwarding this letter of introduction and information. I am writing to ask your help in a study of peer support services for individuals with cancer. I am a registered nurse and this study is part of my PhD dissertation in the Department of Health Studies & Gerontology at the University of Waterloo under the supervision of Professors Sharon Campbell and Anita Myers. The project is supported by the National Cancer Institute of Canada and the Centre for Program Evaluation and Behavioural Research at the University of Waterloo. My research is part of an effort to learn more about peer support services in generally, specifically services in Ontario.

At present, little is known about cancer peer support programs including how programs recruit, promotional strategies utilized, who attends, and who facilitates. We hope by learning more, we can do a better job co-ordinating services and developing promotional strategies for individuals with cancer. It is my understanding that you are knowledgeable about the support group offered by your organization.

Participation in this study is voluntary. It will involve an interview of no more than 30 minutes in length to take place via telephone at a mutually agreed upon time. I may also ask you to distribute questionnaires to peer support program participants and facilitators.

During the interview I will ask you to describe your peer support program; how the program is promoted; facilities (e.g., parking); and general characteristics of participants and facilitators. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me. With your permission, the interview will be tape-recorded to facilitate collection of information. All information you provide will remain completely confidential. Neither your name, nor your peer support group's name will appear in any electronic data, thesis, or report resulting from this study. Data collected during this study will be retained for 3 years in a locked office. Only researchers associated with this project will have access.

As we discussed, I have attached a copy of the participant and facilitator questionnaires for you to examine. Peer support participants and facilitators may decline to complete all or any the questionnaire. Again, all information they provide will be kept completely confidential, they will not be asked to give their names and therefore, no identifiers will appear in any thesis or report.

There are no known or anticipated risks to you as a participant in this study. I would like to assure you that this study has been reviewed and received ethics clearance through the

Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. I hope that the results of my study will be of benefit to those organizations directly involved in the study, other peer support organizations not directly involved in the study, as well as to the broader research and cancer care community.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 1-866-301-1453 or by email at njmpearc@uwaterloo.ca. I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Nancy J.M. Pearce, RN, BScN, MSc
PhD Candidate, Health Studies & Gerontology
University of Waterloo
1-866-301-1453

Please note: If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of the Office of Research Ethics of the University of Waterloo at (519) 888-4567 Ext. 6005. You can also contact my supervisor, Dr. S. Campbell at (519) 888-4567 ext. 4583 or email at sharoncm@healthy.uwaterloo.ca.

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by Nancy Pearce of the Department of Health Studies & Gerontology at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be tape recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at (519) 888-4567 ext. 6005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐ YES ☐ NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐ YES ☐ NO

Participant Name: ____________________________ (Please print)

Participant Signature: ____________________________

Date: ____________________________

Appendix E: Study 1 Program Contact Feedback Letter

Date

Dear Program Contact:

I would like to thank you for your participation in this study. As a reminder, this study is part of an effort to learn more about peer support programs in generally, specifically programs in Ontario.

Please remember that any data pertaining to yourself or your agency/program will be kept confidential. No names will appear in any written report. Findings will be reported for groups only.

Once all the data are collected and analyzed for this project, I plan on sharing this information with the research and cancer care community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me at either the phone number or email address listed at the bottom of the page. I anticipate that the overall study will be complete in the Fall of 2006. If you would like a summary of the results, please let me know now by providing me with your email address. When the study is completed, I will send it to you.

As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, Ext., 6005.

Sincerely,

Nancy J.M. Pearce, RN, BScN, MSc
PhD Candidate, Health Studies & Gerontology
University of Waterloo

Appendix F: Study 1 Questionnaire Distribution Letter of Explanation

Date

Dear Program Contact:

As I mentioned when we last spoke, I have enclosed X client questionnaires and letters of information for you to distribute to your support group members. As well, I have included four letters of information and questionnaires for the program facilitator to complete. The facilitator questionnaires have been placed in their envelopes so that you will be able to distinguish them from the client questionnaires.

As we talked about, clients and facilitators are free to choose whether or not they would like to complete the questionnaire. Individuals are free to take the questionnaire home and mail it directly to me if they wish. For those who complete the questionnaire at the meeting, I have supplied a self-addressed express post envelope for you to use. I would be very grateful if you would take the time to fill out the brief question at the bottom, tear it off, and return it along with the questionnaires. This information will assist me in determining how representative the replies I receive are of the clients as a whole.

Once again, thank you for taking the time to speak with me and for agreeing to undertake this task. If you have any further questions or require any clarification, please call or email.

Sincerely,

Nancy J.M. Pearce, RN, BScN, MSc
PhD Candidate, Health Studies & Gerontology

- -

Total number of clients attending meeting ________ Number of facilitators_________
Group: F01

Appendix G: Study 1 Facilitator Questionnaire

1. How long have you been facilitating this cancer peer support program?

1-2 months_______
3-6 months_______
7-12 months______
1-2 years_________
3-5 years_________
over 5 years_______

2. Prior to this program, have you facilitated other cancer peer support programs?

No ______
Yes______ if yes, overall, how long have you facilitated cancer peer support?

1-2 months_______
3-6 months_______
7-12 months______
1-2 years_________
3-5 years_________
over 5 years_______

3. Briefly, tell what lead you to become a program facilitator?

____
____
____
____
____
____

4. What do you personally gain from facilitating such programs?

____
____
____
____
____
____
____

5. To what extent do you agree or disagree with the following statements:

a) ***"People who have had cancer themselves make the best support program facilitators"***

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

b) ***"Facilitators who are similar in age and gender to their participants can better understand their concerns"***

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

c) ***"Non-professional facilitators can do just as good a job as professionals"***

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

d) ***"Experience as a facilitator is just as important as training"***

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

e) ***"Most individuals with cancer are over the age of 65"***

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

Please tell me a bit about yourself….

6. Have you yourself been diagnosed with cancer?

Yes _______ (proceed to question 7)
No _______ (Skip to question 8)

7. With what type of cancer were you diagnosed? ___________________

7b. When was the cancer diagnosed?

Month ______________ Year _______________

7c. Where are you in your cancer experience? (Please check √ one):

Newly diagnosed____
Diagnosed, undergoing treatment____
Completed treatment for cancer____

7d. Is this:

The first diagnosis ______
A recurrence ______

8. What year were you born? _______________

9. Were you born in Canada?

Yes_______
No________ if no, where were you born? ____________
at what age did you come to Canada_______________

10. Are you? Male ______ or Female_____

11. In which city/town/township do you live?________________________

12. How far did you go in school?

Completed high school Yes _______ No ________
Some college/university __________
College/university graduate ________
If you have a degree/diploma, what is it in? _______________________

13. Are you currently employed?

Yes______ full time_____ part time_____ type of occupation ______________

No ______ (proceed to question 13b)

13b. I not currently employed because I am

Retired________
A homemaker_________
Unable to work due to illness________

Thank you for taking the time to answer this questionnaire

Appendix H: Study 1 Program Facilitator Letter of Information

Dear Sir/Madam:

My name is Nancy Pearce and I am a registered nurse and currently a doctoral student in the Department of Health Studies and Gerontology at the University of Waterloo under the supervision of Professors Sharon Campbell and Anita Myers. I am doing a study to examine peer support programs for individuals with cancer. At present, we know little about peer support programs in Ontario or elsewhere. We hope that by learning more abut the programs and individuals facilitating them we can do a better job of promoting and co-ordinating these services for individuals with cancer.

