

DO YOU CARE2TALK? EXAMINING AN ONLINE APPROACH TO PSYCHOSOCIAL  
SUPPORT FOR YOUNG ADULTS WITH CANCER

by

Liane S. Kandler

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Supervisor: Dr. Scott M. Sellick

Co-Supervisor / Second Reader: Dr. John Jamieson

External Examiner: Dr. Lynn Martin

GSC Representative: Dr. Kirsten Oinonen



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## Abstract

Cancer in young adulthood is unique in that there are clear biological, epidemiological, and etiological differences attributed to this age frame (Bleyer, 2002; Canadian Cancer Statistics, 2007; Cancer in Young Adults in Canada, 2006). Similarly, the psychosocial challenges are also unique and the need for specialized psychosocial care has been clearly advocated (Bleyer, 2002; Corsini & Ammerman, 2008; Pentheroudakis & Pavlidis, 2005; Thomas, Seymour, O'Brien, Sawyer, & Ashley, 2006; Zebrack, Chesler, Penn, & Katz, 2005). In an attempt to assess and meet the psychosocial needs of young adults with cancer in Northwestern Ontario, patients aged 18 to 44 years were mailed a questionnaire package and invited to participate in an online information and support group. Demographic, medical, and psychosocial patient characteristics were assessed. Levels of distress, social support, and active use of the online group were measured. Primary goals of the research were to assess interest in online support in young adults with cancer, predictors of interest, and relationships among distress measures and social support. Significant differences emerged between individuals interested and not interested in participating in the online group, with women and those with a previous history of Supportive Care use being more likely to be interested. Significant predictors of interest in participating online included gender, distress, social support, and previous use of Supportive Care services. Higher distress scores were correlated across measures, and generally associated with lower social support. The implications of these findings for providing supportive care services to young adults with cancer are discussed.

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## Introduction

Until very recently, cancer in young adults has been largely ignored (Bleyer, 2005). The last 40 years have seen considerable advances towards improved treatment, care, and support in pediatric oncology (Pentheroudakis & Pavlidis, 2005), yet these advances have not been mirrored in the care being provided to young adults. Canadian Cancer Statistics (2007) estimates that 10,000 young adults between the ages of 20 and 44 are diagnosed with cancer annually, 2,000 of whom will die from the disease. These patients are diagnosed in the most productive period of their lives, with a disease that is predominantly considered one of older adulthood. Cancer incidence rates are also rising in males and females 20-29 as well as in females up to 39 (Canadian Cancer Statistics, 2007). However, despite these rising incidence rates, the Canadian Advocacy Coalition of Canada (2007) identified only four official support groups for young adults with cancer. This represents a decline from the six support groups identified by Young-Adult-Cancer, an online support group targeted at young adults that has been in virtual operation since 2004. This signifies that even on a national level support is sparse and the need for age appropriate services for young adults is increasing. A questionnaire mailing to assess the needs of young adult cancer patients, and an online support group to meet those psychosocial needs, was therefore proposed. The following details the research and theoretical foundations upon which this project was based.

### 1.1 Cancer Statistics

In the past decade (1990-1999) 6% of males and 11% of females in Canada in the 20-44 age range were diagnosed with cancer, totalling 100,374 cases and representing approximately 9% of all cancer cases in adulthood (Canadian Cancer Statistics, 2007). For males in the 20 to 44 age range, the most common type of cancer was testis (14%), and the most common cause of

death was due to lung cancer (15%). For females 20 to 44, the most common type of cancer, and cause of death, was breast cancer, representing 34% and 31% of cases respectively. Although incidence and mortality rates in Ontario are generally below the national average, age-standardized incidence rates in the 20 to 44 age range are the highest nationally (Cancer in Young Adults in Canada, 2006). Locally, at the Thunder Bay Regional Health Sciences Centre (TBRHSC), young adults aged 18 to 40 represent approximately 4.6% of adult cancer cases (paediatric excluded).

Worldwide, the distribution of common cancers in young adulthood has been identified as unique to this age group (Bleyer, 2002; Cancer in Young Adults in Canada, 2006; Thomas, Seymour, O'Brien, Sawyer, & Ashley, 2006). In Canada, the three most common cancer diagnoses in men aged 20 to 44 include testis (14%), non-Hodgkin lymphoma (11%), and melanoma (9%). In men aged 45 and older, prostate (26%), lung (20%) and colorectal (14%) are the most common. For Canadian women between the ages of 20 and 44, breast (34%), cervical (10%) and thyroid cancer (9%) have the highest incidence rates. For women over the age of 45, breast (30%), colorectal (14%) and lung (13%) are the most common. For women 20 to 44 years, breast, lung, cervical, brain, and colorectal cancers account for nearly two-thirds of cancer deaths. Lung, brain, non-Hodgkin lymphoma, leukemia and colorectal cancer account for just over half of cancer deaths in men aged 20 to 44 (Cancer in Young Adults in Canada, pg. 14). This indicates that cancer type and mortality rates differ in younger as opposed to older adults.

In addition to the distinctive cancer distribution, young adults with cancer typically have poorer outcomes than do older adults or children. Although reasons for this are not clear, several theories have been put forth (Thomas et al., 2006). It has been hypothesized that alterations in the cancer biology of young adults causes unfavourable reactions to chemotherapy and radiation.

This would affect the ability to effectively deliver therapy as well as decrease the effectiveness of

the therapy provided. This theory would therefore imply that a 6 year old, 26 year old, and 66 year old with the same type of cancer would each benefit from different treatments, or benefit differently from the same treatments. A second theory put forth for poorer cancer outcomes in young adulthood is the relative rarity of cancer occurrence within this age range. Of the cancers diagnosed in adults over the age of 20, slightly more than 9% are diagnosed in younger adults 20 to 44 years of age (Cancer in Young Adults in Canada, 2006), meaning that the majority of adult cancer cases are diagnosed after the age of 45. This results in a broad dispersal of treatment for young adults, rather than treatment in localized specialty centers. Low participation in clinical trials, which are typically being associated with improved outcome, is also cited as a central problem. A third theory suggests that lack of adherence to treatment, resulting in loss of dose intensity, may also play a role in decreasing positive outcome measures. This relates to the feelings of invincibility that often accompany late adolescence and young adulthood, and a desire to increase autonomy rather than adhere to strict treatment regulations. In light of the evidence supporting the uniqueness of the cancer distribution and poor trend in outcome prognosis, Pentheroudakis and Pavlidis (2005) emphasized the need for support and care tailored to this age frame, similar to the manner in which specialized care is offered for pediatric and gerontology oncology patients.

Aside from the biological, epidemiological, and etiological differences of cancer in young adulthood, a great deal of recent research has focused on the psycho-social challenges unique to this demographic group. The need for not only specialized medical care, but also specialized psychosocial care for adolescents and young adults has been clearly advocated (Bleyer, 2002; Corsini & Ammerman, 2008; Pentheroudakis & Pavlidis, 2005; Thomas et al., 2006; Zebrack, Chesler, Penn, & Katz, 2005).

## 1.2 Psychosocial Care Models

A conceptual framework or model of psychosocial care is critical to guiding program planning, educational services, and research initiatives. Three theoretically and research grounded models have emerged as relevant to the provision of psychosocial care for young adults with cancer. These models were therefore examined for their viability to guide the research project.

Guided by the Chesler and Barbarin Stress Coping Model (Chesler & Barbarin, 1987), Zebrack and colleagues (2005) suggested the organization of the psychosocial issues of young adults with cancer along 5 dimensions: intellectual, practical, interpersonal, emotional, and existential. Intellectual issues involve the amount of information the cancer patient is interested in receiving and the manner in which he or she prefers information be communicated. Practical issues relate to the hospitalization and treatment experience, and disruptions in school or occupation that are likely to occur. Relationships with peers and parents are the focus of the interpersonal aspect of this model. Emotional issues include psychological and emotional distress, as well as actual and perceived support. Finally, existential or spiritual issues have also been identified as a core component of the Stress-Coping Model, and are defined in terms of facing uncertainty, desire for hope, and psycho-spiritual adaptation. This model's strength stems from its ability to organize the cancer experience into observable categories and identify patient needs from different perspectives, although depending on the intervention or purpose for which the model is destined, the umbrella categories may prove to be too broad.

As an alternative to the Stress-Coping Model, the psychosocial needs of young adults with cancer are often outlined by focusing on the individual and identifying the unique challenges faced. Bleyer (2002) suggested that independence and autonomy, education and completion of

schooling, social development, peer pressure and peer relationships, sexual maturation, intimacy and marriage, fertility issues, parenting, employment, and insurability are all key challenges faced by young adults with cancer. Bleyer also suggests that these issues are especially poignant during this age range, more so than at any other point during the lifespan. Bleyer refers specifically to the 18 to 35 year old, stating that life may consist of educational and occupational planning, beginning a family, or increasing independence. It is a time often characterized by a sense of invincibility, and a time to explore and to learn. For the young adult cancer patient, it becomes a question of how to stay motivated and plan for a future that may never happen and how to deal with the “what if’s” that accompany living with a life threatening illness. Finally, Bleyer highlights that the adverse effects of cancer treatments on the self-image of young adults can be overwhelming. At a time when self-image is being developed and is often still fragile, patients may have to cope with invasive and mutilating surgery, weight gain, stunted growth, hair loss and extreme acne, among other consequences. Although comprehensive, Bleyer’s (2002) conceptualization of psychosocial needs based on unique challenges provides less structure than the Chesler and Barbarin Stress Coping Model (Chesler & Barbarin, 1987).

A third model is the Supportive Care Framework for Cancer Care proposed by Fitch (1994). Theoretically based, the framework is derived from extensive patient and family interviews, surveys, and consultation session with interdisciplinary professionals (Fitch, Porter, and Page, 2008). Given the specific nature of cancer care, this model was designed to aid care providers in organizing and imparting relevant and essential information to patients. Seven dimensions are included in the framework: (1) psychological, relating to self-worth, coping, and body image; (2) social, relating to relationships, family, and occupation; (3) spiritual, relating to suffering, pain, and meaning in life; (4) informational, relating to the provision of disease, symptom, and treatment information; (5) practical, relating to finances, legal concerns, and

childcare; (6) emotional, relating to sentiments such as fear, anger, despair, or hopelessness; and (7) physical, relating to symptoms such as nausea, pain, or fatigue (Fitch et al., 2008; see Figure 1). Fitch and colleagues (2008) articulated needs relating to each dimension. For the spiritual dimension, the individual need is to assess the purpose and meaning in life; the needs in the information dimension relate to reducing confusion, anxiety, fear, and distress through information acquisition (see Fitch et al., 2008 for full evaluation).

When using a psychosocial model, it is incumbent upon the care provider to choose a model that is comprehensive, but also one that works within the healthcare system. Smaller hospitals may be challenged in the resources available, and opt to meet all patients needs through a single department. Larger hospitals may have departments specializing in the provision of spiritual care, psychological care, and practical care issues, meaning that a fully comprehensive model might not be the most suitable. At the Thunder Bay Regional Health Sciences Centre (TBRHSC), the mandate of the Oncology Supportive Care Program is to meet the emotional, social, practical, and spiritual needs, and to assist the patient with cancer-related concerns and issues in the practical and informational realm. Personnel including a non-denominational spiritual care counsellor, a dietitian, a psychologist, quit smoking coach, and social worker are available to provide practical information as well as emotional support.

Of the three models reviewed, the Supportive Care framework (Fitch, 1994) most accurately matches the services offered by the Supportive Care program at the TBRHSC. In addition, this model offers both global dimensions and specific examples to help the care provider assess the patient's needs. Although not specifically geared towards young adults, the framework is well articulated and encourages a patient centered approach to care (Fitch et al., 2008). For these reasons, the Supportive Care framework was chosen to guide the project.



### 1.3 Distress

Regardless of the model or framework employed by the healthcare facility, the need to address the psychosocial needs of all cancer patients is being increasingly recognized. In 2005, the Canadian Strategy for Cancer Control (CSCC) (Rebalance Focus-Action Group, now known as Cancer Journey Action Group) officially recognized distress as the sixth vital sign, and as a measure by which to gauge patient functioning. Distress joins the vital signs of temperature, blood pressure, heart rate, respiration, and pain (National Pharmaceutical Council, 2001), the traditional measures used to gauge patient functioning. Distress is conceptualized as psychosocial, practical, and physical concerns (Cancer Journey Action Group, 2009) and deals with all aspects of social, emotional, and quality of life issues (CAPO; Canadian Association of Psychosocial Oncology, 2008). Bultz and Carlson (2006) noted that significant distress affects approximately 35 to 45% of cancer patients (Carlson and Bultz, 2004; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) and up to 58% of palliative care cancer patients (Potash and Brietbart, 2002) in North America, with similar levels evidenced worldwide. Levels of distress are most likely to increase when an individual appraises a situation, be it consciously or unconsciously, and concludes that the threat they are feeling cannot be diminished (Fitch et al., 2008). As the cancer experience is composed of many difficult situations and decisions, it is clear that there are many opportunities for a patient to experience increased distress, and all patients require some level of distress screening (see Figure 2). The addition of distress as a vital sign is in line with psychosocial oncology's holistic approach to cancer care, starting with prevention and continuing to bereavement (CAPO, 2008).

Negative affect stemming from emotional distress may affect the patient and his or her daily interactions. Beckford, Finney Rutten, Arora, Moser, Hesse (2008) examined the role of

negative affect as a potential impediment to the processing of health information. Negative affect was operationalized as cancer worry and symptoms of depression, and the information processing variables consisted of attention to health information and cancer information-seeking experiences. Results indicated that increased cancer worry was associated with increased attention to health information from media sources. In addition, higher levels of both cancer worry and depression symptoms were associated with decreased success in perceived information seeking experiences, such that individuals with greater levels of negative affect experienced increased difficulty in understanding, obtaining, and accessing cancer information. However, the authors also note a relationship with socio-demographic factors, such that increased education was associated with increased attention to health information and more effective information screening (Beckford, et al., 2008). Although the underlying mechanisms are not clear, these findings may have important implications for the provision of health information. In particular, individuals who are experiencing significant levels of emotional distress may have difficulty obtaining or comprehending their health information, potentially exacerbating the original distress. Further research is necessary to replicate these results, meaning that conclusions should be drawn carefully in the interim. However, these results continue to highlight the need to help cancer patients manage their illness-related emotions.

Carlson and Bultz (2004) also researched and elaborated on the economic benefits of psychosocial interventions as well as their efficacy in reducing emotional distress. Based on this research, distress has been recognized not only as a pervasive issue for cancer patients, but also as one that can yield long-term cost savings when effectively addressed (Carlson & Bultz, 2004). The addition of distress as a vital sign therefore highlights its documented and significant impact on patient care, psychological health, and medical cost (Bultz and Carlson, 2006; Carlson and

Bultz, 2004). It is also a clear indication of growing support for the importance of mind and spirit in cancer care, and a concrete shift towards a holistic approach to effective care.

#### 1.4 Distress and Cancer Development

Although the potentially detrimental effects of emotional distress are clear, the relationship between emotional factors and cancer development is debated. It is most commonly theorized that psychological factors, such as life events or social support, influence changes at the hormonal level. These hormonal fluctuations are thought to affect immunological functioning, thereby influencing cancer incidence and progression (Garssen & Goodkin, 1999). A review of the research examining these links has yielded mixed results (Garssen & Goodkin, 1999). Life events such as psychosocial factors were examined in relation to cancer prognosis, with two studies supporting a link between greater life stress and greater recurrence as well as shorter survival time (Forsen, 1991; Funch & Marshall, 1983) and two studies finding no relationship (Barraclough, Pinder, Cruddas, Osmond, Taylor, & Perry, 1992; Hislop, Waxler, Coldman, Elwood, Kan, 1987). Similar mixed results were found for psychological factors such as bereavement, social support, hopelessness, active coping style, and negative emotions (Garssen & Goodkin, 1999). Given the mixed positive and negative results, potentially compounded by a file drawer effect for additional negative results, the existence of a simple relationship is highly questionable. Clearer results have emerged on the role of repression, such that repression has consistently been found to influence cancer progression (Epping-Jordan, Compas, & Howell, 1994; Jensen, 1987; Weinberger, Schwartz, & Davidson, 1979). Garssen and Goodkin (1999) suggest that it may be necessary to examine the psychological as well as biomedical interactions between factors in an increasingly comprehensive manner to obtain a clearer image of the true relationships among variables.

In an attempt to merge these earlier findings and current literature, a recent review by Garssen (2004) examined the potential impact of several psychological factors on cancer development. As cancer is a long-term illness, the author included only longitudinal studies in the final analysis. With this criterion in place, no single psychological factor emerged as having a clear influence on cancer development. Although some psychological factors, such as helplessness and repression, appeared to contribute to cancer development, interactions between biological and psychological factors did not clearly emerge. The author suggests that evaluating the interaction between both biological and psychological factors at a micro level may lead to consistent results (Garssen, 2004). Further broad-scale research will be necessary if potential interactions are to be addressed.

Although a clear causal link between psychological factors and cancer development and progression is not empirically supported, this is not to say that emotional distress does not affect quality of life and psychological health. Emotional distress has been titled the sixth vital sign in cancer care due to the consistent finding of increased emotional distress in cancer patients, and the benefits of psychosocial care, ranging from quality of life to improved treatment adherence (Carlson, Angen, Cullum, Goodey, Koopmans, Lamont, et. al., 2004; Carlson and Bultz, 2004; Ashbury, Findlay, Reynold, & McKerracher, 1998).

### 1.5 Treating Distress

Despite the clear need to monitor emotional distress, helping young adults with cancer deal with the psychosocial aspects of the disease has proven challenging for a number of reasons. Perhaps of central difficulty is the lack of a tailored approach. Paediatric programs offer specific support to children and their families. Specific centres are designed to offer the highest quality specialized medical and psychological support to these young patients in centralized locations. Tailored and expert care continues for years, in many instances from the time of diagnosis when

the patient might be only a few years old, right through adolescence and until age 16 or 18. Although this may imply that paediatric patients and their families are displaced to receive services, this also entails an improved quality of service. Similarly, geriatric programs and hospital cancer centres typically provide services geared towards older adulthood largely due to the cancer prevalence rates in older adulthood. Younger adult cancer patients have, to some extent, been lost in the gap, lacking the specialized resources granted to paediatric or geriatric patients.

This lack of specialized resources for young adults arguably extends to the psychosocial arena. For the young adult coping with a diagnosis and trying to maintain a life schedule of commitments including school courses, work requirements, or family commitments, attending counselling provided by the hospital during regular office hours or participating in a pre-scheduled support group may not be a viable option. In smaller hospital centres where relatively few individuals are diagnosed annually, young adults with cancer may feel isolated by the unique difficulties and challenges they are facing. In addition, for the generation that has learned to communicate by telephone, e-mail, and online conferencing, a face to face encounter with a counsellor or a group may be a daunting endeavour. It is clear that in order for the psychosocial needs of young adults cancer patients to be met, unique methods of reaching out are required.

#### 1.6 Treatment Viability

In contemplating psychosocial treatments for young adults with cancer, it is imperative that options be viable for implementation within today's health care system, a system in which budget constraints are a reality. Carlson and Bultz (2004) addressed the concept of psychosocial care for cancer patients as a key measure in providing cost-effective cancer treatment. In drawing conclusions from their literature review, the authors state that not only is psychological and emotional distress a significant problem for between one half and one third of cancer patients, but

that distress can be effectively tempered and addressed through treatment (Carlson & Bultz, 2004). Although limited research has examined the monetary benefits of treatment for distress within oncology patients, the existing research does suggest that fewer health care visits occur when distress is treated by a psychosocial clinician. It is also important to consider the potential cost offset that occurs when individuals effectively manage their emotional and psychological distress before it potentially becomes an overt diagnosable and impairing clinical disorder such as major depression or an anxiety disorder.

An additional consideration when examining viable treatment interventions for young adults with cancer is the local environment. At the TBRHSC this is of particular concern given the unique geographic area served. The area covered by Northwestern Ontario includes 58% percent of the total provincial landmass, but under 2% of the province's population ( $N=235,000$ ). With a ratio of 0.38 people per square kilometre, it is challenging to ensure that services are accessible. Given the number of cancer patients and their respective cancer types, it is often not viable to offer age or disease targeted supportive care treatments. Furthermore, the distance may cause difficulties for patients (Sellick, Desa, & MacDonald, 1996), with travel burdens including the time required to make the trip, added expenses, and seasonal weather conditions. Patients travelling from distant regions may be forced to schedule supportive care appointments to coincide with medical appointments, rather than having continuous services at their disposal or available at peak times of distress. Lack of personal transportation may present additional challenges. Even for those who are relatively mobile, the cancer treatments offered often cause significant side-effects, hindering independence. For patients who do travel significant distances, being displaced from familiar landmarks and people may provide an additional stressor.

The distance between the diagnosing provider or treatment centre and patient home also has clear treatment implications. Research has generally found that increased travel distance is an

obstacle for timely screening, impacting early diagnosis and subsequent treatment (Girgis, Bonevski, Perkins, & Sanson-Fisher, 1999; Kreher, Hickner, Ruffin, & Lin, 1995; Lightfoot et al., 2005). In a sample of women with stage I or II breast cancer, patients living a further distance from the hospital were less likely to undergo breast-conserving surgery and more likely to undergo a mastectomy (Meden, St. John-Larkin, Hermes, & Sommerschild, 2002; Nattinger, Kneusel, Hoffmann, & Gilligan, 2001). Although both of these surgeries are considered effective, breast-conserving surgery is the less invasive of the two and as effective as a mastectomy only when combined with radiation therapy. Along similar lines, women with stage I or II breast cancer living 40 or more miles from their treatment centre were less likely to receive radiation following breast-conserving surgery, despite the 35% risk of a re-occurring tumour in 5 years (Nattinger et al., 2001). These results were again reflected in a sample of melanoma patients, as increased Breslow thickness at time of diagnosis was associated with a further distance to travel (Stitzenberg, et al., 2007). These findings did not, however, apply at the extreme, since patients who travel exceedingly long distances for particular treatments are typically those who are empowered and highly engaged in their treatment (Lamont, et al., 2003; Kreher, Hickner, Ruffin, & Lin, 1995; Stitzenberg, et al., 2007). Although further research is necessary to understand any causal links and to elucidate underlying relationships, a clear and documented relationship between distance to treatment or provider and cancer treatment is emerging. As the TBRHSC serves a large and sparsely populated area of Northwestern Ontario, these findings have direct implications for patient and family centred care.

A supplementary issue for consideration is social support. Defined as the function and quality of social relationships, social support is an interactive process and may refer to perceived support, received support, need for support, and so forth (Schwarzer, Krall, & Rieckmann, 2003). Relationships between social support and health variables have been clearly documented (Knoll

& Schwarzer, 2002; Schwarzer et al., 2003). The need to examine relationships among demographic factors (age, gender), social support, and health, has also been expounded (Schwarzer et al., 2003). An understanding of how social support and distress relate to cancer in young adulthood in particular is therefore warranted.

To summarize, it was concluded that viable psychosocial treatments for young adult cancer patients in Northwestern Ontario should cover geographical distance, be time flexible, cost-effective, attempt to reduce distress, and to account for social support.

### 1.7 Internet Use and Online Support

In considering the unique psychosocial needs of young adults with cancer and the distinctive characteristics of the geographic area and population served by the TBRHSC, it is evident that an innovative approach to supportive care is necessary. In an effort to assess the need for specialized care for young adults with cancer, Corsini and Ammerman (2008) surveyed 60 cancer patients aged 18-35 years, 70.7% of whom who were unaware of resources in their area devoted to young adults with cancer. A third of respondents also indicated that adequate support was not received. Of the 60 respondents, 55% indicated an interest in receiving services over the internet. This last point speaks to an ease with online communication that has become central in how many individuals in this age frame communicate. Email has largely replaced the traditional post, google the dictionary and encyclopaedia, and facebook has altered traditional networking. Although an online support group is a resource-efficient manner of reaching out to many, it is not a format suited to all individuals. As noted, 55% of those surveyed by Corsini and Ammerman (2008) were interested in online support, which denotes that the remaining 45% were not interested. This implies that online support, although a viable method should not be the sole option.



Interest in online support appears to be related to demographic characteristics. Research has consistently found that internet users who are cancer patients are more likely to have a higher education and income level (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Satterlund, McCaul, & Sandgren, 2003; Peterson & Fretz, 2003). New literature is also emerging on the characteristics that render individuals more or less likely to engage in online support groups. Shaw and colleagues (2006) looked at predictors of participation in a computer support group among female breast cancer patients. The researchers provided computer training and access to all study participants to ensure equal access and a base skill set, and set out to examine any pre-existing differences in demographics variables, clinical factors, physical and mental health factors, healthcare-related variables, and social support factors that were associated with volume of participation in the computer based support group. The only significant difference that emerged between active and inactive participants was that women who self-identified themselves prior to the study as active participants in their healthcare were more likely to be more active online. Further analyses on active participants employed a linear regression to control for demographic variables. Of the demographic variables of active participants, race was significant indicating that Caucasian women wrote more. Having a higher energy level, a positive relationship with their doctor, fewer concerns about the cancer, and higher perceived health competence were all significantly related to a greater volume of words written. The authors conclude optimistically, noting that providing computers, training, and access to participants served as an equalizer, reducing the differences that might have been expected on age, race, education, or income. These findings lend credence to the viability of computer based support groups for individuals of various demographic groups.

In an attempt to understand the psychological characteristics that relate to premature drop out, Lieberman (2007) examined attrition rates in a professionally led Internet support group for

individuals with Parkinson's. Results indicated that individuals with higher death shame and anxiety were more likely to drop out. Liberman et al., (2003) note that demographic variables have been consistently linked to attrition rates, with lower socio-economic status associated with higher drop out. However, attempts to isolate personality factors that relate to attrition have been less successful.

Attrition rates in traditional psychotherapy remain high. A meta-analysis of attrition rates in studies where psychotherapy was administered indicated a dropout rate of 47 percent (mean) (Wierzbicki & Pekarik, 1993). However this varies by disorder severity as well as treatment type. The literature on attrition in professionally led online interventions indicates dropout rates of approximately 20 to 22 percent are being commonly reported (Lieberman et al., 2003; Winzelberg et al., 2003).

With regards to group composition and format, several factors have been identified in the literature as conducive to decreasing attrition and reducing the anxiety and fear often associated with joining new groups. Among the most common are structure, homogeneity, information, and demographic variables. Structure has been extensively researched as a positive mechanism in support groups. In a review of 51 studies, Dies (1994) found that 78 percent of groups with greater structure experienced lower attrition rates. Group homogeneity also serves an important purpose, bringing together individuals with clear and salient commonalities. Group homogeneity in the cancer field is typically characterized by age, gender, or disease site, with empirical evidence supporting these divisions.

In regards to homogeneity, Liberman (2007) found that homogeneously composed groups showed significantly greater improvements as compared to heterogeneously composed. The positive effects of group homogeneity are thought to emerge from the sharing of common characteristics, concerns, barriers, and problems. This in turn is thought to impact the

cohesiveness of the group, facilitating communication and helping to assuage initial fears and anxiety (Lieberman, 2007).

A full understanding of the expectations of the intervention has also been cited as a useful manner of decreasing fear and anxiety (Lieberman, 2007). This training may be provided through an interview session, through written materials such as a brochure, or with a training session. Theoretically, this is based on the Bandura's concept of expectation setting as a way of decreasing uncertainty and setting expectations for behaviour (Bandura, 1997). Providing potential participants with the necessary information to format their role within the group and in relation to others may provide a sense of purpose and alleviate the distress of participating in a new group.

Demographic variables have been extensively examined for their influence on recruitment of group members and attrition. No relationship between level of online participation and age or educational level has been reported (Gustafson, et al., 1994; McTavish, Gustafson, Owens, et al., 1995). However, there has been consistent empirical support for demographic variables affecting reactions to a cancer diagnosis and use of coping strategies (Epping-Jordan, et al., 1999; Gourash, 1978). Demographic variables have also been found to be among the most robust predictors of attrition in health interventions (Lieberman, 2007). This suggests that further examination of the influence of demographic variables on participation in online support groups may be warranted.

To date, research on the effectiveness of online support groups or interventions has been sparse. Individuals have cited several benefits to online groups, including the anonymity that helps to increase honesty and self-disclosure, especially for sensitive or embarrassing concerns (Eysenbach, 2003). That said, the past decade has seen an upsurge in research on computer support groups, and the role of computers and the internet in the provision of health information to patients (Eysenbach, 2003). It is now estimated that millions of individuals are seeking health

information and participating in health based support groups online (Fox & Fallows, 2003). More specifically, 39% of the developed world is estimated to have internet access, including approximately 2.3 million individuals with cancer who are online (Eysenbach, 2003).

Professionals in the health field are following the same trend, shifting towards the circulation of health information in an online or computer based manner. One of the more recent examples is Cancer Control P.L.A.N.E.T. Canada, an information distribution site that launched in January 2009. Developed by the Surveillance Action Group of the Canadian Partnership Against Cancer (CPAC), and in conjunction with the National Cancer Institute (NCI) in the United States, the goal of this site is to provide professionals with comprehensive and up to date information on cancer control, and to provide the tools for informed decision making and comprehensive cancer control plans. The Cancer Control P.L.A.N.E.T. Canada website highlights the current trend towards online information sharing and dissemination of research. At a provincial level, the modernization of hospital chart keeping now entails electronic records in many Ontario hospitals, a definite shift in the manner that health information is circulated. Given the speed and efficiency with which information can be accessed and shared online, this shift is not surprising.

### 1.8 Supports in Survivorship

With the medical advantages and technology of today, survival rates for many types of cancer are on the rise. However, this increased survivorship implies that a larger number of individuals are being exposed to cancer treatments and procedures for prolonged periods of time, and are attempting to come to terms with the medical, physical, psychological, social, and emotional by-products of cancer care. In many cases cancer has shifted from being an acute life threatening illness to a chronic illness. Survivorship has therefore become a key issue. Emerging research has identified the long term effects of distress into survivorship (Hoffman, McCarthy,

Recklitis, & Ng, 2009). More specifically, Hoffman and colleagues (2009) found that, compared to a non-cancer patient sample, cancer patients were more likely to report increased distress in the long term (minimum five years from diagnosis, median 12 years). In addition, adults diagnosed in young adulthood (less than 45 years) were also more likely to report distress. This research was consistent with findings from the breast cancer literature; women diagnosed with breast cancer in young adulthood were more likely to experience significant distress in the long term (Cimprich, Ronis, & Martinez-Ramos, 2002; Ganz, Greendale, Petersen, Kahn, & Bower, 2003). The need for appropriate psychosocial interventions to address the lifelong challenge of living with cancer, and dealing with the side-effects of treatment, is therefore clearly warranted.

Research evidence supports the need for psychosocial support for those in survivorship. However, the manner in which to alleviate emotional distress is not so clear. Spiegel and Diamond (2001) found preliminary evidence linking inappropriate or poor emotional expression in the aftermath of a cancer diagnosis with deleterious effects. Classen, Koopman, Angell, & Spiegel (1996) found evidence of an inverse relationship between distress and expression of emotions, such that trying to repress emotions appears to lead to increased distress. As emotional distress is a pervasive issue for cancer patients, psychosocial interventions targeted at facilitating emotional expression may provide relief.

Spiegel & Diamond (2001) found that expression of emotions in group or individual therapy decreases the use of repressive coping strategies, resulting in both positive and negative emotion expression. The authors elaborate on why group therapy in particular has been found to be advantageous for cancer patients, focusing on the umbrella concepts of social support, helper-therapy principle, and cost effectiveness. In terms of social support, the common experience of a cancer diagnosis is a highly influential factor, creating bonds among strangers when an individual's existing support system has become isolated. The helper-therapy principle refers to

the dyadic relationship of giving and receiving support, and was originally coined by Riessman (1965, page 27). Patients at different stages of cancer, and different treatment levels, can serve as a source of information, support, and motivation to others. This can also help to increase self-esteem, encouraging individuals to feel like valuable and contributing group members. Finally, group therapy as opposed to individual counselling is clearly a cost-efficient method of resource allocation, enabling a greater number of clients to be reached with comparable resources.

### 1.9 Conclusions

Evidence of clear biological, epidemiological, and etiological differences have emerged in cancer development and prognosis in younger as opposed to older adults (Bleyer, 2002; Canadian Cancer Statistics, 2007; Cancer in Young Adults in Canada). The psychosocial challenges faced by younger adults are also unique to this demographic group, and the need for specialized psychosocial care has been clearly advocated (Bleyer, 2002; Corsini & Ammerman, 2008; Pentheroudakis & Pavlidis, 2005; Thomas et al., 2006; Zebrack et al., 2005). Although research does not support psychological factors as contributing to the development of cancer, (Garssen, 2004) psychological factors such as emotional distress have been consistently linked to quality of life and psychological health (Carlson et al., 2004; Carlson & Bultz, 2004; Ashbury et al, 1998). To this end, emotional distress has been recognized as the sixth vital sign (National Pharmaceutical Council, 2001) and is estimated to affect 35 to 45 percent of cancer patients (Carlson & Bultz, 2004; Zabora et al., 2001).

At the TBRHSC, all incoming patients are given the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), an emotional distress screening tool, to complete on the occasion of their first visit to the Regional Cancer Centre as part of their intake process. Patients scoring above threshold are invited to meet with a Supportive Care counsellor, whereas patients scoring below threshold are informed of the services offered by Supportive Care but not directly

contacted. Although this is an effective way of screening for emotional distress and meeting the psychosocial needs of local cancer patients, it poses difficulties for others. Accessing supportive care services in person may not be feasible for those living in other areas of Northwestern Ontario. For other patients, the effects of cancer treatments may impede mobility, or facing a counsellor one-on-one or in a group may be daunting. Due to its expansive geographical distribution, the TBRHSC has been pushed to adopt innovative approaches to health care management in an attempt to meet patient needs. Recent progress includes the use of Telehealth systems for patient consultation as well as employee training. Although Telehealth and the provision of follow-up cancer care in the regions has decreased the need to travel great distances for medical or psychosocial treatment, patients continue to report unmet psychosocial needs (NRC-Picker, 2009). Specifically, NRC-Picker data collected at the TBRHSC indicates that patients wanted, but did not receive, services in the areas of counselling, spiritual care, support groups, dietary issues, and more (see Figure 3). Patient needs are clearly unmet, despite efforts to disseminate information on the Supportive Care services available at the TBRHSC. This may suggest that the current information delivery source is not effective for all patients.

An online approach to supportive care was proposed. An online support group for cancer patients was hypothesized to be a cost-effective manner of reaching out to cancer patients and survivors in Northwestern Ontario, and helping to decrease cancer related emotional distress by connecting patients. Based on the literature available, online support is likely to appeal to a young adult demographic, and emerging evidence suggests that online interventions can be effective. In addition, the Supportive Care Framework (Fitch, 1994) provided clear guidelines by which to organize the online group. In addition to online support, relationships among distress measures were considered to be of central importance. There is a clear and documented need to screen and treat distress in cancer patients, and in particular in young adults (Bultz & Carlson,

2006; Carlson & Bultz, 2004; Hoffman et al., 2009). However, with the vast number of distress screening tools available, the lack of information focusing on distress screening in young adulthood, and the poor understanding of relationships between measures, evaluating different distress measures is clearly important.

A two part research study to address the interest in, and efficacy of, an online support tool and resource site was therefore conducted. Part one consisted of a questionnaire mailing to assess patient demographics, interest in participating in an online group, patient distress on a variety of distress measures, and social support. Part two consisted of the administration of an online group for young adult cancer patients and recent survivors known as project care2talk ([www.care2talk.ca](http://www.care2talk.ca)). Although the online group yielded large amounts of additional data, the goal was to focus on specific hypotheses as detailed below. The additional data will therefore be analysed as part of a separate project.

### 1.10 Hypotheses

The exploratory goal of the care2talk project was to assess the interest of young adult cancer patients in utilizing a web-based support group as compared to traditional in-person support. Specific hypotheses put forth were as follows: (1) that significant differences would emerge between individuals who choose to participate in the online group, as compared to those who declined; (2) that demographic differences between groups, computer familiarity, and social support would emerge as significant predictors of online interest, and online use; (3) that distress measures would be strongly correlated with one another, and show significant relationships with social support; and (4) that increased levels of participation online would predict increased self-reported satisfaction with the online support group.



## Methods

### 2.1 Participants

Since October 10, 2000, the Oncology Supportive Care Program at the Thunder Bay Regional Health Sciences Centre (TBRHSC) has been collecting psychosocial, demographic, and medical data on all cancer patients. At time of admission, patients completed a “Consent for Release of Information Form” (appendix A). This form explains that information from patient interviews and records may be used for research purposes, and provides an invaluable resource for patient monitoring and program evaluation.

Based on this information, it was possible to isolate specific demographic groups. Cancer patients aged 18 to 44 years were invited to participate in the questionnaire mailing and online group, provided their initial appointment with the Cancer Centre occurred between September 2004 and November 2009. Although the 18 to 44 year old age range is arguably a broad one, it was selected for both theoretical and practical reasons. Practically, the 18 to 44 year old age frame is consistent with that put forth by Canadian Cancer Statistics, 2007. In addition, given the low number of young adults diagnosed across Canada, and in Northwestern Ontario in particular, it was necessary to target a relatively wide age frame in order to render the provision of services viable. Theoretically, the challenges faced by young adults 18 to 44 years old are similar across this age frame, yet different from the older adult age group. Young adults may experience concerns with fertility and conception or childcare, whereas it is more likely than any children of older adults are adults themselves. Finishing education, gaining employment, or maintaining employment are the life challenges associated with young adulthood, whereas older adult are more likely to be in the process of contemplating retirement or retired. These differences are echoed across the major life areas, clearly supporting this age division between younger and older adulthood.