This study is not being conducted by ***(insert name of agency)***. I have asked (***name of facilitator/program director***) to distribute this letter and the enclosed questionnaire, as I do not have your contact information. If you agree to participate in the study, you will complete the enclosed questionnaire and return it, sealed, in the envelope provided to ***(program director).*** The answers will be mailed directly to me and will not be seen by anyone else. It will take about 10 minutes of your time. Participation is voluntary.

You may answer all of the questions or decide to skip some. All of your answers will be confidential. **You will not be asked to give your name**. I will analyze the information collected and prepare a report. The report will show overall results and will not report individual answers. I will keep the information for 3 years in a locked office. Then it will be destroyed.

If you have any questions please contact ***(insert name of program director)***.

Thank you for considering my request. Please keep this letter of information.

Sincerely,

Nancy Pearce
R.N., BScN, MSc, PhD Candidate
Health Studies & Gerontology
University of Waterloo
1-866-301-1453

Note: The Office of Research Ethics at the University of Waterloo has approved this study. If you have any concerns resulting from your participation in this study, please contact the Office of Research Ethics at (519) 888-4567 ext. 6005.

Appendix I: Study 1 Client Questionnaire

1. How long have you been attending this program?

__________ months or ___________ years

2. How did you hear about this program? (check √ as many as apply)

Friend_________
Fellow patient__________
Family member_________
Family Doctor__________
Oncologist/specialist_______
Nurse________
Pamphlets/posters____________ (where did you see them__________________)
Newspaper Ad ________________
Other (please specify)______________

3. What were your personal reasons for coming to this program?

____
____
____
____
____

4. Did you have any reservations or concerns about attending this program?

____
____
____
____
____

5. Have you encountered any difficulties getting to or attending this program (for example, the time of the program or transportation to and from)?

____
____
____
____
____

6. In the past, have you participated in any other support program?

No____
Yes ____ (proceed to questions 6b & c)

6b. Please list these programs

____
____
____
____

6c. Are you still participating in any of these programs?

Yes ______ No ______

7. With what type of cancer have you been diagnosed? ________________________

8. When was the cancer diagnosed first?

Month _______ Year ____________

9. Where are you in your cancer experience? (Please check √ one):

Newly diagnosed____
Diagnosed, undergoing treatment____
Completed treatment for cancer____ how long ago_____
Other____, please explain_______________________________________

10. Have you had a recurrence of your cancer?

No____ Yes_____

11. Where were you in your cancer experience when you began participating in this support program? (Please check √ one):

Newly diagnosed____
Diagnosed, undergoing treatment____
Completed treatment for cancer____ how long _____
Recurrence___

12. Do you have any other diagnosed health problems? (check √ as many as apply)

No_____
Yes_____:
Heart trouble_____
High blood pressure______
Chronic asthma, emphysema, or bronchitis_______
Diabetes______
Arthritis______
Osteoporosis______
Kidney trouble______
Liver trouble_______
Vision difficulties not corrected by glasses______
Difficulty hearing _______ Do your wear hearing aids?________

13. Are you currently taking any medication prescribed by a doctor (other than medication related to your cancer treatment)?

No______ (skip to question 13)
Yes______ (proceed to question 13b)

13b. How many different prescription medications do you take each day? _____

14. Do you live alone?

Yes_____
No______ with spouse__________ adult child__________ other___________

15. Do you drive?

Yes___
No____ Is someone able to drive you?____ or do you use public transit?_______

16. To what extent do you agree or disagree with each of the following statements:

a. “I don’t want to impose on others”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

b. “I don’t like to complain”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

c. “People shouldn’t dwell on illness”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

d. “People who have had cancer themselves make the best support for others with cancer”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

e. “ Program participants who are similar to me in age and gender can better understand my concerns”

1	2	3	4	5
strongly agree	moderately agree	neurtal	moderately disagree	strongly disagree

f. “People who have had cancer themselves make the best support program facilitators/leaders”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

g. “Program facilitators/leaders who are similar in age and gender to their participants can better understand their concerns”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

h. “Non-professional facilitators/leaders can do just as good a job as professionals”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

17. Is there someone (family, friend, neighbour) you can you really count on to listen to you when you need to talk?

Yes ______ Who is this mainly____
No one_____

18. What is your date of birth? __________________

19. Were you born in Canada?

Yes_______
No________ *if no, where were you born?* _____________
*at what age did you come to Canada*________________

20. Are you? Male ______ or Female_____

21. In which city/town/township do you live?________________________

22. How long do you spend travelling to the program? ________________ or

I don’t travel, the program volunteer visits me__________

23. How do you usually get to the program? (Please check √ one):

Drive myself__________
Driven by others_________ my driver attends a program at the same time _____
Taxi ____________
Public transit (bus, streetcar, subway)__________
Walk/bike__________
The program volunteer visits me_________

24. To what extent do you worry about transportation costs (driving, parking, taxis or public transit) to get to and from this program?

1	2	3	4
often	sometimes	rarely	never

25. How far did you go in school?

Completed high school Yes __________ No ________
Some college/university __________
College/university graduate ________

26. Are you currently employed?

No ______ (proceed to question 26b)
Yes______ full time_____
part time_____

26b. I am not currently employed because I am

Retired________
A student _________
Between jobs________
A homemaker_________
Unable to work due to illness________

Thank you for taking the time to answer these questions.

Appendix J: Study 1 Participant Letter of Information

Dear Sir/Madam:

My name is Nancy Pearce and I am a registered nurse and currently a doctoral student in the Department of Health Studies and Gerontology at the University of Waterloo. I am working under the supervision of Professors Sharon Campbell and Anita Myers. I have asked (***name of facilitator/program director***) to give you this letter and the enclosed questions, as I do not have your contact information.

I am doing a study to learn more about cancer peer support programs. At present, we know little about cancer peer support programs. We hope that by learning more about the programs and the people attending we can do a better job of promoting and co-ordinating these services.

If you agree to participate in the study, you will complete the enclosed questions and return them, sealed, in the envelope provided to (***name of facilitator/ program director***). The answers will be mailed directly to me and will not be seen by anyone else. It will take about 10 minutes of your time. Participation is voluntary.

This study is not conducted by (***insert name of agency/program***). You do not have to take part in the study to use the services of **(*insert name of agency/program)***. You may answer all of the questions or decide to skip some. **You will not be asked to give your name**. All of your answers will be confidential. I will examine the information collected and prepare a report. The report will show overall results and will not report any individual answers. I will keep the information collected for 3 years in a locked office. Then it will be destroyed.

If you have any questions, please contact (***name of program director)***. Thank you for considering my request. Please keep this letter of information.

Sincerely,

Nancy Pearce
R.N., BScN, MSc, PhD Candidate
Health Studies & Gerontology
University of Waterloo
1-866-301-1453

Note: The University of Waterloo's Office of Research Ethics has reviewed this study and given it ethics clearance. If you have any question about your participation in this study, you can contact the Office of Research Ethics at (519) 888-4567 ext. 6005.

Appendix K: Study 1 Program Contact Interview Guide

Program Name______________________ Location__________________ ID_________

Contact Person________________ Date of Interview___________________

Start time__________________ End time_________________________

I am asking you to take part in an interview, which should take no more than 45 minutes, to describe your peer support program. This discussion is part of a PhD thesis project being conducted through the University of Waterloo by myself.

Your participation is totally voluntary and no one in the agency will have access to the information provided. You may choose when, and if, to answer questions. You are free not to answer any if you prefer.

All the information you give will be kept confidential and no individual or agency/program will be identified in the thesis, summary report, or publication. You may withdraw this consent at any time without penalty by advising me during the interview.

Do you agree to participate in this study?

☐ YES ☐ NO

Do you agree to the use of anonymous quotations in any thesis or publication that comes of this research?

☐ YES ☐ NO

Part I – Program Description *("Tell me about your program…")*

1. What kinds of services do you offer? (*e.g., group? One-to-one?*)

2. Is this program associated or part of a larger organization? If so, what role does this organization play.

3. What does the program consist of? (*components, activities*)

4. Are there any guidelines for the discussion (i.e., not to mention physicians name, compare tx regimens?)

5. How frequently does the program run? (*e.g., once a week? Once a month?*)

6. Do participants have a choice of days or times?

7. At what time of day is the program offered?

8. How frequent is it offered? (*once a week? Month?*) For how long? (*ongoing or a limited number of sessions?*)

9. Do you stop for the summer?

10. In how many settings is the program offered/Where are your meetings held?

11. Is there a fee to participate? If so, how much?

12. How many participants normally attend a session or group?

13. What is the program capacity? Is it usually filled? If so, do you have a wait list?

14. Do you have procedures in place to collect client feedback? (*if so, describe i.e., client satisfaction surveys, comment sheets, exit interviews, follow-up phone calls*)

15. If so, what has this feedback indicated?

Part II – Accessibility *("Please tell me about your program setting…")*

16. Is parking available? If yes, on site or nearby? Free or a charge?

17. Is site on a public transportation route? If yes, how far away is the stop?

18. How is the walking terrain in the area? Good *(even ground, sidewalks*) poor?

19. Are there stairs?

20. Is the entrance wheelchair or walker accessible? (*are ramps present*)

21. Is snow or ice removed from entrance area?

22. *If relevant:* Is the area (entrance) well lit at night?

23. Is the area considered safe for walking alone?

24. Is there an information desk/reception?

25. Where in the building is the room located, approximate size of room (*stairs to climb? Elevator? How difficult is it to find?)*

26. Are washrooms located nearby?

Part III – Program Promotion *(" How do your clients hear about your program?")*

27. Do you advertise/promote your program or are they referred? (*Any eligibility criteria?)*

28. If so, how?

29. pamphlets/flyers:
30. Advertise in newspapers:
31. CCS transportation:
32. Local radio:
Local tv:

33. Where do you distribute the pamphlets/flyers?

Regional cancer centres:
Local hospitals:
Oncologists offices:
Family doctors offices:
Community centre:
Pharmacies:
Other:

34. Do support persons accompany clients?

35. Do you promote to a certain type of clientele?

Part IV – Program Facilitators *(“Who are your facilitators?”)*

36. How many facilitators do you have?

37. How many are male? How many female?

38. What is the age range?

39. How many are former/current cancer patients (*what %*)?

40. With what kinds of cancer have they been diagnosed?

41. If ongoing program…How often do the program facilitators change? If sessional…Does the facilitator complete the whole session or is it shared?

42. Do your facilitators take attendance at each session? For each person or total number of participants per session? Do you have any other information on usage/participation rates? Do you contact absentees? Dropouts?

43. How are facilitators selected? (interviewed? By whom?)

44. Is there a training and/or orientation program for facilitators?

45. If so, please describe what this entails?

46. Have all the facilitators participated in the training program?

47. What characteristics or experience do you look for in selecting facilitators?

48. Volunteer? Or paid staff member?

Part V – Clientele *("Tell me about your clientele/participants?")*

49. Who is the program intended for? (if not already noted)

50. Age

51. Gender

52. Type of cancer, time since diagnosis? Treatment Status?

53. Other information (education, income, employment status, etc.)

54. Do you routinely collect any information on your clients? (e.g., registration or intake form? If so, when and how?

Part VI - Describe yourself

I need a bit of background information on you in order to describe our study sample:

55. Gender

56. Age

57. Position

58. Length of time in this position

59. Background/experience

60. Part V: To what extent do you agree with the statement:

61. “Most individuals with cancer are over the age of 65”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

Part VI

62. ***If they don’t see a lot of older adults in program***…”Why do you think that you do not see a lot of older adults in your program?”

63. Finally, I would like to discuss the client and facilitator profiles I sent to you. Do you have any questions about them or about how you would collect the data?

I’d like to thank you for your participation and would like to once again assure you that your responses will be kept confidential.

Appendix L: Support Groups Identified During Environmental Scan

1. Area: *Northwestern*

Program	Type
1. Atikokan Prostate Cancer Support Group	group
2. Thunder Bay & District Breast Cancer SG	group
3. Thunder Bay Ostomy	group
4. Thunder Bay & Area Prostate Group [TBay CCS]	group
5. Dryden Breast Ca SG	group
6. Kenora Cancer Support Group	group

2. Area: *Ontario North East*

7. Sudbury & District Breast Cancer Support Group	group
8. Sudbury & District Ostomy Association	group
9. Living with Cancer [Algoma CCS]	group
10. Multiple Myoloma [Sault Ste. Marie]	group
11. Sault Ste. Marie Ostomy Chapter	group
12. Men’s Support Group [North Bay CCS]	group
13. North Bay Ostomy	group
14. Timmins Breast Cancer SG [Health Unit]	group
15. Parry Sound Breast Ca group	group