## 2.2 Part One: Questionnaire Mailing

Phase one of the questionnaire mailing took place on January 4<sup>th</sup>, 2010. Questionnaire packages were mailed to the 237 patients (153 women) who met the inclusion criteria. A letter from Supportive Care was attached to each questionnaire package, detailing the rights of the participant and the contents of the questionnaire package (appendix B), providing the individual the opportunity to decide whether they would like to proceed with the research. Inside the questionnaire package, an information letter served as an introduction and invitation to participate in the questionnaire and the online group portion of the research (appendix C). The letter highlighted the right of the individual to refuse to participate without impacting their medical treatment or access to traditional supportive care services. The paper and pencil questionnaires accompanying the invitation letter consisted of the following: demographic questionnaire (appendix D) developed by the investigator, to obtain demographic and background information, as well as information pertaining to computer use and ability, involvement in health care, and use of online support; Berlin Social Support Scale (BSSS; Schulz & Schwarzer, 2003) (appendix E); the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) (appendix F); the Personal Well-being Checklist (PWC; Canada Journey Action Group, 2009) (appendix G); the Edmonton Symptom Assessment System (ESAS; Canada Journey Action Group, 2009) (appendix H); the Canadian Problem Checklist (Canada Journey Action Group, 2009) (appendix I); a letter pertaining to the online portion of the study (appendix J); and a consent form for the online study (appendix K).

The Hospital Anxiety and Depression Scale, the Personal Well-Being Checklist, the Edmonton Symptom Assessment System, and the Canadian Problem Checklist all address aspects of distress, but none have been identified as comprehensive tools to screen for psychosocial, physical, and practical concerns (Canada Journey Action Group, 2009). In view of the relative

brevity of the measures, all were given to participants in an attempt to obtain a clear representation of distress and to understand the relationships among measures. This is of particular importance in light of the risk of long term distress in cancer patients diagnosed in young adulthood (Hoffman et al., 2009), and the lack of research examining distress measures in young adulthood.

The HADS is a 14 item emotional distress screening tool widely used with cancer patients. The measure is composed of the subscales of anxiety and depressive symptoms, with 7 items loading on each subscale. Each item is scored on a 4 point scale ranging from 0 to 3, allowing for a maximum score of 21 on each subscale, and a maximum total score of 42. A score above 11 on either scale is thought to be indicative of probable emotional distress. Similarly, scores of 8 or above on both scales are also considered to be within probable risk range. The HADS takes approximately three to five minutes to complete. Though objections regarding the sensitivity and specificity of the HADS have been expressed (Lloyd-Williams, Friedman, & Rudd, 2001), it is widely used and considered to be a reliable screening tool (Carroll, Kathol, Noyes, Wald, & Clamon, 1993; Razavi, Delvaux, Farvacques, & Robaye, 1990; Sellick & Edwardson, 2007). Large scale sample data support the strong psychometric properties of the HADS, based on factor structure, internal consistency, and intercorrelations (homogeneity) of subscales (Mykletun, Stordal, & Dahl, 2001).

The Personal Well-being Checklist (PWC) screens for psychosocial and practical concerns in cancer patients, however it lacks comprehensive screening of physical concerns. This measure was developed by the Tom Baker Cancer Centre in Calgary, Alberta. Research attesting to the validity of the instrument is in progress but has yet to be published. The PWC is composed of thermometer assessments, a problem checklist, 10 statements relating to anxiety and

depressive symptoms listed on a 5-point scale, and questions relating to demographics, nutrition, and cancer history. Estimated completion time was 5 to 10 minutes.

The Edmonton Symptom Assessment System (ESAS) is empirically supported as a valid and reliable tool, as well as being the most commonly used screening tool in Canada (Chang, Hwang, & Feuerman, 2000; Kirkova, et al., 2006; Linden, Yi, Barroetavena, MacKenzie, & Doll, 2005; Nekolaichuk, Watanabe, & Beaumont, 2008). The ESAS adequately screens for physical and psychosocial, but not practical concerns. Described as a 9 item screening measure that assesses symptom severity on a scale ranging from 0 to 10, with 0 indicating the absence of the symptom and 10 the most severe presence of the symptom, the ESAS can be completed in approximately 2 to 5 minutes.

To complement the ESAS, a Canadian Problem Checklist was included to assess psychosocial, practical, and physical concerns not addressed by the ESAS scales (Canada Journey Action Group, 2009). Consisting of 21 items falling under the 6 categories of emotional, spiritual, practical, social/family, informational, and physical concerns, the Canadian Problem Checklist requires an estimated 1 to 3 minutes to complete.

The Berlin Social Support Scale (BSSS) is a 52 item measure specifically designed to measure social support in adult cancer patients and their partners (Schulz & Schwarzer, 2003). Items are rated on a 4 point scale, with possible selections consisting of (1) strongly disagree, (2) somewhat disagree, (3) somewhat agree, and (4) strongly agree. The measure contains 5 subscales: perceived social support, received social support, need for support, support seeking, and protective buffering. The scales tap into both cognitive and behavioural facets of social support. The reliability and the validity of the measure have been evaluated and meet acceptable standards (Schulz & Schwarzer, 2003; Schulz & Schwarzer, 2004).

The letter to participants detailed what participation in the online group would entail, and highlighted the topics and issues to be addressed during the group sessions (appendix H). The goal of the letter was to clarify the details of the online group, as a full understanding of the intervention has been cited as a useful manner of decreasing fear and anxiety on the part of the participant (Lieberman, 2007). This is theoretically based on Bandura's concept of expectation setting. The goal was to allay distress by decreasing the uncertainty surrounding the group and by allowing the individual to create expectations regarding their role within the group.

One week after the questionnaires were presumed to have been delivered, Supportive Care staff members (psychologist, receptionist, undergraduate student) attempted to follow up with participants by telephone. Participants were asked to confirm receipt of the questionnaire package, and encouraged to voice any comments or questions. Patients were also clearly notified that their choice to participate or refuse would in no way impact their medical care or access to psychosocial services at the TBRHSC. Phone calls were repeated at various times of the day, however for confidentiality reasons messages were not left for those who could not be reached. If we were unable to reach an individual after two weeks, and the package was not "returned to sender" by Canada Post, then it was assumed to have been received. An addressed and stamped envelope was included in each package to facilitate questionnaire return. Potential participants were advised that those returning the questionnaires would be entered into a prize draw for one of four 25 dollar gift certificates for Chapters/Indigo. This random prize draw was completed in February 2010.

### 2.3 Part Two: Online Group

Patients who consented to participating in the online study by returning the completed consent form were contacted and provided additional documentation by email. This documentation included the necessary information to access the website and contact information

to reach the researchers. Guided technical help was available from the researcher throughout the study for those requiring further assistance.

It is understood that discussing the cancer experience may cause distress to the individual. As such, the researcher was responsible for reviewing all posted messages and chat content once during every 48 hour period. All content was then reviewed on a weekly basis with the researcher's supervisor. In the event that website content posted by an individual or questionnaire responses indicated significant distress, such content was immediately brought to the attention of the researcher's supervisor. The individual was then contacted and offered additional services through the TBRHSC Supportive Care Centre.

### 2.3.1 Website Structure

Access to the website was password protected to ensure the privacy of the individual. Participants had the opportunity to choose a personalized user name and password for site access. Technical help was automatically available through the website in the event that either was forgotten. Website access was granted within the 48 hours prior to the first scheduled chat session. All participants in the first chat session were advised of their right to withdraw from all or part of the research at any time. Participants were informed that revealing personal information was at their discretion, and briefed on the norms and expectation of confidentiality that accompany group therapy. For individuals who did not log onto the website for the first chat session, this information was summarized and forwarded as an internal mail message on care2talk. Website navigation options were explained to participants in the first group chat session as well, detailing the option of private live chat with other online members, access to a message posting board, access to posting board for questions, a resource page, and the incoming mail function. Website access was provided only in English.

In an effort to decrease attrition the group was professionally led and semi-structured (Dies, 1994; Lieberman, 2007). On a weekly basis, different topics for discussion were introduced to the group, as was outlined in the information for potential participants (appendix I). On the Monday prior to the online discussion, additional resources pertaining to the discussion topic were posted online. This enabled participants to familiarize themselves with the topic. Participants were able to pose questions live during the chat sessions, or to post questions on the message board. Participants were advised that questions relating to medical prognosis and medical advice would not be entertained as the focus was psychosocial support and resources.

### 2.3.2 Online Group Measures

The following measures were administered to participants over the course of the 10 week online group. Although there was the option of receiving the questionnaires via mail for those who preferred a hard copy, this option was not employed. Participants were therefore sent an internal mail message through the website with the link to the online questionnaires.

Questionnaires were created using Fluidsurveys, a Canadian based company, thereby insuring the data would be housed on a Canadian website. Measures administered consist of the HADS (Appendix F), Berlin Social Support Scale (appendix E), the Personal Well-being Checklist (PWC; Canada Journey Action Group, 2009) (appendix G), the Edmonton Symptom Assessment System (ESAS; Canada Journey Action Group, 2009) (appendix H), and the Canada Problem Checklist (Canada Journey Action Group, 2009) (appendix I). A schedule of questionnaire administration can be found in Appendix L.

As there remains a sizable gap pertaining to our knowledge of the psychosocial needs of young adults and cancer survivors with various types of cancer, a series of qualitative open ended questions were also be administered at the outset and conclusion of the study using the website's internal mail function. Questions pertaining to the participant's interest and reasons for

participating were administered at the beginning of the study (appendix M). Questions addressing likes and dislikes associated with the individual's online experience were administered at the conclusion (appendix N). Participants were advised that for each questionnaire returned, their name would be entered into a random prize draw for one of four 50 dollar gift certificates from Chapters / Indigo. This draw was completed in April 2010.

In addition to questionnaires administered, use of the website was monitored to create a measure of website involvement. The intention was to assess both passive and active website usage. Active use was defined as occasions where the participant contributed to the online environment through text, be it in the chat room, on a discussion board, or elsewhere. Passive participation referred to members who accessed the website's various pages, resource lists, and read user-generated online content, but did not actively contribute. It was planned to assess passive participation by tracking the time spent on the website by each participant, and the access statistics per page. Unfortunately, for technical reasons relating to the website platform this was not possible. Active participation was therefore the sole measure of online use. A summary of the website specifications can be found in appendix O. Ethical approval for the research project was granted by the research ethics boards at the TBRHSC (see Appendix P) and Lakehead University (see Appendix Q).

## 2.4 Data Sources and Screening

### 2.4.1 Data sources

Data from three separate sources were included in the following analyses. The first data source was the Supportive Care research database. All young adult cancer patients to whom questionnaire packages were mailed had previously signed a "Consent for Release of Information Form" at the TBRHSC. Information gathered from medical records relating to demographic, medical, and psychosocial distress was entered into the Supportive Care database. Information



from this database was merged with information from the questionnaire mailing, ensuring that basic medical information and distress at time of diagnosis were available for analysis. The second source of data was the information returned in the questionnaire mailing. Finally, the third source of data was the care2talk website itself. Based on the ten week pilot program, a composite variable of total words typed on the website was created as an index of active website use. This “total words” variable represents all written content posted to the website, be it during chat, in the discussion forum, or on the comment posting board.

#### 2.4.2 Data cleaning and screening

Reversed items on the BSSS and HADS were coded and appropriately entered into the dataset. Descriptive and frequency statistics were examined for abnormalities in the data indicative of data entry errors by screening minimum and maximum values in descriptive statistics and abnormal entries in frequency statistics.

Prior to statistical analysis, all data were screened for violations of normality and outliers. Log transformations were effectively applied to two variables, total number of contacts with Supportive Care and total number of CPC spiritual variables endorsed. The total words variable was treated differently due to a considerable difference in the mean (903.45) and 5% trimmed mean (481.37), and exceedingly high skewness (55.76) and kurtosis (273.56) that remained high despite transformations. This variable was therefore re-coded into an ordinal variable (see Table 1).

#### 2.5 Analyses

Data were analyzed using SPSS 18.0. To test the first hypothesis, that significant differences would emerge between individuals who choose to participate in the online group as compared to those who declined, the descriptive statistics for all variables (demographic,

medical, psychosocial) were computed, and tested using independent samples t-test and Chi square analyses, as appropriate. The second hypothesis stated that demographic differences between groups, computer familiarity, and social support (independent variables) would emerge as significant predictors of online interest, and online use (dependent variables). To examine predictors of interest in participating in an online group, a sequential logistic regression analysis was computed. Gender was entered at the first step, computer comfort at the second, followed by distress variables and prior Supportive Care use at the third and fourth steps, respectively. The sequence in which variables were entered into the model was theoretically based, as previous research indicates that gender effects (Grande, Myers, & Sutton, 2006), and computer familiarity (Shaw et al., 2006) affect interest in online support. Distress related variables and previous use of Supportive Care services were then entered as individuals with greater distress and positive attitude towards Supportive Care have been found to be more likely to participate in cancer support groups (Grande et al., 2006). To assess actual online use, as opposed to interest in online support, the total words entered variable was analyzed. Relationships between the total words entered variable and psychosocial distress variables were examined using Pearson Product Moment correlations to assess whether participants with greater distress were more likely to be active online.

The third hypothesis, that distress measures (HADS, ESAS, CPC, PWC) would be strongly correlated with one another and show significant relationships with the social support measure (BSSS), was analyzed using Pearson Product Moment correlations. A paired samples t-test was also analysed to assess significant differences in the HADS scores from time at admission to time of questionnaire mailing. The fourth hypothesis stated that increased levels of participation online would predict increased self-reported satisfaction with the online support group. Due to poor response rate on the self-report satisfaction questionnaire ( $n=4$ ), this

hypothesis was not tested.

## Results

### 3.1 Assessing interest in online support

Of the complete sample to which questionnaires were mailed ( $n=237$ ), 49 participants were confirmed to have changed address with no forwarding coordinates. The remaining 188 (129 women) were therefore assumed to have received the questionnaire package. Seventy-one individuals (54 women) returned the completed questionnaire packages, representing a 36% response rate. Of these individuals, 42 (36 women) agreed to participate in the online group beginning February 15, 2010, as opposed to 29 (18 women) who declined to participate, but nonetheless completed and returned the questionnaire package. Therefore, 22.3% of individuals (42 of 188) demonstrated interest in participating in the online group.

### 3.2 Hypothesis 1

*Differences between patients who agreed ( $n=42$ ) and declined to participate ( $n=29$ ) in the online support program*

The questionnaire responses of those who agreed and declined to participate in the online support program were compared. Medical, psychosocial, demographic, and computer-related disparities were tested for significance using independent samples t-tests and Chi square analyses.

The demographic variables of gender, age, education, family income, and spiritual beliefs were compared using independent samples t-tests (see Table 2). Dichotomous variables, mainly living arrangements, English as a first language, and whether the individual was a previous client of Supportive Care at the TBRHSC, were compared using Chi square analyses (see Table 3). Of these variables, gender and Supportive Care client status were significant, with females and individuals who were previous clients of Supportive Care being more likely to agree to participate in the online group. No analyses were completed for the demographic variables

relating to primary source of income, marital status, and ethnicity due to low frequencies in the categories (see Table 4).

Medical information for individuals interested and not interested in participating in the online group was compared. Independent samples t-tests were used to analyze stage at diagnosis, changes in weight, changes in food intake, satisfaction with medical treatment, and satisfaction with the ability to have questions answered by the doctor (see Table 5). Chi square analyses were used to compare dichotomous variables, mainly the presence of metastatic disease at diagnosis, active treatment status, and smoking status (see Table 6). Only active treatment status was significant, as individuals who agreed to participate in the online group were more likely to be in active treatment. Cancer prevalence was also examined (see Table 7, Figure 4). Due to low frequencies in the categories, the highest prevalence category (breast cancer) was compared to all other cancer types. Individuals who agreed to participate in the online group had a higher incidence of breast cancer, whereas individuals who declined to participate online had higher incidence rates in the majority of the remaining cancer types, Chi square (1,  $n=65$ )=6.703,  $p=0.010$ .

Significant differences in psychosocial distress, as measured by the HADS, PWC, CPC, and ESAS emerged between the two groups when compared using independent samples t-tests. Patients who agreed to participate in the online support group indicated significantly higher anxiety on the HADS anxiety subscale (see Table 8). These patients also checked significantly more items on the CPC emotional, practical, family and social, and physical health subscales, indicating problems in these areas. Total items checked on the CPC overall was also significantly higher for those who agreed to participate in the online group (see Table 9). No significant differences on the ESAS emerged (see Table 10). The PWC consists of three thermometer measures (distress, pain, fatigue) and a composite psychosocial distress measure. Of these PWC

measures, only the distress thermometer scores were significantly higher for those interested in the online group (see Table 11). The PWC also includes a checklist of problems present or expected. The PWC checklist problems of family conflict, changes in appearance, making treatment decisions, and sleep, as well as the total number of problems present or expected across groups, were significantly more often endorsed by those interested in online support (see Table 12).

The BSSS subscales of perceived support available, support seeking, actually received support, and protective buffering were compared between groups, with only the latter emerging as significant. Individuals interested in online support scored significantly higher on protective buffering, indicating they were more likely to attempt to shield others from their distress (see Table 13).

With reference to computer use and access, patients who were interested in participating in the online support group were more likely to endorse seeking information online as well as from other patients (see Table 14). In addition, these patients were more likely to have computer and internet access at home, to spend more time on the computer at home, and to be more comfortable with computer use overall (see Tables 15, 16, and 17).

### 3.3 Hypothesis 2

#### *Predicting interest in using online support based on questionnaire mailing data (n=71)*

A sequential logistic regression was conducted to assess interest in participating in the online support group. Gender entered at the first step. Comfort with computer use was entered at the second step. Distress related variables (PWC distress, HADS anxiety subscale, and BSSS protective buffering scale) were entered at the third step. Previous use of Supportive Care services was entered at the final step. All steps were significant (see Table 18) and the total model explained 63.1% of the variance in interest in online support (Nagelkerke R squared).

Odds ratios indicated that women were over 5.5 times more likely to say yes to the online group, and that individuals with a history of Supportive Care use were 7.7 times more likely to agree to participate. Although 90.3% of the cases were correctly classified, this decreased to 79.3% after correcting for chance using kappa (see Table 19).

*Use of online support, as measured by total words entered online*

In addition to predicting interest in participating in the online support group, a secondary interest was to assess frequency of online use, as indicated by the total words entered online. Pearson Product moment correlations were used to analyze relationships between psychosocial variables and the total words variable (see Table 20). Only two measures were significant. Individuals who were more active online were likely to have a history of more Supportive Care visits, and indicated more current and expected problems on the PWC.

### 3.4 Hypothesis 3

*Examining the HADS measure over time (n=66) and correlations among the distress measures (HADS, PWC, ESAS, CPA)*

The HADS was originally administered at first admission to the TBRHSC Cancer Centre. This measure was compared with the HADS completed during the questionnaire mailing, with the time interval between administrations being a mean of 2.17 years (SD=1.664). HADS scores were highly positively correlated; paired sample t-tests did not indicate any significant difference in mean scores over time, however mean scores were slightly higher at the time two questionnaire mailing as compared to time of admission (see Table 21). All further correlational analyses including the HADS refer to the HADS completed during the questionnaire mailing.