3. Area: *Ontario East*

16. Breast Cancer Action Kingston	group
17. Breast Cancer Action Ottawa	group
18. Napanee & Area Breast Cancer SG	group

Program		Type
19.	Colorectal Cancer Association [Ottawa]	group
20.	Kingston Prostate Support Group	group
21.	Living with Cancer Almonte [Lanark CCS]	group
22.	Living with Cancer Brockville [Lanark CCS]	group
23.	Merrickville Prostate Ca Group	group
24.	Brockville Breast Ca SG	group
25.	Napanee & District Breast Ca Support Group	group
26.	United Ostomy Support Group [Ottawa]	group
27.	Deep River Prostate Support Group	group
28.	Arnprior Breast Ca SG [Renfrew CCS]	group
29.	Group Support Pembroke [Renfrew CCS]	group
30.	Living with Ca Renfrew [Renfrew CCS]	group
31.	Living with Ca Eganville [Renfrew CCS]	group
32.	Renfrew County Prostate Support Group	group
33.	Pembroke Breast Ca SG	group
34.	Perth Falls Prostate Support Group [Lanark CCS]	group
35.	Brockville Prostate Support Group [Lanark CCS]	group
36.	Kanata & District Breast Cancer Support Group	group
37.	Lymphoma Support Group [Ottawa]	group
38.	Mind Over Cancer	group
39.	Multiple Myeloma Support Group of Ottawa	group
40.	Ottawa Adult Brain Tumor Support Group	group

Program		Type
41.	Prostate Cancer Association of Ottawa Carleton	group
42.	United Ostomy Support	group

4. Area: *Central Lakelands*

43.	Barrie Man to Man Prostate[CCS Barrie]	group
44.	Collingwood Prostate Support Group	group
45.	Living with Breast Ca [CCS Barrie]	group
46.	Living with Ca , Allistion [CCS Barrie]	group
47.	Wings Breast Ca Support	group
48.	Grey Bruce Breast Cancer group [Bluewater CCS]	group
49.	Hanover & area Cancer group [Bluewater CCS]	group
50.	Living with Cancer Kincardine [Bluewater CCS]	group
51.	Meaford & Area Prostate Group	group
52.	Owen Sound Cancer Group [Bluewater CCS]	group
53.	Owen Sound Prostate Group	group
54.	Ajax Brain Tumour Support Group	group
55.	Southhampton Men’s Support Group	group
56.	Hearth Place Breast Cancer group [Oshawa]	group
57.	Hearth Place Colon Cancer Support group	group
58.	Hearth Place Gyne Cancer Support Group	group
59.	Hearth Place Lung Cancer group	group
60.	Hearth Place Metastatic Cancer Group	group
61.	Hearth Place Lymphoma Support Group	group

Program		Type
62.	Hearth Place One-to-One	1 to 1
63.	Us Too Prostate Cancer Support Group[Durham]	group
64.	Our Ovarian Cancer Team [Whitby]	group
65.	Huntsville Breast Cancer Support	group
66.	Orillia Prostate Awareness Group	group
67.	Parry Sound & District Breast Cancer SG	group
68.	Haliburton Highlands Prostate Support [Minden]	group
69.	Kawartha Lakes Cancer Support Group[Lindsay]	group
70.	Kawartha Lakes Prostate Ca Group [Lindsay]	group
71.	Living with Cancer Bobcaygeon [not CCS]	group
72.	Northumberland Prostate Cancer Support Group	group
73.	Living with Cancer Northumberland [CCS Peterb.]	group
74.	Peterborough Breast Ca Group	group
75.	Peterborough Prostate Support Group[CCS]	group
76.	Belleville Prostate Support Group [Hastings CCS]	group
77.	Omega Cancer Support Group [Picton]	group
78.	Quinte Cancer Support Group [Trenton]	group
79.	ABC Calm Breast Ca group [Hastings CCS]	group

5. Area: *South Central*

80.	Brampton Breast Ca Support [CCS Brampton]	group
81.	CCS Mississauga [Living with Cancer]	group
82.	Brampton Prostate Support	group

Program	Type
83. Toronto & District Multiple Myeloma	group
84. Newmarket Prostate Support Group	group
85. Halton Peel Ostomy Association	1 to 1
86. Wellspring Halton-Peel	group
87. Wellspring Halton-Peel	1 to 1
88. Connecting Rainbows Breast ca [CCS Markham]	group
89. Richmond Hill Prostate group	group
90. Markham Prostate Awareness [CCS Markham]	group

6. Area: *Toronto Region*

91. Man to Man Prostate (CCS Central Toronto)	group
92. Living with Ca (CCS Scarborough)	group
93. Scarborough Breast Ca [CCS Scarborough]	group
94. Cancer Anonymous	group
95. Etobicoke Breast Cancer Support Group	group
96. Gilda’s Club Wellness group	group
97. Kew Beach Cancer Support Group	group
98. Ostomy Toronto (Toronto District)	1 to 1
99. Ostomy Toronto (Toronto District)	group
100. Wellspring Peer Support (Toronto)	1 to 1
101. Wellspring Peer Support (Odette House)	1 to 1
102. Wellspring Graduate Patient (Toronto)	group
103. Wellspring Graduate Patient (Odette House)	group

Program	Type
104. Wellspring Breast Cancer (Toronto)	group
105. Wellspring Breast Cancer (Odette House)	group
106. Wellspring Lung Ca Support Group	group
107. Wellspring Lymphoma Support Group	group
108. Wellspring Metastatic Ca Group	group
109. Wellspring Ovarian Ca group	group
110. Wellspring Gynaecologic Support (Odette House)	group
111. Wellspring Gay Men & Partners	group
112. Wellspring Aboriginal Cancer Group	group
113. Willow’s Breast Cancer Support	1 to 1
114. Jewish Women with Ca	group

7. Area: *Central West*

115. Burlington Breast Cancer Support Group	group
116. Centre Wellington Women’s S.G. [Fergus]	group
117. Homefront Cancer Services [Stoneycreek]	group
118. Living with Cancer [CCS Niagara]	group
119. Niagara Breast Cancer Support Group	group
120. Guelph-Wellington Prostate S.G.	group
121. St Catherine’s Living with Prostate [CCS Niagara]	group
122. Welland Breast Ca S.G.	group
123. Wellsprings Breast Cancer[Niagara]	group
124. Wellspring General [Niagara]	group

	Program	Type
125.	Breast Cancer Support [Burlington]	group
126.	Breast Cancer Support [Burlington]	group
127.	Breast Cancer Support [Hamilton]	group
128.	Living with Ca [CCS Burlington]	group
129.	Prostate Cancer SG [CCS Burlington]	group
130.	Dundas N. Wentworth Prostate [CCS Hamilton]	group
131.	Hopesprings (Cambridge)	group
132.	CCS (Guelph)	group
133.	Breast Cancer Action & Support	group
134.	Circle of Friends Breast ca support (Cambridge)	group
135.	Living with Cancer [CCS Waterloo]	group
136.	Hopesprings Prostate (Waterloo)	group
137.	Hopesprings Leukemia (Waterloo)	group
138.	Hopesprings 1 to 1	1 to1
139.	Hopesprings Breast	group
140.	Hopesprings Patient	group
141.	Circle of Friends (Hamilton)	group
142.	Hamilton Ostomy Chapter	group
143.	Brainy Bunch	group
144.	Hamilton Multiple Myeloma Group	group
145.	Wellwood Resource Centre	1 to 1
146.	Wellwood Gyneacologic Cancer	group