The HADS anxiety scale positively correlated with all CPC scales, indicating that individuals with more self-reported problems scored higher on the anxiety screening scale. Individuals who scored higher on the depression screening scale of the HADS were more likely

to indicate problems in the areas of emotional, spiritual, family and social, or physical health concerns, and were likely to list more problems overall. Similarly, higher total distress scores on the HADS were associated with more self-reported problems in all areas except practical concerns. Correlations ranged from  $r=.295$  to  $.696$  (see Table 22).

The HADS scales (anxiety, depression, total distress) positively correlated with all ESAS scales, with correlations ranging from  $.480$  to  $.867$  (see Table 23). Individuals with greater anxiety, depressive, or total distress symptoms were also more likely to indicate greater problem severity on the ESAS scales (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, feeling of wellbeing, shortness of breath, total ESAS score).

The HADS was positively correlated with the all PWC measures (psychosocial scale, distress thermometer, pain thermometer, fatigue thermometer, total thermometer score), indicating that individuals with high distress had elevated scores across both measures. Correlations ranging from  $.380$  to  $.849$  (see Table 24).

Scores on the CPC scales were then compared to the ESAS scales. Correlations between scales were generally significant, with the exception of the practical and informational scales of the CPC which were less likely to be correlated with the ESAS scales. Significant correlations ( $r=.242$  to  $.688$ ) were all positive, showing that individuals with greater self-reported problems on the CPC scales were more likely to report greater symptom severity on the ESAS (see Table 25).

In regards to the PWC and CPC measures, individuals with higher scores on the PWC distress thermometer and total thermometer were more likely to score higher on all CPC scales, whereas results were mixed for the pain and fatigue thermometers with over half of the CPC scales positively correlating. The PWC psychosocial distress measure was not correlated with informational or physical health problems, however higher scores on the PWC distress scale were



associated with more self-reported problems on the remaining CPC scales. Correlations ranged from  $r=.256$  to  $.632$  (see Table 26).

Finally, higher scores on all ESAS scales (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, feeling of wellbeing, shortness of breath, total ESAS score) were associated with higher scores on the all PWC measures (see Table 27). Correlations ranged from  $r=.250$  to  $.903$ .

*Relationships between the BSSS and distress measures (HADS, CPC, ESAS, PWC)*

The BSSS subscales of perceived support available, support seeking, actually received support, protective buffering, and the total BSSS score, were compared to the distress measures using Pearson Product moment correlations. The PWC psychosocial distress scale was negatively correlated with BSSS scales with the exception of protective buffering, indicating that individuals who reported higher levels of distress also reported less perceived support available, sought less support, scored lower on actually received support, as well as lower on the total BSSS scales. Correlations ranged from  $-.257$  to  $-.589$ . The remaining PWC scales were significantly correlated with only isolated BSSS scales (see Table 28).

The BSSS perceived support scale was significantly correlated with the majority of ESAS scales, indicating that individuals who scored lower on perceived support were more likely to have higher scores on the ESAS ( $r=-.290$  to  $-.516$ ). The BSSS scales of support seeking and actually received support were significantly negatively correlated with isolated ESAS scales, whereas no significant relationships among the BSSS protective buffering and ESAS scales emerged (see Table 29).

Scores on the protective buffering scale of the BSSS were significantly correlated with more self reported problems on the CPC emotional, practical, family and social, and physical health scales, as well as the total CPC score ( $r=.270$  to  $.332$ ). Individuals who endorsed problems

on the CPC family and social scale were more likely to also report less actual received support and total support as measured by the BSSS (see Table 30).

Finally, results from the HADS were compared to scores on the BSSS (see Table 31). Individuals with higher levels of HADS scores on all scales endorsed having less perceived support, less actual support, and less social support overall as measured by the BSSS. Similarly, the attempt to protectively buffer others was associated with significantly higher levels of anxiety and total distress as measured by the HADS. Support seeking was associated only with the HADS depression scale, such that those who sought more support from others also reported fewer depressive symptoms. Correlations ranged from  $-.251$  to  $-.610$  (see Table 29).

## Discussion

### 4.1 Interest in Online Support

A seminal goal of the research was to assess interest in online support among young adult cancer patients. One in five of the young adults surveyed demonstrated interest in the online group, as indicated by returning the completed consent form to participate in the online portion of the care2talk project. This compares to slightly fewer than three in five young adults who are patients of the Cancer Centre at the TBRHSC becoming clients of Supportive Care, as defined by at least one visit with a Supportive Care counsellor. When comparing only the results of the questionnaire mailing, 59% (42 of 71) individuals agreed to participate in the online group. This finding is consistent with the results reported by Corsini and Ammerman (2009) wherein 55% of the 60 young adult cancer patients surveyed indicated interest in online services (total number approached was not reported).

Although the majority of patients who agreed to participate in the online group were also Supportive Care clients, a subset of them (21.4%) were not. This suggests that there are individuals to whom online services appealed when traditional Supportive Care services did not. The implications of this are clear: if the psychosocial needs of young adults with cancer are to be effectively met, then a variety of Supportive Care resources, including online support, may be necessary.

### 4.2 Group Differences

It was hypothesized that significant differences would emerge between individuals who choose to participate in the online group, as compared to those who declined. This hypothesis was partially supported. The majority of the demographic and medical variables examined did not yield significant differences between groups. In terms of demographic differences, gender was significant with females more likely to participate. This is consistent with gender differences in

Supportive Care use overall, as 44% of women cancer patients, compared to 29% of men cancer patients, have used the Supportive Care services at the TBRHSC in the past nine years. This finding is also consistent with the literature in the field, with women emerging as more frequent participants in psychosocial care (Grande et al., 2006). Individuals who were previous clients of Supportive Care were more likely to agree to participate in the online group. This may indicate that openness to psychosocial care or a familiarity with the Supportive Care team serves as impetus for participation. Consistent with the previous research, (Gustafson et al., 1994; McTavish et al, 1995) other demographic variables, in particular age and education, were not related to interest in online use.

Individuals across groups did not differ in their stage of cancer, or the presence of metastatic disease at diagnosis. They were equally likely to be in active treatment, and similarly satisfied with their medical treatment and ability to have questions answered by their doctor. Of interest was the unique distribution of disease site across groups, with a higher incidence of breast cancer in those who agreed to participate in the online group. However, this is likely a result of the gender differences in the sample as breast cancer remains the most common cancer diagnosis in women accounting for 29% of all cancer cases (Canadian Cancer Statistics, 2007).

In regards to psychosocial differences among groups, individuals who agreed to participate in the online group indicated higher levels of psychosocial distress overall, and were more likely to endorse having current or expected problems in the areas of emotional, family and social, and physical health concerns as well as specific concerns with family conflict, changes in appearance, making treatment decisions, and sleep. Essentially, those who agreed to participate in the online group, effectively seeking psychosocial care, were individuals with a greater number of self reported problems, concerns, and distress. This is consistent with the previous literature indicating increased anxiety and depressive symptoms in individuals who participated in cancer

support groups (Grande et al., 2006). As cancer treatments become increasingly effective and more young adults are surviving, more adult-onset cancer patients are living as survivors. However, long-term survivors (minimum five years, median 12 years since diagnosis) have been found to be at elevated risk of severe psychological distress, in particular survivors who were young adults at the time of diagnosis (Hoffman et al., 2009). This further emphasizes the need to continue to screen for distress, and to continue offering Supportive Care services.

Finally, previous research has supported the impact of computer familiarity on interest in participating in online groups (Shaw et al., 2006). Providing a computer training course was beyond the scope of the present project, and given the younger demographic focus it was also decided that most individuals would have a certain exposure to computer use, be it through personal or professional means. No differences in computer access at work or school, or time per day on the computer while at work or school, were found. In regards to personal use, no differences were found in the use of social networking websites. However, individuals interested in the online group were more likely to seek information from the internet, and from other patients. These individuals were also more likely to have a computer at home, internet access in the home, and to spend a greater amount of time on the computer at home. Perhaps most importantly, this group also endorsed a greater level of comfort with computer use overall. This indicates a logical resource need in order for online support to be a viable option: computer access, internet service, and time to access both in the home environment, perhaps then leading to greater comfort with computer use overall.

To summarize, certain key differences between individuals who accepted and declined participation in the online group emerged. Females with greater distress, more life problems, a history of Supportive Care use, who are open to seeking information online or from friends, and who have computer access and are comfortable with computer use appear to be those most likely

to participate. Recognizing these differences can help to evaluate alternative means of reaching other demographic subsets, or the possibility of tailoring online care to other populations as well as the population to whom these services typically appeals.

#### 4.3 Predicting Interest in Online Support

The second hypothesis stated that demographic differences between groups, computer familiarity, and social support, would emerge as significant predictors of online interest, and online use. This hypothesis was supported. The logistic regression model was significant and explained over 60% of the variance in interest in online support, classifying nearly 80% of cases correctly when chance had been corrected for. This indicates that women who are more comfortable online, have higher distress (as per the PWC), higher anxiety (as per the HADS), have a history of supportive care use, and who have a tendency to protectively buffer those around them from their stress, are more likely to be interested in participating in an online group. The odds ratios show that women are over 5.6 times more likely than men to participate online, and individuals with a history of Supportive Care use are over 7.7 times more likely to be interested in participating online. These findings are generally consistent with the literature on participation in cancer support groups overall, wherein participants were more likely to be female and hold favourable views of support services (Grande et al., 2006). Although this type of online support appealed to a specific demographic, women with a history of Supportive Care use, this does not necessarily attest to interest in online specialized online support. Specialized groups might include prostate cancer support for older men, or breast cancer support for younger women. Although men were less likely to indicate interest in participating in this online support group, this does not necessarily reflect disinterest in online support overall. This distinction requires further evaluation.

#### 4.4 Relationships among Distress Measures

The third hypothesis was broad in nature, suggesting that significant relationships would exist among distress measures, as well as with the social support measure. Although previous research has assessed some of the relationships among measures (Vignaroli et al., 2006), these relationships have not been evaluated specifically within a young adult sample, in reference to social support, or among all measures. The hypothesis was supported, as all scales on the HADS, PWC, and ESAS significantly correlated with one another.

A unique pattern emerged from the CPC, arguably less of a distress measure and more of a checklist of present or expected problems. Across the HADS, ESAS, and the PWC, the CPC scales of practical concerns and informational concerns were those least likely to be significantly correlated. Essentially, for this sample, practical and informational concerns appear to relate less to distress symptoms overall. Although the reasons for this are not clear, research suggests that patients in general are more likely to passively seek cancer-related information by attending to the topic presented (newspaper, television), but younger cancer patients and in particular those with higher education were more likely to seek information from the internet and newspaper (Carlsson, 2000). This active information search may impart a sense of control. Similarly, practical concerns may be less of a distressing issue for young adults if they, consistent with information seeking, take an active as opposed to passive approach to any concerns.

The BSSS was predictably associated with particular scales among distress measures. Across the PWC and HADS scales, as individuals who reported greater support from those close to them were less likely to report distress. Individuals who felt as though they had support from those close to them were less likely to report problems on the family and social scale of the CPC. Individuals who tried to buffer family and friends from their cancer-related distress reported increased problems on the family and social scale.

#### 4.5 Potential Benefits of Online Support

Although there are many potential benefits of online support, there are arguably two main reasons why this delivery method should be pursued. The first relates to cost. In a health-care environment where programs are required to justify their costs and benefits, experiences with the care2talk program indicate that online support is a relatively low-cost low-maintenance endeavour. The economic benefits of decreasing distress in cancer patients have also been clearly documented (Carlson & Bultz, 2004). In addition, online groups require no infrastructure or formal meeting environments, only an online domain and data storage location.

Second, although open access groups are widely available and easily accessible online, these groups do not provide a safe environment and lack regulations to ensure privacy and confidentiality, and do not offer failsafe methods to contact users should they indicate extreme levels of distress. Hospital and Supportive Care-led online support programs, such as care2talk, require that patients provide up to date contact information. Through medical records, it is possible to confirm the patient information provided. The group content is surveyed to ensure correct and appropriate information is being circulated, and appropriate counselling professionals are available to respond to queries and concerns. Patient distress levels are surveyed, and individual Supportive Care services are available to patients in need of additional help. Essentially, there is a transparency and assurance of service that accompanies a hospital-regulated support group, as opposed to a general online group. This is important for the safety of the client, especially as cancer patients increasing turn to the internet realm for information and support (Eysenbach, 2003).

#### 4.6 Practical and Clinical Implications of the Research

A key practical and clinical application of the research relates to new program development and breadth of services offered by a Supportive Care program. The purpose of



Supportive Care is to help patients and their families adjust to the cancer diagnosis and treatment, help manage stress and distress, address practical problems, provide spiritual care, and so forth. The ability of Supportive Care to meet these needs is annually evaluated by an independent association, NRC Picker (2009), who continue to report unmet patients needs. With the knowledge that one in five patients are interested in online support, and that there are patients to whom traditional Supportive Care services have not appealed while online services did, providing online care may be a method of extending the reach of the program and addressing the unmet needs of these patients.

A second implication relates to distress as the sixth vital sign. Although distress has been put forth as a measure comparable to pain, heart rate, blood pressure, temperature, or respiration, common practice in Supportive Care is to evaluate distress only at time of admission to the cancer centre, as opposed to screening on a regular basis. Although this is effective at targeting those with initially high levels of distress, it does little to assess those with ongoing distress over time, such as the sample of patients who agreed to participate in the online group. As compared to individuals who declined participation, individuals who agreed to participate online reported higher levels of distress. Across groups, distress levels on the HADS measure completed at time of admission and time of questionnaire mailing were also comparable, indicating a consistency in distress. This research supports the need to routinely assess distress, and to ensure that patients are regularly advised of the Supportive Care services and programs available to them. This is of particular importance considering research indicating increased distress in cancer patients diagnosed in young adulthood (Hoffman et al., 2009).

A third practical concern relates to competencies and training for counsellors to provide care online. Guidelines for the provision of psychosocial care online are emerging, with particular emphasis on topics relating to online training, competency for online work, and related

myths of online clinical work (Fenichel et al., 2002). The experiences of online clinicians are being assessed (Stephens et al., 2010), and an online training manual is being prepared for publication (Canadian Partnership against Cancer, 2009). In support of online clinical care, promising theoretical and research evidence supports the ability of a strong therapeutic alliance to be fostered in an online relationship (Cook & Doyle, 2002; Leibert et al., 2006; Reynolds et al., 2006; Taylor & Luce, 2003). However, from a clinical perspective, an important question to ask is whether there should be specific competency areas associated with online care, much in the way specific competency areas and populations have been identified by Canadian Psychological Association (CPA, 2000). Legislative guidelines are emerging and require careful consideration (CPA 2006; Manhal-Baugus, 2001), however the lack of comprehensive guidelines suggests it is imperative that the clinician who undertakes online therapy consider the potential ethical and legal implications of the care modality.

#### 4.7 Theoretical Implications of the Research

Although this research is preliminary, results support the importance of considering the distress levels of young adults over time, and the specific life concerns and problems that are highly endorsed as sources of distress. Specifically, young adults who responded to the questionnaire mailing reported distress levels similar to those reported at time of diagnosis, meaning that their distress was just as high despite the passage of time. In addition, individuals interested in participating in the online group (as opposed to those who declined to participate) reported significantly more concerns on the CPC emotional, family and social, and physical health scales, suggesting that these topics are greater stressors. This supports both the need to regularly screen for distress in young adult cancer patients, and the possibility that particular problem areas may be of greater importance in this age frame. These results may have important implications for the Supportive Care Framework (Fitch, 1994) that is widely used to guide

supportive care departments and the provision of psychosocial care. Specifically, tailoring this model to reflect the unique needs of young adult cancer patients may be warranted.

#### 4.8 Limitations of the Research

Certain practical and ethical restrictions limited the ability to pursue enrolment or encourage ongoing participation. To begin, the population itself places certain restrictions on recruitment. As the young adults with cancer included in the study varied in terms of their diagnosis and level of active treatment, it was decided that follow-up would consist of only one telephone contact (number of attempts varied) as opposed to several. For confidentiality reasons no telephone messages were left for those who could not be contacted. This procedure may have resulted in a lower questionnaire response rate and by association, lower enrolment in the online program.

A second limitation stems from the lack of quantitative data from [www.care2talk.ca](http://www.care2talk.ca). The original intention was to track active as well as passive website use. Active use was defined as occasions where the participant contributes to the online environment by entering text, whereas passive participation referred to members who accessed the website's various pages but did not actively contribute. For technical reasons relating to the webpage platform it was not possible to assess passive use. With active participation being the sole measure of online use, the ability to clearly assess website use and participant involvement may have been limited.

Along similar lines, another key limitation of the research relates to technical issues encountered with the website and embedded online functions (chat, discussion board). Although the website was thoroughly tested with several internet browsers (Internet Explorer, Mozilla Firefox, Google Chrome) prior to launch, some difficulties emerged over the course of the pilot program. In the chat function, participants were occasionally "timed out" wherein they were disconnected from the chat room and obliged to reconnect to continue. This reconnection process

typically took three to five minutes, during which the chat room conversation moved on. Similar problems occurred in the discussion forum from time to time. Finally, during one professionally-led chat session, the external server shut down thereby effectively ending the chat session.

Although these issues were unforeseen technological errors that were for the most part unavoidable, they none the less have an impact on the individual user. Increased frustration with the technology, in particular for individuals who are less comfortable online, may simply serve to decrease participation, or end participation completely.

#### 4.9 Strengths of the Research

All young adult cancer patients diagnosed in the past five years at the TBRHSC Cancer Centre were invited to participate in the research, meaning that the entire population was sampled. Data was also collected from several sources (medical records, questionnaire mailing, online use), providing both breadth and depth of information. This is particularly important when the lack of basic data on interest in online use is considered.

This research was novel in its ambitions, and successful in creating a support network and online resource specific to young adult cancer patients in Northwestern Ontario. Aid from multiple disciplines (psychology, social work, spiritual care (chaplaincy), sexual health, nutrition) enabled a variety of useful discussion topics to be addressed, also forwarding the notion of online collaborative care. All online sessions were conducted by highly qualified professionals with no less than five years (and up to over twenty years) of experience, who were provided brief training for online support. This research was also directly in line with newly implemented patient and family centered care initiatives at the TBRHSC, ensuring that the highest quality of care is accessible to all patients.

A third strength of the research relates to the strong theoretical base on which it was established. The online group structure, format, and implementation was guided by established

research on group structure, treatment adherence, and attrition as well as clear emerging research on cancer in young adulthood and online resources.

#### 4.10 Future Directions for Research

This research succeeded in identifying baseline measures relating to the interest in internet based support for young adult cancer patients, as well as the characteristics of individuals most likely to be interested. Future research initiatives are now necessary to assess the generalizability of these findings, and to assess whether other cancer populations could be targeted through the use of tailored online interventions. An appropriate example would be the creation of an online support group for prostate cancer patients and survivors, as a method of targeting men with typically lower Supportive Care use.

Although it is clearly feasible to provide a secure online environment in which to connect with other patients and to access resources, the actual effectiveness of online therapy requires careful consideration. In addition to the issue of evaluating therapeutic alliance in an online environment, two other key issues emerge at this time. One, it is clear that evaluation of both group and individual online therapy will require careful research and consideration. Although the group format is in many ways a natural progression from the chat room environment, individual online therapy options should not be overlooked as a viable alternative (Fenichel et al., 2002). This leads to the second issue, the efficacy of online therapy. The need for strong methodological research to evaluate online therapy has been clearly advocated (Eysenbach, 2003; Fenichel et al., 2002; Taylor & Luce, 2003). Perhaps the optimal research progression would begin by adapting methods that have been shown to be efficacious in reducing distress in particular cancer populations, and adapting them for online use and evaluation. Extensive literature on the benefits of supportive expressive group therapy for advanced and metastatic breast cancer patients exists (Classen et al., 2001; Giese-Davis et al., 2002; Goodwin et al., 2001; Kissane et al., 2004; Spiegel

et al., 2007;). Given the debilitating nature of the disease, this would perhaps be an appropriate area in which to begin.

Based on the practical experiences stemming from the care2talk pilot project, a number of considerations for future online support development can be drawn. To begin, it may have proven useful to schedule a series of orientation sessions, to ensure that all individuals who indicated interest in the online group had access to the group at least once. Essentially, a mandatory introduction session may have helped to increase interest, and decrease fears and apprehension associated with the new support group. A second consideration relates to the Supportive Care professionals who conducted the weekly sessions. Although all had a number of years of experience, a single counsellor may have helped with group continuity and cohesion, and to foster a therapeutic alliance. Finally, the schedule of questionnaires administered over the course of the online group was clearly too taxing on the participants, as response levels remained quite low. Although it is important to collect data, especially considering the lack of research in this field, the comfort of the participant and the viability of measure frequency should be carefully considered. By examining the relationships among distress measures, it is also possible to assess the sensitivity and specificity of measures to ensure the appropriate information is obtained with the minimal number of questions.

#### 4.11 Summary

The current study extends previous literature by identifying a baseline interest in online Supportive Care services, predictors of interest in online use, and by clearly elucidating the relationships among the distress measures, and between social support and distress. The provision of psychological care online is an emerging field and exciting in its novelty. Young adults with cancer are clearly interested in online support, connecting with other patients online, and accessing information over the internet. It is arguably the responsibility of hospitals and

cancer centres to ensure these patients have a safe and secure environment in which to do so, and ensuring their distress and Supportive Care needs are being successfully met.

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Tables

Table 1

*Frequency table and ordinal values used to create the "total words" variable (n=42)*

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Word count	Frequency	Ordinal value	Category	Group n
0	26	1	0 words	26
5	1	2	0- 100 words	3
17	1	2		
27	1	2		
435	1	3	101- 1000 words	4
621	1	3		
757	1	3		
965	1	3		
1283	1	4	1001- 2000 words	4
1608	1	4		
1671	1	4		
1778	1	4		
2759	1	5	2001- 3000 words	2
2867	1	5		
3781	1	6	3001-4000 words	1
8408	1	7	greater than 5000 words	2
10,963	1	7		

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Table 2

*Demographic variables and significant differences between groups*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
Gender				<i>t</i> (37.3)=2.343*
Men	17 (23.9)	6 (14.3)	11 (37.9)	
Women	54 (76.1)	36 (85.7)	18 (62.1)	
Age at diagnosis	<i>M</i> =33.75, <i>SD</i> =6.652	<i>M</i> =34.21, <i>SD</i> =7.045	<i>M</i> =33.07, <i>SD</i> =6.094	<i>ns</i>
Age at study outset	<i>M</i> =36.54, <i>SD</i> =6.436	<i>M</i> =36.98, <i>SD</i> =6.546	<i>M</i> =35.90, <i>SD</i> =6.332	<i>ns</i>
Education completed				<i>ns</i>
Middle school	3 (4.2)	1 (2.4)	2 (6.9)	
High school	12 (16.9)	9 (21.4)	3 (10.3)	
College	16 (22.5)	10 (23.8)	6 (20.7)	
Some university	9 (12.7)	6 (14.3)	3 (10.3)	
Completed university	16 (22.5)	8 (19.0)	8 (27.6)	
Postgraduate	8 (11.3)	6 (14.3)	2 (6.9)	
Missing	7 (9.9)	2 (4.8)	5 (17.2)	
Family income				<i>ns</i>
Less than \$30 000	9 (12.7)	4 (9.5)	5 (17.2)	
Less than \$50 000	3 (4.2)	1 (2.4)	2 (6.9)	
Less than \$80 000	17 (23.9)	11 (26.2)	6 (20.7)	
Less than \$100 000	10 (14.1)	8 (19.0)	2 (6.9)	
More than \$100 000	12 (16.9)	9 (21.4)	3 (10.3)	
Missing	20 (28.2)	9 (21.4)	11 (37.9)	

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 2

*Continued*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
Comfort in spiritual beliefs				<i>ns</i>
1-Never	8 (11.3)	3 (7.1)	5 (17.2)	
2-	9 (12.7)	7 (16.7)	2 (6.9)	
3-Sometimes	21 (29.6)	14 (33.3)	7 (24.1)	
4-	12 (16.9)	9 (21.4)	3 (10.3)	
5-Very often	11 (15.5)	6 (14.3)	5 (17.2)	
Missing	10 (14.1)	3 (7.1)	7 (24.1)	
Pray or am spiritual				<i>ns</i>
1-Never	9 (12.7)	4 (9.5)	5 (17.2)	
2-	13 (18.3)	9 (21.4)	4 (13.8)	
3-Sometimes	17 (23.9)	12 (28.6)	5 (17.2)	
4-	12 (16.9)	7 (16.7)	5 (17.2)	
5-Very often	11 (15.5)	7 (16.7)	4 (13.8)	
Missing	9 (12.7)	3 (7.1)	6 (20.7)	

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 3

*Demographic variables and differences between groups by Chi square analysis*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	$\chi^2$	<i>n</i> ( <i>df</i> )	<i>p</i>
Living arrangements				.399	63(1)	.528
Alone	6 (9.5)	3 (6.7)	3 (12.5)			
Not alone	57 (90.5)	36 (92.3)	21 (87.5)			
English as first language				1.258	66(1)	.262
Yes	64 (97.0)	39 (94.1)	25 (100)			
No	2 (3.0)	2 (5.9)	0			
Received Supportive Care				4.392	71(1)	.036
Yes	49 (69.0)	33 (78.6)	16 (55.2)			
No	22 (31.0)	9 (21.4)	13 (44.8)			

*Note.* Chi square analysis is comparing individuals who agreed and did not agree to participate in the online group.



Table 4

*Description of demographic data relating to income, education, and ethnicity*

	Total group (n=71) N (%)	Agreed to participate online (n=42) N (%)	Did not agree to participate online (n=29) N (%)
<b>Primary income source</b>			
Retirement pension	1 (1.4)	1 (2.4)	0 (0)
Disability benefits	14 (19.7)	6 (14.3)	8 (27.6)
Social assistance	1 (1.4)	1 (2.4)	0 (0)
Parents / guardian	4 (5.6)	2 (4.8)	2 (6.9)
Partner / spouse	6 (8.5)	6 (14.3)	0 (0)
Employment	35 (49.3)	21 (50.0)	14 (48.3)
Employment insurance	1 (1.4)	1 (2.4)	0 (0)
Missing	9 (12.7)	4 (9.5)	5 (17.2)
<b>Marital status</b>			
Single	10 (14.1)	4 (9.5)	6 (20.7)
Married	41 (57.7)	28 (66.7)	13 (44.8)
Separated	3 (4.2)	3 (7.1)	0 (0)
Divorced	1 (1.4)	0 (0)	1 (3.4)
Widow/er	0 (0)	0 (0)	0 (0)
Common-law	8 (11.3)	6 (14.3)	2 (6.9)
Committed relationship	2 (2.8)	0 (0)	2 (6.9)
Missing	6 (8.5)	1 (2.4)	5 (17.2)

*Note.* No analyses were completed due to low frequencies in the categories.

Table 4

*Continued*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)
<b>Ethnicity</b>			
White / Caucasian	55 (77.5)	35 (83.3)	20 (69.0)
First Nation	2 (2.8)	2 (4.8)	0 (0)
Southeast Asian	2 (2.8)	1 (2.4)	1 (3.4)
Métis	1 (1.4)	1 (2.4)	0 (0)
South Asian	1 (1.4)	1 (2.4)	0 (0)
Latin American / Hispanic	1 (1.4)	0 (0)	1 (3.4)
Multiple Ethnicities	3 (4.2)	0 (0)	3 (10.3)
Missing	7 (9.8)	2 (4.8)	4 (13.8)

*Note.* No analyses were completed due to low frequencies in the categories.

Table 5

*Medical variables relating to disease factors and satisfaction with care*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%) <sup>1</sup>
Stage at diagnosis	<i>M</i> =1.78, <i>SD</i> =1.05	<i>M</i> =2.14, <i>SD</i> =1.02	<i>M</i> =1.75, <i>SD</i> =1.07
Zero	2 (2.8)	0 (0)	2 (6.9)
One	18 (25.4)	11 (26.2)	7 (24.1)
Two	20 (28.2)	14 (33.3)	6 (20.7)
Three	10 (14.1)	6 (14.3)	4 (13.8)
Four	6 (8.5)	5 (11.9)	1 (3.4)
Missing	15 (21.1)	6 (14.3)	9 (31.0)
Weight			
Decreased	8 (12.3)	6 (14.3)	2 (6.9)
Stayed the same	40 (61.5)	25 (59.5)	15 (51.7)
Increased	17 (26.2)	10 (23.8)	7 (24.1)
Food intake			
Less than usual	14 (21.5)	10 (23.8)	4 (13.8)
Unchanged	41 (63.1)	23 (54.8)	18 (62.1)
More than usual	10 (15.4)	8 (19.0)	2 (6.9)

*Note.* Medical variables were not significantly different across groups. <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 5

*Continued*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%) <sup>1</sup>
Satisfaction with medical treatment to date	<i>M</i> =4.29, <i>SD</i> =.93	<i>M</i> =4.32, <i>SD</i> =.76	<i>M</i> =4.25, <i>SD</i> =1.19
1-Not satisfied	2 (3.1)	0 (0)	2 (6.9)
2-	1 (1.5)	1 (2.4)	2 (6.9)
3-Somewhat satisfied	6 (9.2)	4 (9.5)	6 (20.7)
4-	23 (35.4)	17 (40.5)	14 (48.3)
5-Very satisfied	33 (50.8)	19 (45.2)	24 (82.8)
Missing	6 (9.2)	1 (2.4)	5 (17.2)
Ability to have questions answered by your doctor	<i>M</i> =3.89, <i>SD</i> =1.13	<i>M</i> =3.93, <i>SD</i> =.96	<i>M</i> =3.83, <i>SD</i> =1.40
1-Not satisfied	3 (4.6)	0 (0)	3 (10.3)
2-	4 (6.2)	3 (7.1)	1 (3.4)
3-Somewhat satisfied	15 (23.1)	11 (26.2)	4 (13.8)
4-	18 (27.7)	12 (31.0)	5 (17.2)
5-Very satisfied	25 (38.5)	14 (33.3)	11 (37.9)
Missing	6 (9.2)	1 (2.4)	5 (17.2)

*Note.* Medical variables were not significantly different across groups. <sup>1</sup>Independent samples *t*-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 6

*Medical variables and differences between groups by Chi square analysis*

	Total group (n=71) N (%)	Agreed to participate online (n=42) N (%)	Did not agree to participate online (n=29) N (%)	$\chi^2$	n (df)	p
Metastatic disease at diagnosis						
Yes	6	5	1	1.291	63(1)	.256
No	57	34	23			
Presently in active treatment				3.901	71(1)	.048
Yes	32	23	9			
No	39	19	20			
Smoking Status				1.235	61(1)	.266
Smoking	17	9	8			
Not smoking	44	30	14			

*Note.* Chi square analysis is comparing individuals who agreed and did not agree to participate in the online group.

Table 7

*Cancer prevalence rates*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)
Primary disease site			
Breast	23 (32.4)	19 (45.2)	4 (13.8)
Gynecological	9 (12.7)	5 (11.9)	4 (13.8)
Genitourinary	6 (8.5)	2 (4.8)	4 (13.8)
Thyroid	6 (8.5)	3 (7.1)	3 (10.3)
Gastrointestinal	7 (9.9)	4 (9.5)	3 (10.3)
Hodgkin's disease	2 (2.8)	1 (2.4)	1 (3.4)
Malignant melanoma	1 (1.4)	0 (0)	1 (3.4)
Skin (non- melanoma)	2 (2.8)	1 (2.4)	1 (3.4)
Non-Hodgkin's lymphoma	4 (5.6)	2 (4.8)	2 (6.9)
Brain & nervous system	4 (5.6)	1 (2.4)	3 (10.3)
Leukemia	1 (1.4)	0 (0)	1 (3.4)
Head & neck	2 (2.8)	2 (4.8)	0 (0)
Other (lung, bone,)	3 (4.2)	1 (2.4)	2 (6.8)

Table 8

*HADS scores (mean, standard deviation) and differences between groups*

	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =25) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
HADS anxiety scale				
Mean	7.42	8.24	6.04	$t(64)=2.141^*$
SD	4.09	3.67	4.33	
HADS depression scale				
Mean	4.94	5.22	3.56	ns
SD	4.37	3.62	4.14	
HADS total				
Mean	12.36	13.46	9.59	ns
SD	7.75	6.48	7.85	

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 9

*CPC scores indicting items endorsed as problems and differences between groups*

	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =25) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
CPC emotional				
Fears / worries	34 (51.5)	27 (65.9)	7 (28.0)	$t(64)=-3.160^{**}$
Sadness	24 (36.4)	19 (46.3)	5 (20.0)	$t(58.9)=-2.321^*$
Frustration / anger	31 (47.0)	23 (56.1)	8 (32.0)	<i>ns</i>
Changes in Appearance	15 (22.7)	12 (29.3)	3 (12.0)	<i>ns</i>
Intimacy / sexuality	22 (33.3)	18 (43.9)	4 (16.0)	$t(61.3)=-2.573^*$
Total emotional scale	<i>M</i> =1.91, <i>SD</i> =1.49	<i>M</i> =2.41, <i>SD</i> =1.43	<i>M</i> =1.08, <i>SD</i> =1.19	$t(64)=-3.910^{**}$
CPC spiritual				
Meaning / purpose of life	9 (13.6)	7 (17.1)	2 (8.0)	<i>ns</i>
Faith	6 (9.1)	3 (7.3)	3 (12.0)	<i>ns</i>
Total spiritual scale	<i>M</i> =.23, <i>SD</i> =.49	<i>M</i> =.24, <i>SD</i> =.43	<i>M</i> =.20, <i>SD</i> =.58	<i>ns</i>
CPC practical				
Work / school	24 (36.4)	19 (46.3)	5 (20.0)	$t(58.9)=-2.321^*$
Finances	29 (43.9)	20 (48.8)	9 (36.0)	<i>ns</i>
Getting to & from appointments	10 (15.2)	8 (19.5)	2 (8.0)	<i>ns</i>
Accommodations	4 (6.1)	2 (4.9)	2 (8.0)	<i>ns</i>
Total practical scale	<i>M</i> =1.02, <i>SD</i> =.97	<i>M</i> =1.20, <i>SD</i> =.84	<i>M</i> =.72, <i>SD</i> =1.10	<i>ns</i>

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.



Table 9

*Continued*

	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =25) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
<b>CPC Family and Social</b>				
Feeling a burden to others	14 (21.2)	10 (24.4)	4 (16.0)	<i>ns</i>
Worry about family and friends	25 (37.9)	17 (41.5)	8 (32.0)	<i>ns</i>
Feeling alone	17 (25.8)	15 (36.6)	2 (8.0)	$t(63.8)=-3.036^{**}$
Total family and social scale	$M=.85,$ $SD=.92$	$M=1.02,$ $SD=.99$	$M=.56,$ $SD=.71$	$t(64)=-2.047^*$
<b>CPC informational</b>				
Understanding illness and treatment	11 (16.7)	6 (14.6)	5 (20.0)	<i>ns</i>
Talking with health care team	8 (12.1)	6 (14.6)	2 (8.0)	<i>ns</i>
Making treatment decisions	10 (15.2)	8 (19.5)	2 (8.0)	<i>ns</i>
Knowing about available resources	7 (10.6)	7 (17.1)	0 (0)	$t(40)=-2.870^{**}$
Total informational scale	$M=.55,$ $SD=.79$	$M=.66,$ $SD=.82$	$M=.36,$ $SD=.70$	<i>ns</i>
<b>CPC physical health</b>				
Concentration / memory	29 (43.9)	23 (56.1)	6 (24.0)	$t(56.4)=-2.737^{**}$
Sleep	33 (50.0)	27 (65.9)	6 (24.0)	$t(64)=-3.555^{**}$
Weight	30 (45.5)	20 (48.8)	10 (40.0)	<i>ns</i>
Total physical health scale	$M=1.39$ $SD=1.07$	$M=1.71,$ $SD=.98$	$M=.88,$ $SD=1.01$	$t(64)=-3.283^{**}$
CPC Total	$M=5.94,$ $SD=4.27$	$M=7.24,$ $SD=3.79$	$M=3.80,$ $SD=4.21$	$t(64)=-3.434^{**}$

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 10

*ESAS scores (mean, standard deviation) and differences between groups*

	Total group (n=66)	Agreed to participate online (n=41)	Did not agree to participate online (n=25)
Pain	$M=2.32, SD=2.77$	$M=2.55, SD=2.47$	$M=1.96, SD=3.31$
Tired	$M=4.33, SD=2.84$	$M=4.63, SD=2.45$	$M=3.84, SD=3.39$
Nausea	$M=1.38, SD=2.33$	$M=1.22, SD=1.74$	$M=1.64, SD=3.08$
Depression	$M=2.35, SD=2.63$	$M=2.83, SD=2.43$	$M=1.56, SD=2.80$
Anxiety	$M=2.52, SD=2.49$	$M=2.88, SD=2.34$	$M=1.92, SD=2.66$
Drowsy	$M=2.50, SD=2.90$	$M=2.61, SD=2.64$	$M=2.32, SD=3.34$
Appetite	$M=2.58, SD=2.87$	$M=2.95, SD=2.59$	$M=1.96, SD=3.25$
Wellbeing	$M=3.09, SD=2.52$	$M=3.44, SD=2.32$	$M=2.52, SD=2.77$
Shortness of Breath	$M=1.51, SD=2.23$	$M=1.63, SD=2.25$	$M=1.32, SD=2.23$
Other	$M=1.30, SD=2.79$	$M=1.79, SD=3.26$	$M=0.56, SD=1.75$
Total out of a possible 90	$M=23.33, SD=19.38$	$M=25.73, SD=16.47$	$M=19.40, SD=23.23$

*Note.* ESAS scores were not significantly different between groups.