	Program	Type
147.	Wellwood Hope & Cope	group
148.	Wellwood Breast Cancer	group
149.	Brantford Breast Ca Lunchbag Support [red cross]	group
150.	Brantford Breast Ca Support Group	group
151.	Brantford Prostate Ca Group[CCS]	group
152.	Living with Prostate Ca Simcoe	group

8. Area: *South Western*

153.	Bosom Buddies [London]	group
154.	Chatham CCS Support Group	group
155.	London Brain Tumor Support Group	group
156.	London & District Ostomy Association	group
157.	London & District Ostomy Association	1 to 1
158.	London Prostate Cancer & Support Group	group
159.	Multiple Myeloma Support Group	group
160.	St Thomas & Area Prostate Support Group	group
161.	Wellspring Support Group	group
162.	Wellspring Breast Peer Support	1 to 1
163.	Essex County Chapter of New Voices	group
164.	Living with Cancer [Essex County CCS]	group
165.	Multiple Myeloma Support Group[Windsor]	group
166.	Living with Cancer [CCS Windsor]	group

Program		Type
167.	Living with Cancer [CCS Huron Perth]	group
168.	Living with Breast Ca [CCS Huron Perth]	group
169.	Living with Cancer Seaforth [CCS Huron Perth]	group
170.	Living with Cancer Stratford [CCS Huron Perth]	group
171.	Stratford Prostate Cancer SG [CCS Huron Perth]	group
172.	Lambton Peer Support Group [CCS Lambton]	group
173.	Lambton Prostate Cancer SG [CCS Lambton]	group
174.	After Breast Ca SG Tillsonburg [Oxford CCS]	group
175.	After Breast Ca SG Woodstock [Oxford CCS]	group
176.	Life after diagnosis [Oxford CCAC]	1 to 1
177.	Windsor Essex County Prostate CSG	group

Appendix M: Peer Support Participants' Beliefs by Overall and by Gender

Belief Statement	**Total Sample N (%)**	**Males n (%)**	**Females n (%)**
Someone to count on (n=220)			
Yes	201 (93.1)	93 (92.1)	108 (93.9)
Missing	4	2	2
I don't like to impose (n=220)*			
Strongly agree	75 (34.9)	33 (28.9)	42 (42.0)
Moderately agree	76 (35.3)	37 (32.5)	39 (39.0)
Neutral	39 (18.1)	28 (24.6)	10 (10.0)
Moderately disagree	16 (7.4)	11 (9.6)	5 (5.0)
Strongly disagree	9 (4.2)	5 (4.4)	4 (4.0)
Missing	5	3	2
I don't like to complain (n=220)			
Strongly agree	74 (34.3)	38 (33.3)	36 (35.6)
Moderately agree	95 (44.0)	48 (42.1)	46 (45.5)
Neutral	28 (13.0)	16 (14.0)	12 (11.9)
Moderately disagree	14 (6.5)	10 (8.8)	4 (4.0)
Strongly disagree	5 (2.3)	2 (1.8)	3 (3.0)
Missing	4	3	1
People shouldn't dwell on illness (n=220)			
Strongly agree	75 (34.2)	38 (32.8)	37 (36.3)
Moderately agree	83 (37.9)	44 (37.9)	38 (37.3)
Neutral	37 (16.9)	22 (19.0)	15 (14.7)
Moderately disagree	21 (9.6)	10 (8.6)	11 (10.8)
Strongly disagree	3 (1.4)	2 (1.7)	1 (1.0)
Missing	1	1	0
People with cancer best support person (n=220)			
Strongly agree	148 (67.9)	72 (62.1)	75 (74.3)
Moderately agree	60 (27.5)	37 (31.9)	23 (22.8)
Neutral	4 (1.8)	3 (2.6)	1 (1.0)
Moderately disagree	4 (1.8)	3 (2.6)	1 (1.0)
Strongly disagree	2 (0.9)	1 (.9)	1 (1.0)
Missing	2	1	1
Participants similar in age and gender (n = 220)**	84 (38.7)	52 (45.2)	31 (30.7)
Strongly agree	90 (41.5)	44 (38.3)	46 (45.5)
Moderately agree	21 (9.7)	11 (9.6)	10 (9.9)
Neutral	13 (6.0)	5 (4.3)	8 (7.9)
Moderately disagree	9 (4.1)	3 (2.6)	6 (5.9)
Strongly disagree	3	2	1

Significant gender differences: **p*< .01; **p < .05

Belief Statement	**Total Sample N (%)**	**Males n (%)**	**Females n (%)**
People with cancer make the best support group leaders (n= 105)			
Strongly agree	60 (57.1)	36 (57.1)	24 (57.1)
Moderately agree	30 (28.6)	18 (28.6)	12 (28.6)
Neutral	11 (10.5)	7 (11.1)	4 (9.5)
Moderately disagree	3 (2.9)	2 (3.2)	1 (2.4)
Strongly disagree	1 (1.0)	0 (0.0)	1 (2.4)
Facilitator similar in age and gender (n=105)*			
Strongly agree	31 (29.2)	25 (39.7)	6 (14.3)
Moderately agree	39 (36.8)	21 (33.3)	18 (42.9)
Neutral	18 (17.0)	10 (15.9)	8 (19.0)
Moderately disagree	11 (10.4)	5 (7.9)	6 (14.3)
Strongly disagree	6 (5.7)	2 (3.2)	4 (9.5)
Non-professional facilitators			
(n=105)	32 (30.8)	17 (27.0)	15 (36.6)
Strongly agree	35 (33.7)	27 (42.9)	8 (19.5)
Moderately agree	26 (25.0)	10 (15.9)	16 (39.0)
Neutral	8 (7.7)	7 (11.1)	1 (2.4)
Moderately disagree	3 (2.9)	2 (3.2)	1 (2.4)
Strongly disagree	1	0	1

Significant gender differences: *$p < .01$; **p < .05

Appendix N: Participants' Beliefs by Age Group

Belief Statement	**< 65 years of age n (%)**	**≥ 65 years of age n (%)**
Someone to count on (n=216)		
Yes	100 (90.1)	99 (96.1)
No	11 (9.9)	4 (3.9)
Missing	0	2
Total	111	105
I don't like to impose (n=216)		
Strongly agree	36 (32.4)	36 (36.0)
Moderately agree	41 (36.9)	35 (35.5)
Neutral	15 (13.5)	23 (23.0)
Moderately disagree	12 (10.8)	4 (4.0)
Strongly disagree	7 (6.3)	2 (2.0)
Missing	0	5
I don't like to complain* (n=216)		
Strongly agree	30 (27.0)	42 (41.6)
Moderately agree	53 (47.7)	40 (39.6)
Neutral	13 (11.7)	15 (14.9)
Moderately disagree	10 (9.0)	4 (4.0)
Strongly disagree	5 (4.5)	0 (0.0)
Missing	0	4
People shouldn't dwell on illness* (n=216)		
Strongly agree	30 (27.0)	44 (42.3)
Moderately agree	46 (41.4)	34 (32.7)
Neutral	21 (18.9)	16 (15.4)
Moderately disagree	13 (11.7)	8 (7.7)
Strongly disagree	1 (0.9)	2 (1.9)
Missing	0	1
People with cancer best support person (n=216)		
Strongly agree	77 (70.0)	67 (64.4)
Moderately agree	29 (26.4)	31 (29.8)
Neutral	1 (0.9)	3 (2.9)
Moderately disagree	2 (1.8)	2 (1.9)
Strongly disagree	1 (0.9)	1 (1.0)
Missing	1	1
Participants similar in age and gender		
(n = 216)	37 (33.6)	46 (44.7)
Strongly agree	50 (45.5)	37 (35.9)
Moderately agree	12 (10.9)	9 (8.7)
Neutral	8 (7.3)	5 (4.9)
Moderately disagree	3 (2.7)	6 (5.8)
Strongly disagree	1	2
Missing		