Table 11

*PWC psychosocial scores (mean, standard deviation) and differences between groups*

	Total group ( <i>n</i> =64)	Agreed to participate online ( <i>n</i> =40)	Did not agree to participate online ( <i>n</i> =24)	Independent samples t-test <sup>1</sup>
<b>PWC Thermometers</b>				
Distress	<i>M</i> =3.66, <i>SD</i> =3.04	<i>M</i> =4.38, <i>SD</i> =2.91	<i>M</i> =2.43, <i>SD</i> =2.90	<i>t</i> (60)=-2.552*
Pain	<i>M</i> =2.34, <i>SD</i> =2.78	<i>M</i> =2.41, <i>SD</i> =2.24	<i>M</i> =2.21, <i>SD</i> =3.55	<i>ns</i>
Fatigue	<i>M</i> =4.23, <i>SD</i> =2.90	<i>M</i> =4.70, <i>SD</i> =2.59	<i>M</i> =3.46, <i>SD</i> =3.27	<i>ns</i>
Total score	<i>M</i> =10.09, <i>SD</i> =6.94	<i>M</i> =11.32, <i>SD</i> =6.07	<i>M</i> =8.04, <i>SD</i> =7.90	<i>ns</i>
PWC psychosocial measure	<i>M</i> =18.06, <i>SD</i> =7.66	<i>M</i> =19.20, <i>SD</i> =6.37	<i>M</i> =16.00, <i>SD</i> =9.40	<i>ns</i>

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 12

*PWC scores indicating items endorsed as problems and differences between groups*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
Accommodation	5 (7.6)	2 (4.9)	3 (12.0)	<i>ns</i>
Transportation	12 (18.2)	9 (22.0)	3 (12.0)	<i>ns</i>
Parking	2 (3.0)	2 (4.9)	0 (0)	<i>ns</i>
Drug coverage	10 (15.2)	7 (17.1)	3 (12.0)	<i>ns</i>
Work / school	26 (39.4)	19 (46.3)	7 (28.0)	<i>ns</i>
Finances	29 (43.9)	21 (51.2)	8 (32.0)	<i>ns</i>
Groceries	10 (15.2)	8 (19.5)	2 (8.0)	<i>ns</i>
Burden to others	20 (30.3)	14 (34.1)	6 (24.0)	<i>ns</i>
Worry about family & friends	27 (40.9)	20 (48.8)	7 (28.0)	<i>ns</i>
Talking with family & friends	11 (16.7)	8 (19.5)	3 (12.0)	<i>ns</i>
Talking with medical team	12 (18.2)	9 (22.0)	3 (12.0)	<i>ns</i>
Family conflict	10 (15.2)	9 (22.0)	1 (4.0)	$t(61.2)=-2.340^*$
Changes in appearance	25 (37.9)	20 (48.8)	5 (20.0)	$t(58.9)=-2.533^*$
Alcohol, drugs, gambling	3 (4.5)	3 (7.3)	0 (0)	<i>ns</i>
Smoking	8 (12.1)	3 (7.3)	5 (20.0)	<i>ns</i>
Coping	17 (25.8)	13 (31.7)	4 (16.0)	<i>ns</i>
Making treatment decisions	16 (24.2)	14 (34.1)	2 (8.0)	$t(63.9)=-2.805^{**}$

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 12

*Continued*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
Sexuality	18 (27.3)	14 (34.1)	4 (16.0)	ns
Spirituality	4 (6.1)	2 (4.9)	2 (8.0)	ns
Sleep	32 (48.5)	25 (61.0)	7 (28.0)	<i>t</i> (64)=-2.703**
Total number checked	M=4.35, SD=3.34	M=5.34, SD=3.24	M=2.72, SD=2.88	<i>t</i> (64)=-3.324**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 13

*BSSS scores (mean, standard deviation) and differences between groups*

	Total group ( <i>n</i> =66)	Agreed to participate online ( <i>n</i> =41)	Did not agree to participate online ( <i>n</i> =25)	Independent samples t-test <sup>1</sup>
<b>BSSS Subscales</b>				
Perceived available support	<i>M</i> =27.19, <i>SD</i> =5.29	<i>M</i> =26.82, <i>SD</i> =5.37	<i>M</i> =27.76, <i>SD</i> =5.21	<i>ns</i>
Support seeking	<i>M</i> =25.18, <i>SD</i> =3.87	<i>M</i> =25.22, <i>SD</i> =3.37	<i>M</i> =25.13, <i>SD</i> =4.67	<i>ns</i>
Actually received support	<i>M</i> =49.92, <i>SD</i> =9.33	<i>M</i> =48.95, <i>SD</i> =9.85	<i>M</i> =51.73, <i>SD</i> =8.20	<i>ns</i>
Protective buffering scale	<i>M</i> =13.37, <i>SD</i> =3.91	<i>M</i> =14.12, <i>SD</i> =4.10	<i>M</i> =12.08, <i>SD</i> =3.35	<i>t</i> (63)=-2.08*
Total BSSS score	<i>M</i> =115.95, <i>SD</i> =14.01	<i>M</i> =114.92, <i>SD</i> =14.39	<i>M</i> =117.73, <i>SD</i> =13.48	<i>ns</i>

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 14

*Sources of information consulted by patients and differences between groups*

	Total group ( <i>n</i> =71) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =42) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =29) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
Information sources				
Cancer Centre Doctors	59 (88.1)	36 (85.7)	23 (79.3)	<i>Ns</i>
Pamphlets	42 (62.7)	26 (61.9)	16 (55.2)	<i>Ns</i>
Nurses & Staff	41 (61.2)	25 (59.5)	16 (55.2)	<i>Ns</i>
Internet	38 (56.7)	29 (69.0)	9 (31.0)	<i>t</i> (65)=-3.064**
Family & friends	34 (50.7)	21 (50.0)	13 (44.8)	<i>Ns</i>
Family Doctor	33 (49.3)	18 (42.9)	15 (51.7)	<i>Ns</i>
Other patients	25 (37.3)	20 (47.6)	5 (17.2)	<i>t</i> (61.6)=-2.647**
Other	8 (11.9)	6 (14.3)	2 (6.9)	<i>Ns</i>
Total number of information sources consulted	<i>M</i> =4.13, <i>SD</i> =2.02	<i>M</i> =4.44, <i>SD</i> =1.98	<i>M</i> =3.65, <i>SD</i> =2.02	<i>Ns</i>

Note: \*=*p*<.05, \*\*=*p*<.01. <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 15

*Endorsement of questions relating to computer use and internet service and chi square analysis of differences between groups*

	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =26) <i>N</i> (%)	$\chi^2$	<i>n</i> ( <i>df</i> )	<i>p</i>
Computer at home?	61 (92.4)	41 (97.6)	20 (69.0)	8.87	66 (1)	.003
Personal computer	21 (34.4)	15 (35.7)	6 (20.7)	.258	61 (1)	.611
Shared computer	40 (65.6)	26 (61.9)	14 (48.3)			
Internet at home	58 (90.6)	39 (92.9)	19 (65.5)	5.93	64 (1)	.015
Type of internet access at home?				.639	60 (1)	.405
High speed / cable	54 (90.0)	36 (85.7)	18 (62.1)			
Dial up / slow	6 (10.0)	5 (11.9)	1 (3.4)			
Currently working or attending school?	41 (62.1)	25 (61.0)	16 (55.2)	.060	66 (1)	.806
Internet access at work or school?	33 (78.6)	20 (47.6)	13 (44.8)	.110	42 (1)	.740

*Note.* Chi square analysis is comparing individuals who agreed and did not agree to participate in the online group.



Table 16

*Evaluation of daily computer use and differences in use between groups*

	Total group (n=66) N (%)	Agreed to participate online (n=41) N (%)	Did not agree to participate online (n=25) N (%)	Independent samples t-test <sup>1</sup>
Time per day on computer at home?				$t(65)=2.822^{**}$
No time most days	10 (14.9)	2 (4.9)	8 (30.8)	
15-30 min	20 (29.9)	13 (31.7)	7 (26.9)	
30-60 min	17 (25.4)	11 (26.8)	6 (23.1)	
1-2 hours	13 (19.4)	8 (19.5)	5 (19.2)	
2-3 hours	2 (3.0)	2 (4.9)	0 (0)	
3-4 hours	2 (3.0)	2 (4.9)	0 (0)	
4-5 hours	2 (3.0)	2 (4.9)	0 (0)	
5 hours plus	1 (1.5)	1 (2.4)	0 (0)	
Time per day on computer at work or school?				<i>Ns</i>
No time most days	13 (25.5)	5 (11.9)	8 (27.6)	
15-30 min	5 (9.8)	3 (7.1)	2 (6.9)	
30-60 min	5 (9.8)	3 (7.1)	2 (6.9)	
1-2 hours	7 (13.7)	3 (7.1)	4 (13.8)	
2-3 hours	3 (5.9)	3 (7.1)	0 (0)	
3-4 hours	2 (3.9)	1 (2.4)	1 (3.4)	
4-5 hours	4 (7.8)	1 (2.4)	3 (10.3)	
5 hours plus	12 (23.5)	8 (19.0)	4 (13.8)	

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 16

*Continued*

	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =25) <i>N</i> (%)	Independent samples t-test <sup>1</sup>
How comfortable are you with computer use?				<i>t</i> (33.2)=2.922**
1- Uncomfortable	3 (4.5)	0 (0)	3 (10.3)	
2-	4 (6.0)	0 (0)	4 (13.8)	
3 - Comfortable	11 (16.4)	6 (14.3)	5 (17.2)	
4-	12 (17.9)	9 (21.4)	3 (10.3)	
5- Very comfortable	37 (55.4)	26 (61.9)	11 (37.9)	

Note. \* =  $p < .05$ , \*\* =  $p < .01$ . <sup>1</sup>Independent samples t-test is comparing individuals who agreed and did not agree to participate in the online group.

Table 17

*Examining frequency of use of social networking websites and differences in use between groups*

Endorsement of online social networking	Total group ( <i>n</i> =66) <i>N</i> (%)	Agreed to participate online ( <i>n</i> =41) <i>N</i> (%)	Did not agree to participate online ( <i>n</i> =25) <i>N</i> (%)
Facebook	43 (65.2)	29 (69.0)	14 (48.3)
Twitter	3 (4.5)	2 (4.8)	1 (3.4)
Chat rooms	6 (9.1)	4 (9.5)	2 (6.9)
MySpace	3 (4.5)	2 (4.8)	1 (3.4)
Other	12 (18.2)	8 (19.0)	4 (13.8)
Other	3 (4.5)	1 (2.4)	2 (6.9)
Total used	<i>M</i> =1.06, <i>SD</i> =1.04	<i>M</i> =1.12, <i>SD</i> =0.95	<i>M</i> =0.96, <i>SD</i> =1.17
If social networking is used, how often? ( <i>n</i> =47)			
About once per month or less	5 (10.6)	4 (9.5)	1 (3.4)
About once per week	11 (23.4)	5 (11.9)	6 (20.7)
About once per day	17 (36.2)	11 (26.2)	6 (20.7)
Several times a day	12 (25.5)	10 (23.8)	2 (6.9)
Participated in online support group before?	6 (9.1)	5 (11.9)	1 (3.4)

*Note.* No significant differences were found between individuals who agreed to participate in the online group and those who declined.

Table 18

*Sequential logistic regression examining the interest of young adult cancer patients in participating in an online support group, detailing the contribution of each step (n=62)*

Step	Predictor variable	Chi square	df	p	Nagelkerke R squared
1	Gender	7.10	62,1	.008	14.8%
2	Comfort with computer use	12.92	62,4	.012	22.9%
3	PWC distress	11.84	64,3	.008	17.1%
	HADS anxiety				
	BSSS protective buffering				
4	Previous supportive care use	6.643	64,1	.010	8.3%
	Total model				63.1%

Odds ratio analysis for dichotomous predictors

Predictor variable	Odds ratio	95% C.I.	p
Gender	.178	.047-.673	.011
Previous supportive care use	7.767	1.455-41.464	.016

Table 19

*The observed and predicted frequencies for interest in participating in the online group by logistic regression analysis with cut value of 0.50*

Observed	Predicted		% Correct
	Yes	No	
Yes	36	3	92.3
No	3	20	87.0
Overall % correct			90.3

*Note.* Sensitivity= $36/(36+3)\%=92.3\%$ . Specificity= $20/(20+3)=87.0\%$ . False positive= $3/(3+36)=7.7\%$ . False negative= $13.0\%$ . With kappa correction for chance overall % correct= $79.3\%$ .

Table 20

*Correlations between the total words and psychosocial variables*

	<i>n</i>	Total words entered online
PWC total number problems	40	.374*
PWC distress thermometer	39	-.250
PWC pain thermometer	39	.038
PWC fatigue thermometer	39	-.135
PWC psychosocial distress scale	39	-.076
HADS distress score	40	-.015
Supportive Care client	41	-.151
Total number of contacts with Supportive Care	38	.466**

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 21

*Correlations and mean changes between the HADS at admission (time one) and the HADS at questionnaire mailing (time two) (n=66)*

HADS	HADS time one	HADS time two	<i>r</i>	<i>t</i>
	M (SD)	M (SD)		
Anxiety scale	6.86 (3.98)	7.42 (4.09)	.394**	-1.016
Depression scale	3.92 (3.88)	4.94 (4.38)	.463**	-1.506
Total distress scale	10.79 (6.93)	12.36 (7.75)	.516**	-1.507

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 22

*Correlations among the HADS scales and CPC scales (n=66)*

CPC Scales	HADS scales		
	Anxiety	Depression	Total distress
Emotional	.556**	.423**	.532**
Spiritual	.396**	.372**	.420**
Practical	.317**	.127	.239
Family & social	.642**	.631**	.696**
Informational	.314*	.228	.295*
Physical health	.551**	.503**	.575**
Total score	.644**	.522**	.635**

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .



Table 23

*Correlations among the HADS scales and ESAS scales (n=66)*

ESAS scales	HADS Scales		
	Anxiety	Depression	Total distress
Pain	.485**	.625**	.608**
Tiredness	.529**	.671**	.659**
Nausea	.567**	.577**	.625**
Depression	.611**	.733**	.737**
Anxiety	.809**	.691**	.818**
Drowsiness	.606**	.741**	.738**
Appetite	.615**	.653**	.694**
Feeling of wellbeing	.652**	.735**	.760**
Shortness of breath	.480**	.543**	.561**
Total score	.747**	.836**	.867**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 24

*Correlations among the HADS scales and PWC scales (n=62)*

PWC Scales	HADS scales		
	Anxiety	Depression	Total distress
Psychosocial distress scale	.773**	.786**	.849**
Distress thermometer	.472**	.432**	.496**
Pain thermometer	.380**	.555**	.511**
Fatigue thermometer	.496**	.593**	.595**
Total thermometer score	.544**	.617**	.634**

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 25

*Correlations among the ESAS scales and CPC scales (n=66)*

ESAS	CPC scales						
	Emotional	Spiritual	Practical	Family & social	Informational	Physical health	Total score
Pain	.358**	.368**	.253*	.443**	.352**	.469**	.500**
Tiredness	.299*	.321*	.048	.475**	.247*	.586**	.446**
Nausea	.206	.383**	.059	.316**	.272*	.287*	.319**
Depression	.532**	.392**	.209	.451**	.204	.494**	.535**
Anxiety	.575**	.306*	.226	.575**	.270*	.566**	.601**
Drowsiness	.354**	.341**	.052	.551**	.242*	.503**	.463**
Appetite	.402**	.463**	.229	.478**	.423	.413	.529**
Feeling of wellbeing	.614**	.382**	.314*	.566**	.377**	.674**	.688**
Shortness of breath	.333**	.062	.004	.494**	.184	.482**	.384**
Total score	.524**	.423**	.191	.618**	.361**	.635**	.632**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 26

*Correlations among the PWC scales and CPC scales (n=66)*

CPC scales	PWC scales				
	Psychosocial distress	Distress thermometer	Pain thermometer	Fatigue thermometer	Total thermometer
Emotional	.613**	.487**	.234	.283*	.431**
Spiritual	.382**	.406**	.317*	.148	.373**
Practical	.256*	.418**	.219	.065	.307*
Family & social	.622**	.329**	.397**	.457**	.464**
Informational	.202	.442**	.296*	.069	.330**
Physical health	.581	.486**	.443**	.581**	.632**
Total score	.629**	.582**	.418**	.385**	.580**

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 27

*Correlations among the ESAS scales and PWC scales (n=62)*

ESAS scales	PWC scales				
	Psychosocial distress	Distress thermometer	Pain thermometer	Fatigue thermometer	Total thermometer
Pain	.491**	.542**	.895**	.566**	.771**
Tiredness	.590**	.594**	.656**	.903**	.857**
Nausea	.578**	.383**	.419**	.513**	.494**
Depression	.806**	.448**	.250*	.401**	.441**
Anxiety	.813**	.498**	.418**	.507**	.563**
Drowsiness	.796**	.368**	.531**	.612**	.578**
Appetite	.579**	.606**	.471**	.467**	.600**
Feeling of wellbeing	.715**	.544**	.487**	.503**	.617**
Shortness of breath	.537**	.400**	.375**	.544**	.545**
Total score	.824**	.620**	.631**	.704**	.769**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 28

*Correlations among the BSSS scales and PWC scales*

PWC scales	BSSS scales				Total score (n=58)
	Perceived support available (n=61)	Support seeking (n=63)	Actually received support (n=61)	Protective buffering (n=63)	
Psychosocial distress scale	-.589**	-.272*	-.257*	.239	-.401**
Distress thermometer	-.329*	-.054	-.011	.002	-.165
Pain thermometer	-.129	-.157	-.091	.304*	-.004
Fatigue thermometer	-.230	-.268*	-.099	.118	-.166
Total thermometer score	-.276*	-.180	-.060	.154	-.130

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 29

*Correlations among the BSSS scales and ESAS scales (n=60)*

ESAS scales	BSSS scales				
	Perceived support available	Support seeking	Actually received support	Protective buffering	Total score
Pain	-.221	-.182	-.034	.230	-.053
Tiredness	-.309*	-.294*	-.114	.066	-.205
Nausea	-.330**	-.205	-.036	-.197	-.183
Depression	-.510**	-.265*	-.503**	.182	-.547**
Anxiety	-.516**	-.222	-.296*	.176	-.389**
Drowsiness	-.334**	-.309*	-.222	.085	-.282*
Appetite	-.398**	-.211	-.143	.067	-.221
Feeling of wellbeing	-.481**	-.221	-.311*	.175	-.389**
Shortness of breath	-.290*	-.232	.001	-.053	-.208
Total score	-.479**	-.300*	-.229	.125	-.343**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .

Table 30

*Correlations among the BSSS scales and CPC scales*

CPC scales	BSSS scales				
	Perceived support available (n=63)	Support seeking (n=65)	Actually received support (n=63)	Protective buffering (n=65)	Total score (n=60)
Emotional	-.168	.040	-.082	.297*	-.051
Spiritual	-.191	.002	-.086	.036	-.098
Practical	-.087	.157	.070	.332**	.085
Family & social	-.492**	-.209	-.385**	.312*	-.414**
Informational	-.233	.124	-.058	-.020	-.063
Physical health	-.245	-.095	-.192	.270*	-.207
Total Score	-.311*	.004	-.143	.312*	-.164

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .



Table 31

*Correlations among the BSSS scales and HADS scales*

HADS Scales	BSSS scales				Total score (n=60)
	Perceived support available (n=63)	Support seeking (n=65)	Actually received support (n=63)	Protective buffering (n=65)	
Anxiety	-.563**	-.143	-.251*	.298*	-.315*
Depression	-.552**	-.296*	-.452**	.228	-.500**
Total distress	-.610**	-.243	-.389**	.287*	-.452**

Note. \* =  $p < .05$ , \*\* =  $p < .01$ .

Figures

Figure 1: Supportive Care Framework

Supportive Care Framework (Fitch, 1994)

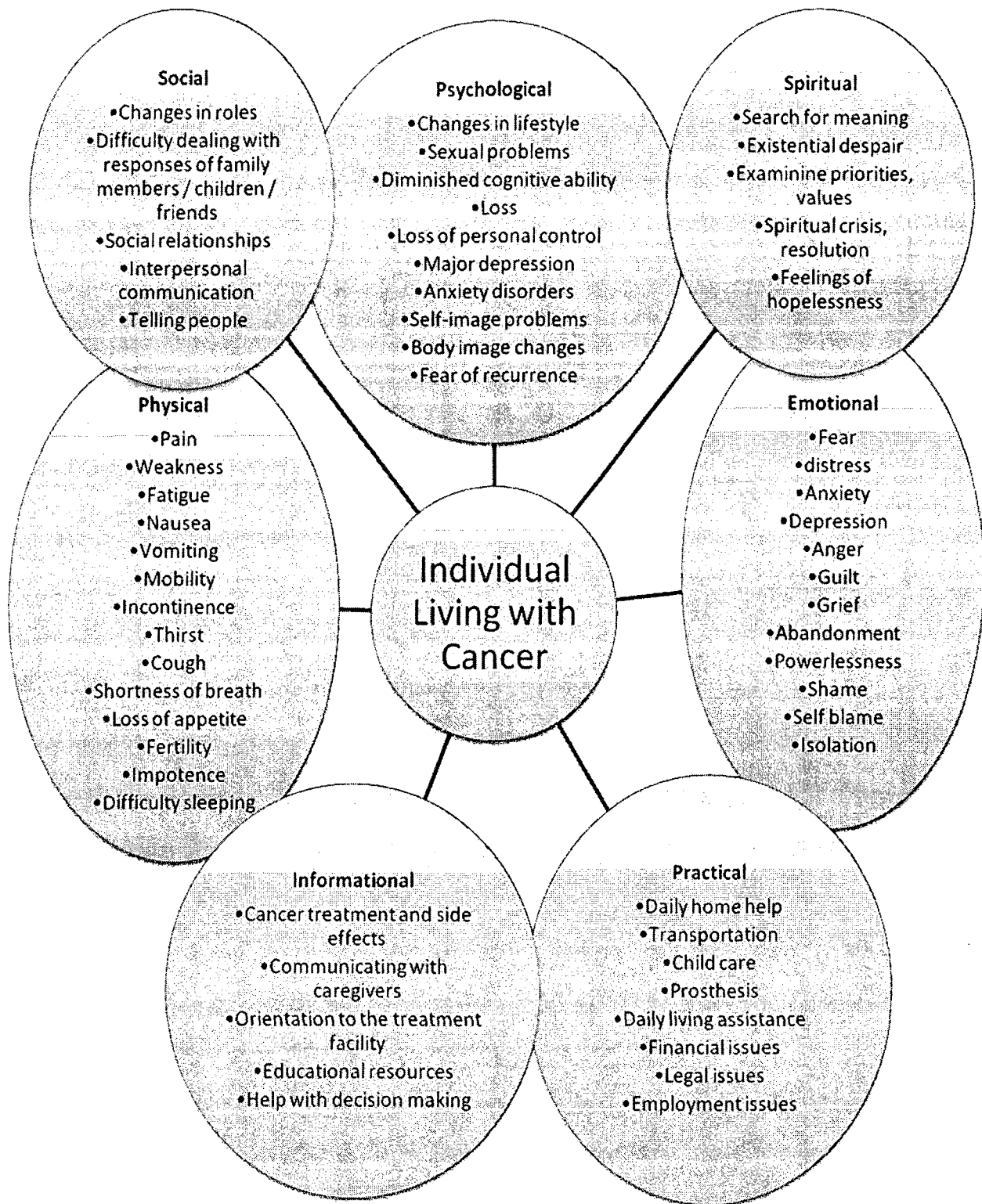
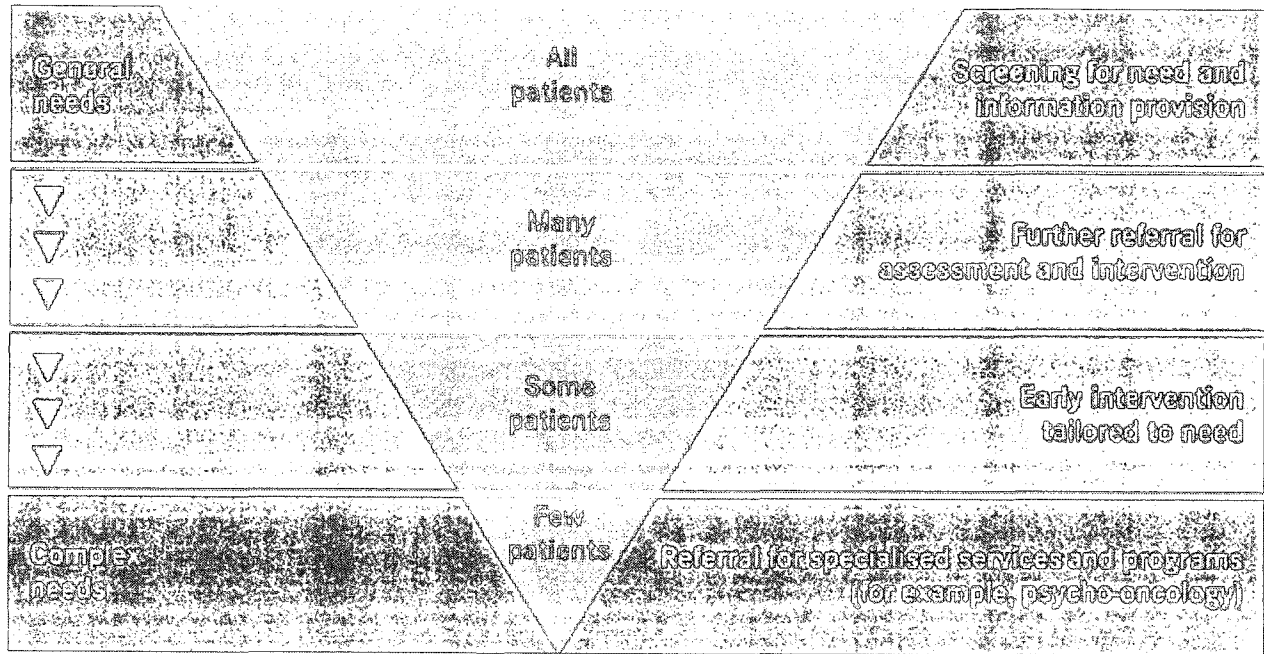


Figure 2: Tiered Model of Supportive Care

Tiered Model of Supportive Care



Model adapted by Supportive Cancer Care Victoria from Fitch, M. 2000. Supportive care for cancer patients'. Hospital Quarterly, 3, 39-46.

Figure 3: NRC-Picker Data



**Ambulatory Oncology Patient Experience-Information, Communication & Education**  
 (continued)  
**Thunder Bay Regional Health Sciences Centre**  
 April - September 2008 (n=323, Response Rate= 54.4%)

		<i>Detail</i>			
Mar-Aug '06	Mar-Aug '07		Ontario ONC AVG	Ontario ONC HP	Canada ONC AVG
<b>Wanted but didn't receive info on services (OP)</b>					
34.4%	25.9%	Counselling/support (social workers, psychologists)  34.0%	18.3%		18.2%
15.6%	22.2%	Spiritual support  20.8%	9.3%		9.6%
42.2%	33.3%	Dietitian  37.7%	21.5%		21.3%
8.9%	7.4%	Speech therapist  13.2%	4.1%		3.8%
11.1%	0.0%	Occupational therapist  15.1%	6.1%		5.8%
26.7%	14.8%	Physical therapist  32.1%	12.1%		11.5%
20.0%	33.3%	Support groups  26.4%	13.1%		14.4%
10.0%	7.4%	Palliative care  11.3%	6.0%		6.5%
24.4%	18.5%	Other  18.9%	9.3%		8.9%

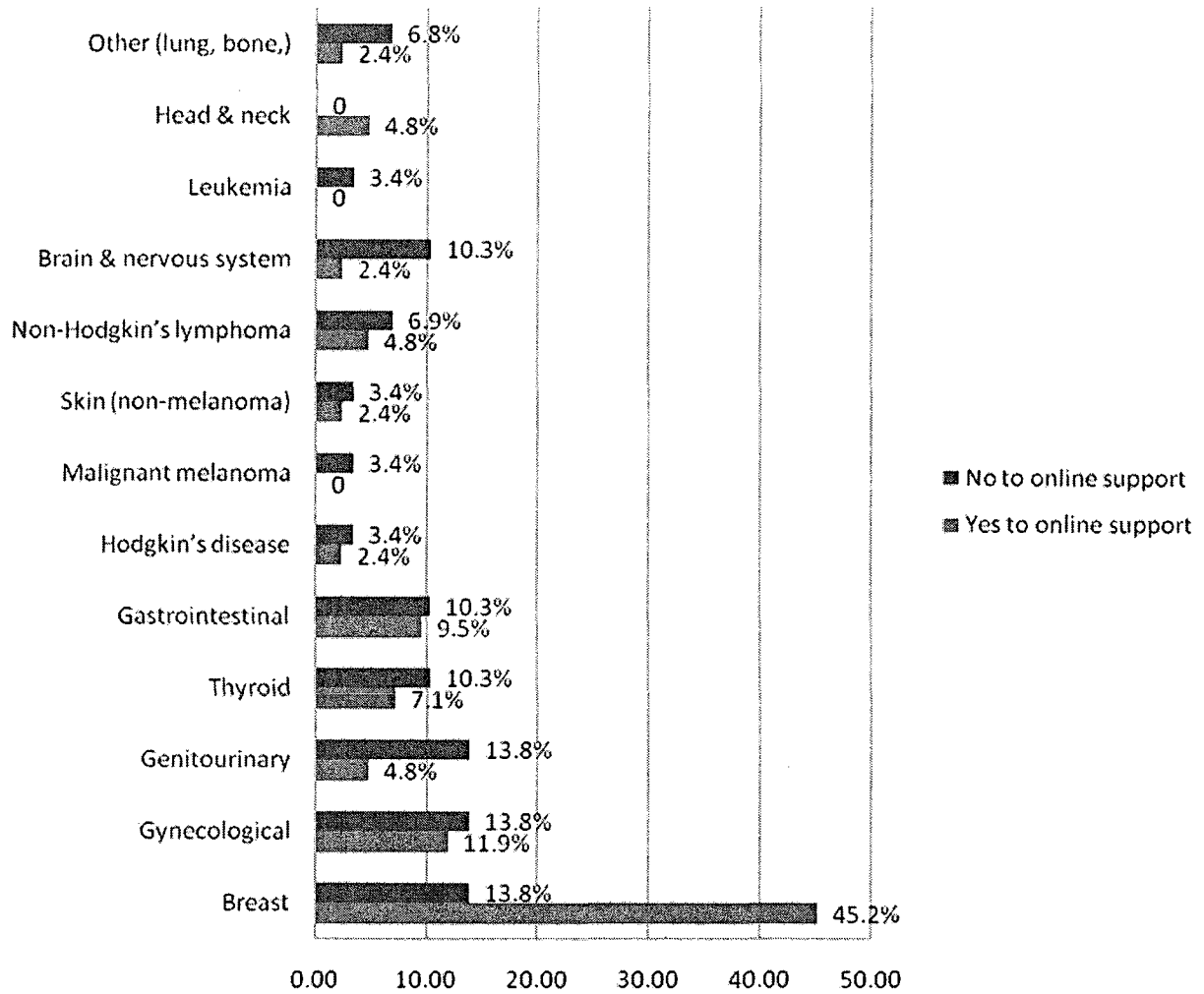
Arrow represents statistically significant differences, at the 95 % confidence level, from your current score.  
 Your current score is: higher or lower .





Figure 4: Cancer Prevalence Rates by Group

### Cancer prevalence by group (percent)



## Appendices

Appendix A: Consent for Release of Information Form



Northwestern Ontario Regional Cancer Care  
 980 Oliver Road, Thunder Bay, ON P7B 6V4  
 Telephone: (807) 684-7200 Fax: (807) 684-5800

CHART #: \_\_\_\_\_

**PLEASE ANSWER THE FOLLOWING QUESTIONS: (Please print)**

Patient's Name: \_\_\_\_\_  
 (as on Health Card) Last Name First Name Middle Name

Maiden Name: \_\_\_\_\_ Language: \_\_\_\_\_

Address: \_\_\_\_\_ Telephone #: \_\_\_\_\_

City Province Postal Code

Date of Birth: \_\_\_\_\_ Place of Birth (optional): \_\_\_\_\_  
 Day Month Year

Family Physician: \_\_\_\_\_

Next of Kin: \_\_\_\_\_ Relationship \_\_\_\_\_

Address and Phone (if different from above) \_\_\_\_\_

Person to Notify other than Next of Kin: \_\_\_\_\_ Relationship \_\_\_\_\_

Address : \_\_\_\_\_ Phone: \_\_\_\_\_

Health Card Number: \_\_\_\_\_ Version Code: \_\_\_\_\_

Do you have other Health Coverage: Yes  No

If yes, please give company name: \_\_\_\_\_ Policy Number: \_\_\_\_\_

Have you ever been seen at a Cancer Centre? Yes  No  If yes, where? \_\_\_\_\_

**PATIENT'S CONSENT FOR RELEASE OF INFORMATION**

I authorize the Northwestern Ontario Regional Cancer Care Program, to release to doctors, hospitals, nursing homes and other health agencies who might be involved in my continuing care, any information or material deemed necessary to facilitate this care. Information may be sent in paper or electronic format. I understand that information from my records may be used for research purposes. The Northwestern Ontario Regional Cancer Care Program will maintain confidentiality.

\_\_\_\_\_  
 Witness

\_\_\_\_\_  
 Signature of Patient or Person Acting for Patient

\_\_\_\_\_  
 Date

New Patient Package given \_\_\_\_\_  
 Initial

Appendix B: Letter from Supportive Care

Lakehead  
UNIVERSITY



January 3rd, 2010

Dear

As Director of the Supportive Care Program at the Thunder Bay Regional Health Sciences Centre, with specific clinical and research responsibilities within the Regional Cancer Care Program, I am inviting you to participate in an exciting research project set to begin in January and be completed by May of 2010.

Ms. Liane Kandler is a graduate student in clinical psychology at Lakehead University, and would like to hear about your experiences, your distress, your social support, and your interest in an online group. Her goal is to obtain a greater understanding of the specific challenges faced by young adults with cancer, but also to try and meet these needs through an online group.

I am enclosing the **Research Information Package**, so you can see what Ms. Kandler's work is all about, what we would expect of you, and what you may expect of us. I supervise Ms. Kandler's work closely.

**There are two parts of this project:**

**Part One:** Questionnaires that would take approximately 30 minutes to complete. Your name is not to be written on these questionnaires. Please return the completed questionnaire to Ms. Kandler.

**Part Two:** A consent form is required to be part of the Online Group. This is where you would actually participate in the online group that is explained in more detail in Ms. Kandler's information package (included in the Research Information Package). Part Two is scheduled to begin February 15, 2010. Please complete the consent form and return it to Ms. Kandler.

Participation is voluntary. You may participate in any part of the project and withdraw at any time without penalty. For example, even if you decide not to complete the questionnaires in Part One, you may still sign-up for Part Two if you return the **Consent Form for the Online Group**.

The **Research Information Package** contains all the necessary information. Please feel free to contact me directly if you have any questions. And, thank you very much.

Sincerely,

---

Scott Sellick, PhD., C. Psych.  
Director, Supportive Care  
Thunder Bay Regional Health Sciences Centre  
980 Oliver Road – Room 3133  
Thunder Bay, ON P7B 6V4

My office: 807-684-7305 (direct line)  
Supportive Care Toll Free: 877-696-7223 (ask the receptionist for my direct line)

**Appendix C: Letter to Participants**



Lakehead  
UNIVERSITY



December 30th, 2009

Dear Potential Participant,

**Thank you for your interest in the present research.**

My name is Liane Kandler and I am a psychology graduate student working with Dr. Scott Sellick in Supportive Care at the Thunder Bay Regional's Cancer Centre. I would like to tell you a bit more about the two parts of the research, so you can decide whether you would like to participate in the present questionnaire mailing, the upcoming online group to take place beginning February 15<sup>th</sup>, 2010, both parts, or, neither.

**Information on Part 1: Questionnaires**

The attached questionnaires ask about you, about your use of computers in daily life, about your support system, and about how you are feeling. We are trying to collect information to look at distress, whether young adult cancer patients (ages 18 to 44 years) feel they have access to enough supportive care services, and whether there is interest in online services.

The questionnaires will take approximately 30 minutes to complete. You may decline to answer questions with which you are not comfortable.

To say thank you for your help, those who complete and return the questionnaires will be entered into a draw to win one of four \$25 gift certificates for Chapter/Indigo which can be used online or in person. There are no additional benefits to participating.

**Information on Part 2: Online Group**

We invite you to participate in an online group for cancer patients and survivors in Northwestern Ontario. This is an opportunity to chat and connect with other patients, to share your experiences, and to access resources. There will also be opportunities to ask questions to various professionals, such as a dietitian, counsellor, or chaplain.

If you are interested in learning more, we have included a letter called "INFORMATION ABOUT ONLINE GROUP".

**If You Agree to Participate in Either Part of the Study:**

If you agree to complete part 1, the questionnaires, please fill out the questionnaires included here and send them back to us in the addressed and stamped envelope when you are done. We really appreciate your help!

If you think you might be interested in participating in the online group, please read the "INFORMATION ON THE ONLINE GROUP and fill out the "CONSENT FORM FOR ONLINE GROUP". You can send this back in the addressed and stamped envelope as well.

Questions?

Contact Liane  
Kandler  
Supportive Care

Tel: 807-684-7308  
Toll Free: 1-877-  
696-7223  
[kandlerl@tbh.net](mailto:kandlerl@tbh.net)

**Important Information for You:**

There is a risk that expressing yourself, sharing messages with others, or participating in chat groups may cause feelings of discomfort, distress, or sadness. If at any time you would like to speak, or meet with, one of our counsellors, please contact us at Supportive Care, at 807-684-7310 or toll-free at 1-877-696-7223 to schedule an appointment.