Significant age group difference * $p < .05$

Belief Statement	**< 65 years of age n (%)**	**≥ 65 years of age n (%)**
People with cancer make the best support group leaders (n= 105)		
Strongly agree	25 (51.0)	34 (61.8)
Moderately agree	17 (34.7)	13 (23.6)
Neutral	4 (8.2)	7 (12.7)
Moderately disagree	2 (4.1)	1 (1.8)
Strongly disagree	1 (2.0)	0 (0.0)
Missing	1	0
Facilitator similar in age and gender (n=105)		
Strongly agree	13 (26.5)	18 (32.7)
Moderately agree	16 (32.7)	22 (40.0)
Neutral	11 (22.4)	7 (12.7)
Moderately disagree	6 (12.2)	5 (9.1)
Strongly disagree	3 (6.1)	3 (5.5)
Missing	1	0
Non-professional facilitators (n=105)		
Strongly agree	19 (39.6)	13 (23.6)
Moderately agree	12 (25.0)	22 (40.0)
Neutral	13 (27.1)	13 (23.6)
Moderately disagree	2 (4.2)	6 (10.9)
Strongly disagree	2 (4.2)	1 (1.8)
Missing	2	0

Appendix O: Study 2 Sample Advertisement

Senior Volunteers: Researchers at the University of Waterloo are looking for seniors (65+0 diagnosed with breast, prostate or bowel cancer in the past five years. We invite you to take part in a discussion about the challenges of living with cancer and the services available to meet these challenges. To volunteer, please contact: N. Pearce at 1-866-301-1453. This study has been approved by the Office of Research Ethics at the University of Waterloo.

Appendix P: Study 2 Recruitment Poster

Department of Health Studies & Gerontology, University of Waterloo

SENIOR VOLUNTEERS NEEDED FOR A STUDY ON CANCER SUPPORT SERVICES

We are looking for adults aged 65 and over previously diagnosed with breast, prostate, or bowel cancer. We invite you to take part in a discussion about the challenges of living with cancer and the services available to meet these challenges. Participation will take approximately 1 hour. In appreciation of your time you will receive an honorarium of $20.00.

If interested, contact Nancy Pearce
at (1-866-301-1453) or
email: njmpearc@uwaterloo.ca.

Thank you!

This study has been reviewed by, and has received ethics clearance through, the Office of Research Ethics, University of Waterloo

Appendix Q: Study 2 Recruitment Script

Primary Researcher:

Hello, my name is Nancy Pearce and I am a registered nurse and currently a doctoral student in the department of Health Studies & Gerontology at the University of Waterloo. I am doing research on cancer support programs under the supervision of Professors Sharon Campbell and Anita Myers. As part of my thesis research, I am conducting discussions with older adults who have been diagnosed with breast, prostate, or bowel cancer in the last five years to learn more about the challenges of living with cancer. We really have very little information about the unique needs of older adults with cancer and I would like to learn more.

If you volunteer as a participant in this study, you will be asked to take part in a small group discussion with 4 to 8 other seniors about the challenges of living with cancer and your cancer support needs.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours.

If you are interested in participating, please fill out one of the individual confidential recruitment cards and I will be in touch with you. Alternatively, you can call (*1-866-301-1453*) and speak with me. Thank you.

Name	Phone Number	Best Days and Times
Jane Doe	1-555-8456	Monday to Friday, 9am-5pm

Appendix R: Study 2 Participant Information

I - I am a registered nurse and I'm doing a doctorate in the Department of Health Studies & Gerontology at the University of Waterloo. I am holding small discussion groups with senior (***men, women or both men and women***) to talk about the challenges of living with cancer and some of the support services available to meet these challenges. I am doing this under the supervision of Professors Sharon Campbell and Anita Myers.

I - Background Information:

- I will be holding these discussions in your area starting ***(insert date).***
- The discussion will last about one hour, and will take place at ***(insert focus group site).***
- Involvement in this discussion is entirely voluntary and there are no known or anticipated risks to participation in this study.
- The topic discussed are quite general (for example, What challenges have you faced?, What helped you to meet these challenges?)
- All information you provide will be considered confidential. Fellow participants will be asked not to reveal any comments heard during the discussion but this cannot be guaranteed. You may decide if or when you wish to contribute to the discussion and may leave the discussion at any time.
- As noted in the ad or poster you saw this study has ethics clearance from the office of research ethics at the University of Waterloo. I will give you a number to contact at the end of the discussion if you have any concerns arising from your participation.
- The final decision to participate is yours…

Appendix S: Focus Group Protocols and Script

Preparation and Set-up:

Bring: tape recorder (check batteries), pens/pencils, nametags, consent, money & receipts

Refreshments (set out)

Preliminaries:

Welcome participants as they arrive and introduce yourself and recorder

Give everyone a name tag

Make light conversation to help participants feel more at ease.

Allow 15 minutes for everyone to settle in (and for refreshments).

Once everyone is seated begin introductions….

Introductions:

Good morning (or afternoon). I'm Nancy and this is (*Name of recorder*). I am a registered nurse and presently I am a graduate student at the University of Waterloo. I would like to thank everyone for coming today.

We have asked you to participate in this discussion today because we would like to know more about the experiences of older adults living with cancer. The discussion should last around 45 minutes. We want to assure you that any comments you make will be kept strictly confidential. The information heard here today will be summarized along with the information from the other discussions taking place to show different views. No individual participant will be identified.

I will be the moderator of the discussion. That means it is my job to keep the discussion focused on the issues. (*Name of recorder*) will be making notes of the discussion as we go along. The note taking guides us when we review the discussion.

Please, feel free to express your view at any time. However, you should also feel free not to make comments or join in the discussion should you prefer.

If everyone agrees, we will audiotape the discussion so that we do not miss any of the valuable comments you make. The tapes allow us to go back and listen carefully to the discussion.

Distribute Information Letter

The first page outlines what I have just told you – any information you provide in the discussion or the checklist at the end of the session will be kept strictly confidential. Please read this first page now – you may take this page home with you should you have any questions or concerns after you leave today.

Give time to read the information letter (first page).

Are there any questions?

Obtain Consent

Please turn to the second page. The first set of boxes concerns your general consent to participate. If you agree to participate in the discussion, please check this part now.

The second set of boxes asks for permission to use anonymous quotations in my thesis and reports. Do you have any questions or concerns about this?

Gather up second page.

Ground Rules

Before we begin, we ask that you try and speak one at a time. Otherwise, we will miss some valuable comments. Keep in mind there are no right or wrong answers; all comments are valuable. It's okay for people to disagree – we all have different experiences and opinions.

Guiding Questions:

Icebreaker: Let's begin by going around the table and introducing ourselves and telling everyone briefly why you decided to take part in this discussion?

Intro: Receiving a diagnosis of cancer can be very stressful. Coping with the treatment can very taxing especially for older adults who may also be coping with other illnesses or conditions. I'd like to start by talking a about your experiences since being diagnosed with cancer.

1. What kinds of challenges or problems have you experienced?
    a. What were the main challenges?
2. How did you deal with these?

3. Has anyone or anything been helpful to you in dealing with these challenges?

    a. Who?
    b. What?
    c. How do they help?

4. Could you have used more assistance? (Prompt: in what areas?)

    a. Why do you think you did not receive this assistance?

Part B:

1. What does support mean to you? (do they distinguish between the various type of support)

2. How about emotional support?

3. Where would you look for emotional support?

4. Would you consider speaking to someone who has had cancer but you don't know about your cancer experience? (probe: for instance a support group/one-to-one support service).

Part C:

1. Have you ever heard of programs such as (*insert formal peer support program? e.g, Reach to Recover*, *local program*)

2. What have you heard about it?

    a. Have you considered participating in this kind of program? Why/why not?

3. (If participated…) What have been your experiences with these programs?
    a. Would you recommend it to others?

4. In you opinion, what can the Canadian Cancer Society or other community agencies can do to assist older adults, such as yourself, living with cancer?

Summary:

Give a brief summary (2-3 minutes) of the main points raised in the discussion.

If there are no further comments I would like to summarize some of the main points raised today….

Do you agree that these are the main points that came out of today's discussion? Is there anything else you would like to add?

Ending:

We would like to thank you for your participation in this discussion group.

We would like to get a bit more information on all participants to provide an overall description of the people who participated here today, as well as in the groups being conduced at other facilities.

Hand out checklist.

Thank you very much for taking the time to come today and offer your thoughts. Your comments will be extremely useful in our study.

Before you go, I have a letter of appreciation I would like to give to each of you…

Appendix T: Study 2 Participant Background Checklist

NOTE: The font will be enlarged for easier reading by older adult participants.

1. What type of cancer do you have?

Breast ___
Prostate ___
Colon/Bowel ___
Other____________________

2. When was your cancer diagnosed? Month _______ Year ____________

3. Where are you in your cancer experience? (Please check √ one):

Newly diagnosed____
Diagnosed, undergoing treatment____
Completed treatment for cancer____
Recurrence____

4. Do you have any other diagnosed health problems? (check √ as many as apply)

Heart trouble_____
High blood pressure______
Chronic asthma, emphysema, or bronchitis_______
Diabetes______
Arthritis______
Osteoporosis______
Kidney trouble______
Liver trouble_______
Vision difficulties not corrected by glasses______
Difficulty hearing _______ Do your wear hearing aids?________

5. Are you currently taking any medication prescribed by a doctor?

No______ (skip to question 6)
Yes______ (proceed to question 5b)

5b. How many different prescription medications do you take each day?

1______
2______
3______
4______
5______
More than 5 ______

6. Do you live alone?

Yes_____

No______ Who with? spouse_______ adult child__________ other___________

7. Do you drive?

Yes___

No____ Is someone able to drive you?____ or do you use public transit?_______

8. To what extent do you agree or disagree with each of the following statements:

"I don't want to impose on others"

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

"I don't like to complain"

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

"People shouldn't dwell on illness"

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

“People who have had cancer themselves make the best support for others with cancer”

1	2	3	4	5
strongly agree	moderately agree	neutral	moderately disagree	strongly disagree

“ Others with cancer who are similar to me in age and gender can better understand my concerns”

1	2	3	4	5
strongly agree	moderately agree	neurtal	moderately disagree	strongly disagree

9. Is there someone (family, friend, neighbour) you can really count on to listen to you when you need to talk?

Yes ______ Who is this mainly_______________________________________
No one_____

10. What is your date of birth? _________________

11. Were you born in Canada?

Yes_______
No________ *if no, where were you born?* _____________
*at what age did you come to Canada*_______________

12. Are you? Male ______ or Female_____

13. In which city/town/township do you live?________________________

14. How do you get to the discussion today? (Please check √ one):*

Drive myself__________
Driven by others_________
Taxi ____________
Public transit (bus, streetcar, subway)__________
Walk/bike__________
The program volunteer visits me_________

15. To what extent do you worry about transportation costs (driving, parking, taxis or public transit) to get to and from medical appointments?

1	2	3	4
often	sometimes	rarely	never

16. How far did you go in school?

Completed high school Yes __________ No ________
Some college/university __________
College/university graduate ________

17. Are you currently employed?

No ______ (proceed to question 17b)
Yes______ full time_____
part time_____

17b. I am not currently employed because I am

Retired________
Between jobs________
A homemaker_________
Unable to work due to illness________

Thank you for taking the time to answer these questions.

* This question was omitted for interview participants.

Appendix U: Study 2 Telephone Interview Script

Note: Participants will have been informed previously about the study details and their participation (during the contact interview).

I – I'm going to ask you some questions about your cancer experience. If you do not wish to answer any of the questions, you may decline to do so. You may stop the interview at any time if you so wish. Before we start, I want to tell you that I would like to tape this interview so that I do not loose any of you valuable comments. I will keep the information I receive confidential. No names of participants will be used. The tapes and notes will be kept in a locked file cabinet for three years. Then they will then be destroyed. I will not identify any individual by name in my thesis or in other reports. Do you have any questions?

P – No

I – Do I have your permission to tape the interview?

P – yes

I – I am going to turn on the tape recorder and then ask you once again if I have your permission to tape the discussion. This is so that I have a record of your giving me the OK.

Start tape-recording

I – Now that the tape recorder is turned on, would you please state: I (name of participant) give Nancy Pearce my permission to tape this discussion

R - I (name of participant) give Nancy Pearce my permission to tape this discussion

I – Thank you. At the end of the discussion, I will ask a short series of questions about yourself so that I can describe participants. You may answer all of the questions or decide to skip some.

Begin interview:

Intro: Receiving a diagnosis of cancer can be very stressful. Coping with the treatment can very taxing especially for older adults who may also be coping with other illnesses or conditions. I'd like to start by talking about your experiences since being diagnosed with cancer.

1. What kinds of challenges or problems have you experienced?
    a. What were the main challenges?
2. How did you deal with these?

3. Has anyone or anything been helpful to you in dealing with these challenges?

    a. Who?
    b. What?
    c. How do they help?

4. Could you have used more assistance? (Prompt: in what areas?)

    a. Why do you think you did not receive this assistance?

Part B:

1. What does support mean to you? (do they distinguish between the various type of support)

2. How about emotional support?

3. Where would you look for emotional support?

4. Would you consider speaking to someone who has had cancer but you don't know about your cancer experience? (probe: for instance a support group/one-to-one support service).

Part C:

1. Have you ever heard of programs such as (*insert formal peer support program? e.g, Reach to Recover, local program*)

2. What have you heard about it?

    a. Have you considered participating in this kind of program? Why/why not?

3. (If participated…) What have been your experiences with these programs?
    a. Would you recommend it to others?

4. In you opinion, what can the Canadian Cancer Society or other community agencies can do to assist older adults, such as yourself, living with cancer?

Summary:

Give a brief summary (2-3 minutes) of the main points raised in the discussion.

If there are no further comments I would like to summarize some of the main points raised today….

Do you agree that these are the main points that came out of our talk? Is there anything else you would like to add?

Ending:

At this point I would like to get a bit more information on all participants to provide an overall description of the people who participate in the study. As I mentioned at the beginning, you may answer all of the questions or decide to skip some.

Administer background checklist.

Thank you very much for taking the time to speak with me today and offering your thoughts. Your comments will be extremely useful in our study.

Appendix V: Study 2 Participants' Beliefs

Participant Beliefs (N=26)	**Total Sample N (%)**	**Males n (%)**	**Females n (%)**
Someone to count on			
Yes	24 (92.3)	10 (83.3)	14 (100.0)
No	2 (7.7)	2 (16.7)	0 (0.0)
I don't like to impose			
Strongly agree	10 (38.5)	3 (25.0)	7 (50.0)
Moderately agree	10 (38.5)	4 (33.3)	6 (42.9)
Neutral	6 (23.1)	5 (41.7)	1 (7.1)
Moderately disagree	0 (0.0)	0 (0.0)	0 (0.0)
Strongly disagree	0 (0.0)	0 (0.0)	0 (0.0)
I don't like to complain			
Strongly agree	12 (46.2)	3 (25.0)	9 (64.3)
Moderately agree	7 (26.9)	5 (41.7)	2 (14.3)
Neutral	3 (11.5)	1 (8.3)	2 (14.3)
Moderately disagree	2 (7.7)	2 (16.7)	0 (0.0)
Strongly disagree	2 (7.7)	1 (8.3)	1 (7.1)
People shouldn't dwell on illness			
Strongly agree	14 (53.8)	5 (41.7)	9 (64.3)
Moderately agree	8 (30.8)	5 (41.7)	3 (21.4)
Neutral	2 (7.7)	0 (0.0)	2 (14.3)
Moderately disagree	1 (3.8)	1 (8.3)	0 (0.0)
Strongly disagree	1 (3.8)	1 (8.3)	0 (0.0)
People with cancer best support person			
Strongly agree	18 (69.2)	9 (75.0)	9 (64.3)
Moderately agree	6 (23.1)	2 (16.7)	4 (28.6)
Neutral	1 (3.8)	1 (8.3)	0 (0.0)
Moderately disagree	1 (3.8)	0 (0.0)	1 (7.1)
Strongly disagree	0 (0.0)	0 (0.0)	0 (0.0)
Similar in age and gender			
Strongly agree	15 (57.7)	6 (50.0)	9 (64.3)
Moderately agree	5 (19.2)	3 (25.0)	2 (14.3)
Neutral	2 (7.7)	1 (8.3)	1 (7.1)
Moderately disagree	3 (11.5)	2 (16.7)	1 (7.1)
Strongly disagree	1 (3.8)	0 (0.0)	1 (7.1)

Appendix W: Suggested Peer Support Group Client Profile

We would like to ask you some questions about yourself…

1. How did you hear about this program? (check √ as many as apply)

Friend_________
Fellow patient__________
Family member_________
Family Doctor__________
Oncologist/specialist_______
Nurse________
Pamphlets/posters____________ (where did you see them__________________)
Newspaper Ad ________________
Other (please specify)______________

2. What is your date of birth? Year______ Month______Day____

3. Are you? Male ______ or Female_____

4. When were you fist told you had cancer? Year__________ Month__________

5. With what type of cancer have you been diagnosed?

Lung ______
Breast_____
Prostate_____
Bowel, (colo-rectal) ______
Lymphoma _______
Leukemia _______
Uterine, ovarian or cervical ______
Other ______

6. Where are you in your cancer experience? (Please check √ one):

Newly diagnosed____
Diagnosed, undergoing treatment____
Finished treatment, having check-ups ____
No treatment, having check-ups _____
Finished check-ups____
Relapse or recurrence undergoing treatment____
Palliative Care________
Other____, please explain_______________________________________

7. In the past month have you received treatment for cancer?

No ____ (skip to question 9)

Yes _____(proceed to question 8)

8. Which treatments did you receive? (check √ as many as apply)

Chemotherapy ______
Radiation treatment ______
Surgery ______
Immunotherapy ________
Hormone treatment _______
Bone marrow/stem cell transplant ______
Other, please specify ___________________________

9. Which treatments for cancer have you *ever* received? (check √ as many as apply)

Chemotherapy ______
Radiation treatment ______
Surgery ______
Immunotherapy ________
Hormone treatment _______
Bone marrow/stem cell transplant ______
Other, please specify ___________________________

10. Do you have any other diagnosed health problems? (check √ as many as apply)

No_____
Yes_____:
- Heart trouble_____
- High blood pressure______
- Chronic asthma, emphysema, or bronchitis_______
- Diabetes______
- Arthritis______
- Osteoporosis______
- Kidney trouble______
- Liver trouble_______
- Vision difficulties not corrected by glasses______
- Difficulty hearing _______ Do your wear hearing aids?________

11. Do you live alone?

Yes_____
No______ with spouse/partner__________ child__________ other___________

12. Were you born in Canada?

Yes_______
No________ *if no, where were you born?* _____________
*at what age did you come to Canada*_______________

13. How long do you spend travelling to the program? ________________

14. How do you usually get to the program? (Please check √ one):

Drive myself__________
Driven by others_________ my driver attends a program at the same time _____
Taxi ____________
Public transit (bus, streetcar, subway)__________
Walk/bike__________
The program volunteer visits me_________

15. How far did you go in school?

Completed high school Yes __________ No ________
Some college/university __________
College/university graduate ________

16. Are you currently employed?

No ______ (proceed to question 16b)
Yes______ full time_____
part time_____

16b. I am not currently employed because I am

Retired________
A student _________
Between jobs________
A homemaker_________
Unable to work due to illness________

Thank you for taking the time to answer these questions.

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