**You may choose to not participate or you may change your mind and withdraw at any time, and this will not affect your medical treatment or access to supportive care services. To withdraw, simply contact Supportive Care by telephone or email to indicate that you no longer wish to participate.**

All the information you provide will be recorded in a confidential way. The information will be kept for 7 years, as is required. Your name, or other identifying information, will not be revealed in any published materials. After the research and support group have been completed, the main findings will be outlined and e-mailed to all participants. If you participate but then choose to withdraw, information collected up until that point will be kept in the above manner.

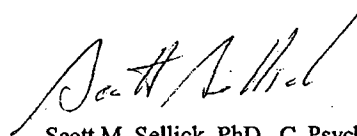
This project was reviewed by and received ethics clearance through the Office of Research Ethics at Lakehead University and the Thunder Bay Regional Health Sciences Centre Research Ethics Board. **The final decision to participate is yours.** If you have any questions about your rights as a research participant, you may contact Lakehead University's Research Ethics Board at 807-343-8283, or Heather Poulter, a member of Thunder Bay Regional Health Sciences Centre Research Ethics Team, at 807-684-6422.

If you have any questions or concerns about the research, please contact Liane Kandler, at 807-684-7308, or at [kandlerl@tbh.net](mailto:kandlerl@tbh.net), or Dr. Scott Sellick, at 807-684-7310.

Regards,



Liane S. Kandler BA (Hons.)  
MA Candidate (2010)



Scott M. Sellick, PhD., C. Psych.  
Director, Supportive Care

Appendix D: Demographic Questionnaire

PID: \_\_\_\_\_

Lakehead  
UNIVERSITY



**QUESTIONS ABOUT YOU**

---

Date of Birth: \_\_\_\_\_

Gender:  Male  Female

In regards to your religious views and spirituality, do these statements represent your beliefs?

I try to find comfort in my religious / spiritual beliefs ( Do not wish to answer)

1                      2                      3                      4                      5  
Never                      Sometimes                      Very Often

I pray or I am spiritual

1                      2                      3                      4                      5  
Never                      Sometimes                      Very Often

**QUESTIONS ABOUT YOUR COMPUTER USE**

---

Do you have a computer at home that you can use?  Yes  No

If YES...Is this computer yours alone, or shared with others?

Mine alone  Shared / family computer

Do you have internet access at home?  Yes  No

If YES...What type of internet access do you have?

High Speed / Cable  Dial-up / Slow connection

Other: \_\_\_\_\_

Are you currently working or attending school?  Yes  No

If YES, do you have internet access at work or school?  Yes  No

If YES...What type of internet access do you have?

High Speed / Cable  Dial-up / Slow connection

Other: \_\_\_\_\_

Questions?

Contact Liane Kandler  
Supportive Care

Tel: 807-684-7308  
Toll Free: 1-877-696-

7223  
kandlerl@tbh.net

In the interest of conserving paper, we've printed front & back- please don't forget to complete the back!

PID:

**In general, how comfortable are you with computer use (internet, typing, etc.)?**

1                      2                      3                      4                      5  
 Uncomfortable                      Comfortable                      Very Comfortable

**Most days, about how much time a day do you spend on the computer when you are at home?**

                                                                   
 No time most days    15 – 30 minutes                      30 – 60 minutes                      1 – 2 hours  
 2 – 3 hours                      3 – 4 hours                      4 – 5 hours                      5 plus hours  
                                                                 

**Most days, about how much time a day do you spend on a computer when you are at work / school?**

                                                                   
 No time most days    15 – 30 minutes                      30 – 60 minutes                      1 – 2 hours  
 2 – 3 hours                      3 – 4 hours                      4 – 5 hours                      5 plus hours  
                                                                 

**QUESTIONS ABOUT YOUR HEALTH CARE...**

**Where have you got information about your cancer diagnosis and treatment?**  
 (please check all that apply)

- Pamphlet / Brochure                       Internet                       Other cancer patients
- Family / Friends                       Nurses/staff                       Cancer Centre Doctors
- Family Doctor

Other: \_\_\_\_\_

**How interested are you in getting more information about cancer, treatment, effects, and related material?**

1                      2                      3                      4                      5  
 Not Interested                      Somewhat Interested                      Very Interested

PID:

**QUESTIONS ABOUT YOUR HEALTH EXPERIENCES...**

---

How satisfied are you with the medical treatment you received during your cancer treatment to date? ( Do not wish to answer)

1                      2                      3                      4                      5  
Not Satisfied                      Somewhat Satisfied                      Very Satisfied

How satisfied are you with your ability to have your medical and health questions answered by your doctor(s)? ( Do not wish to answer)

1                      2                      3                      4                      5  
Not Satisfied                      Somewhat Satisfied                      Very Satisfied

Did you know that the Thunder Bay Regional offers complementary supportive care services to patients and their families?

Yes                       No

Have you ever accessed these complementary supportive care services?

Yes                       No

If yes, how satisfied were you with the services you received?

1                      2                      3                      4                      5  
Not Satisfied                      Somewhat Satisfied                      Very Satisfied

Has a member of your immediate family ever accessed these services to address issues relating to your cancer diagnosis (not their own)?

Yes                       No

**QUESTIONS ABOUT YOUR ONLINE SUPPORT...**

---

Do you use any of the following networking sites? Please check all that apply...

Facebook                       Twitter                       Chat Rooms                       MySpace

Other \_\_\_\_\_ Other \_\_\_\_\_



**Appendix E: Berlin Social-Support Scale**



Date \_\_\_\_\_

PID \_\_\_\_\_

Please read each item and circle the response that best represents how you feel. Don't take too long with your replies: your immediate response will probably be more accurate.		Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
1	There are some people who truly like me.	1	2	3	4
2	Whenever I am not feeling well, other people show me that they are fond of me.	1	2	3	4
3	Whenever I am sad, there are people who cheer me up.	1	2	3	4
4	There is always someone there for me when I need comforting.	1	2	3	4
5	I know some people upon whom I can always rely.	1	2	3	4
6	When I am worried, there is someone who helps me.	1	2	3	4
7	There are people who offer me help when I need it.	1	2	3	4
8	When everything become too much for me to handle, other are there to help me.	1	2	3	4
9	When I am down, I need someone who boosts my spirits.	1	2	3	4
10	It is important for me always to have someone who listens to me.	1	2	3	4
11	Before making any important decisions, I absolutely need a second opinion.	1	2	3	4
12	I get along best without any outside help.	1	2	3	4
13	In critical situations, I prefer to ask others for their advice.	1	2	3	4
14	Whenever I am down, I look for someone to cheer me up again.	1	2	3	4
15	When I am worried, I reach out to someone to talk to.	1	2	3	4
16	If I do not know how to handle a situation, I ask others what they would do.	1	2	3	4
17	Whenever I need help, I ask for it.	1	2	3	4

PID \_\_\_\_\_

<p><b>For these questions, think about the person who is closest to you, such as your spouse, partner, child, friend, and so on. How did this person react to you during the past week?</b></p>		Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
18	This person showed me that he/she loves and accepts me.	1	2	3	4
19	This person was there when I needed him/her.	1	2	3	4
20	This person comforted me when I was feeling bad.	1	2	3	4
21	This person left me alone.	1	2	3	4
22	This person did not show much empathy for my situation.	1	2	3	4
23	This person complained about me.	1	2	3	4
24	This person took care of many things for me.	1	2	3	4
25	This person made me feel valued and important.	1	2	3	4
26	This person expressed concern about my condition.	1	2	3	4
27	This person assured me that I can rely completely on him/her.	1	2	3	4
28	This person helped me find something positive in my situation.	1	2	3	4
29	This person suggested activities that might distract me.	1	2	3	4
30	This person encouraged me not to give up.	1	2	3	4
31	This person took care of things I could not manage on my own.	1	2	3	4
32	In general, I am very satisfied with the way this person behaved.	1	2	3	4

Appendix F: Hospital Anxiety and Depression Scale

PID:

Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. Please complete this form and return it to reception.

*Tick only one box for each section*

**1. I feel tense or 'wound up':**

Most of the time .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A lot of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Time to time. Occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**8. I feel as if I am slowed down:**

Nearly all the time .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very often .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**2. I still enjoy the things I used to enjoy:**

Definitely as much .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only a little .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hardly at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**9. I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Quite often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Very often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**3. I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Yes, but not too badly .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
A little, but it doesn't worry me .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**10. I have lost interest in my appearance:**

Definitely .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't take so much care as I should .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I may not take quite as much care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
I take just as much care as ever .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**4. I can laugh and see the funny side of things:**

As much as I always could .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much now .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely not so much now .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**11. I feel restless as if I have to be on the move:**

Very much indeed .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quite a lot .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not very much .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**5. Worrying thoughts go through my mind:**

A great deal of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
A lot of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
From time to time but not too often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Only occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**12. I look forward with enjoyment to things:**

As much as I ever did .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather less than I used to .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely less than I used to .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hardly at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**6. I feel cheerful:**

Not at all .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Most of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**13. I get sudden feelings of panic:**

Very often indeed .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quite often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not very often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**7. I can sit at ease and feel relaxed:**

Definitely .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Usually .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**14. I can enjoy a good book or radio or TV programme:**

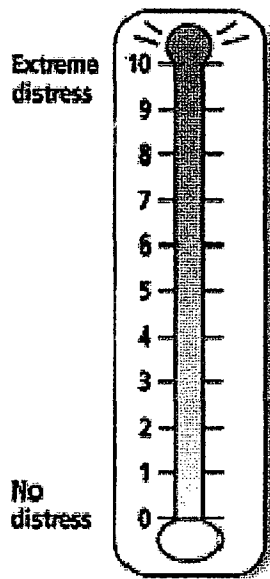
Often .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Very seldom .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Appendix G: Personal Well-being Checklist

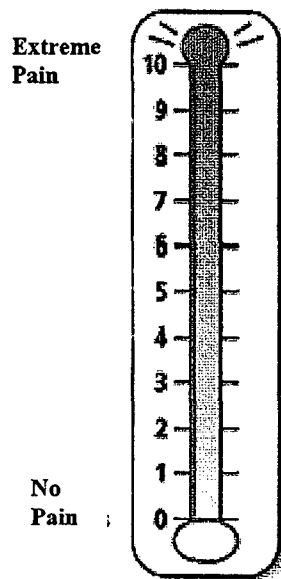
# Personal Well-being Checklist

PID:

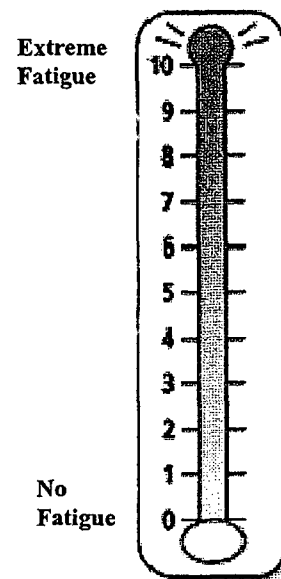
Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.



Please circle your WORST pain during the past week, with 10 being extreme pain, and 0 being no pain.



Please circle the number (0-10) that best describes how much fatigue you have been experiencing during the past week, including today.



Please put a check next to all problems that you now have, or expect to have in the future:

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Accommodation  | <input type="checkbox"/> Burden to others             | <input type="checkbox"/> Coping                     |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Worry about friends/ family  | <input type="checkbox"/> Making treatment decisions |
| <input type="checkbox"/> Parking        | <input type="checkbox"/> Talking with friends/ family | <input type="checkbox"/> Sexuality                  |
| <input type="checkbox"/> Drug Coverage  | <input type="checkbox"/> Talking with medical team    | <input type="checkbox"/> Spirituality               |
| <input type="checkbox"/> Work/School    | <input type="checkbox"/> Family Conflict              | <input type="checkbox"/> Sleep                      |
| <input type="checkbox"/> Finances       | <input type="checkbox"/> Changes in Appearance        |   |
| <input type="checkbox"/> Groceries      | <input type="checkbox"/> Alcohol/drugs/gambling       |   |
|   | <input type="checkbox"/> Smoking                      |   |

PID:

**Nutrition Questions (Please check off the box that corresponds with your answer)**

During the past month my weight has:

- Decreased
- Stayed the same
- Increased

As compared to my normal intake, I would rate my food intake during the past month as:

- Less than usual
- Unchanged
- More than usual

Listed below are a number of statements concerning feelings you may have experienced recently, or are currently experiencing. Please place an "X" in the box that best describes what you have experienced.

During the past week:	Not at all	A little bit	Moderately so	Quite a bit	Very much so
1. I have felt that my heart races and I tremble.					
2. I have felt that I cannot control anything.					
3. I have lost interest in things I usually cared for or enjoyed.					
4. I have felt nervous and shaky inside.					
5. I have felt tense and can't relax.					
6. My thoughts are repetitive and full of scary things.					
7. I have felt restless and find it difficult to sit still.					
8. I have recently thought about taking my life.					
9. In the past year, I have had 2 weeks or more during which I felt sad, blue, or depressed.					
10. I have had 2 years or more in my life when I felt depressed or sad most days even if I felt o.k. sometimes					

PID:

**DEMOGRAPHICS AND CANCER HISTORY**

**Select your primary cancer:**

- Lung
- Breast
- Prostate
- Head and Neck
- Testicular
- Brain
- Leukemia
- Gynaecological
- Skin
- Thyroid
- Lymphoma
- Gastrointestinal (including: colon, rectum, stomach, pancreas, bladder, kidney, liver)
- Not sure
- Other: \_\_\_\_\_
- Do not wish to answer

**Please check whether you have received any of the following treatments for cancer in the past month:**

- Surgery
- Chemotherapy
- Radiation Therapy
- Hormone Therapy
- Bone Marrow/Stem cell transplant
- I have received none of the above
- Do not wish to answer

**Marital Status:**

- Single
- Married
- Separated
- Divorced
- Widow/er
- Common-law
- Committed relationship
- Do not wish to answer

**Living Arrangements:**  Alone  Not alone  Do not wish to answer

**Education:**

- Elementary School (Grades 1-6)
- Middle School (Grades 7-9)
- High School (Grades 10-12)
- Community College
- Some University
- Completed University
- Postgraduate
- Do not wish to answer

**My Ethnicity is:**

- White/Caucasian
- Southeast Asian
- South Asian
- First Nation
- Metis
- Chinese
- Arab/Middle Eastern
- Black/African American
- Latin American/Hispanic
- Multiple Ethnicities
- Do not wish to answer



PID:

**Family Income:**

- Less than \$30 000       Less than \$50 000       Less than \$80 000  
 Less than \$100 000       More than \$100 000       Do not wish to answer

**Primary Source of Income:**

- Pension/Retirement (CPP)    Parents/Guardian       Employment       EI  
 Disability benefits       Partner/Spouse       Student financing  
 Social Assistance       Do not wish to answer       Other: \_\_\_\_\_

**Is English your first language?**       Yes       No

**For the following 4 questions please check off the box that corresponds with your answer.**

1. Before this survey, did you know there is a Supportive Care Centre at the Thunder Bay Regional Health Sciences Centre that can help you through counselling, group programs and financial needs?

- Yes  
 No

2. Have you ever used the services of the Supportive Care Centre such as counselling, support groups, smoking cessation, financial assistance and nutritional counselling in the past?

- Yes  
 No

3. Are you currently using the services of the Supportive Care Centre?

- Yes  
 No

4. Do you plan to use the services of the Supportive Care Centre in the future?

- Yes  
 No  
 Possibly

Appendix H: Edmonton Symptom Assessment System

Edmonton Symptom Assessment System:

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Appendix I: Canadian Problem Checklist

**Canadian Problem Checklist:**

Please check all of the following items that have been a concern or problem for you in the past week including today:

**Emotional:**

- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

**Practical:**

- Work/School
- Finances
- Getting to and from appointments
- Accommodation

**Informational:**

- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

**Spiritual:**

- Meaning/Purpose of life
- Faith

**Social/Family:**

- Feeling a burden to others
- Worry about family/friends
- Feeling alone

**Physical:**

- Concentration/Memory
- Sleep
- Weight

**Appendix J: Participant Letter Pertaining to the Online Group**

Lakehead  
UNIVERSITY



## INFORMATION ABOUT THE ONLINE GROUP

Thank you for your interest in this online group! The main goals of this group are to encourage communication among cancer patients and survivors and to serve as an information resource. Basically, we want to give Northwestern Ontario cancer patients and recovering patients a chance to chat with one another, hence why we're called care2talk. A significant portion of cancer patients also experience distress, which is why we are hoping to provide services, connect you with others, and generally help to meet supportive care needs. By doing this online and 24/7, we aim to provide access to all of Northwestern Ontario, and to ensure that you can access services at a time that is convenient for you. We also plan to collect questionnaire information about your supportive care needs so that we can do our best to assist you in meeting them.

You can check out the main page at [www.care2talk.ca](http://www.care2talk.ca)

The online group will be open for a 10 week period beginning February 15<sup>th</sup>, 2010, with the hopes of becoming a permanent resource if there is enough interest.

Here is an outline of the topics we will cover in the 10 weeks:

1. Introduction session: setting yourself up & getting to know the website.
2. Getting to know each other: Share your experiences to help others learn from you, or you from them. By inviting both cancer patients and cancer survivors to participate, we are hoping that you can help each other and share your experiences.
3. Consult with a nutritionist / dietitian: Do you have questions about your diet? Want tips to meet your nutrition needs?
4. Consult such a social worker about helpful programs and resources to ease your journey through the medical system, or to address health or drug coverage questions.
5. Consult with a sex counsellor about how your sexual health and the potential impacts of treatment.
6. Consult with a spiritual care worker about spiritual resources and beliefs.
7. Share your experiences with the medical system, both positive and negative; what change would you like to see?
8. Your reactions and experiences with family and friends.
9. Thinking back – the best and the worst of times.
10. Closing remarks – a chance to think about the group, what worked and didn't, and what you would like to see in the future.

### Questions?

Contact Liane Kandler  
Supportive Care

Tel: 807-684-7308  
Toll Free: 1-877-696-  
7223

[kandlerl@tbh.net](mailto:kandlerl@tbh.net)

To accompany the topics, we have prepared information to be posted online. Participants will have the chance to either chat online with peers and professionals, and to post questions or comments to the message board. Discussion questions will also be posted on a weekly basis.

From time to time, you will be presented with a notice indicating that there is a short survey we would like you to fill out online, asking about you, how you are doing, and your opinions. If you agree, these can also be sent to your personal email if that is

easier for you. For each questionnaire completed, participants will be entered into a draw to win one of four \$50.00 gift certificates from Chapters / Indigo, which can be used to order online or in person. There are no additional benefits to participating.

We will be keeping track of certain information, such as the amount of time participants spend online, how often they log on, and the content of messages. This information is to help us evaluate how useful the website is, will be kept confidential, and will not be associated with your personal identifying information.

If you agree to participate, we will contact you to provide you with the necessary information to access all parts of the website. For now, access to the website will be password protected to make sure that only patients in Northwestern Ontario have access. After you register online, it will be up to you to decide how often you would like to log on, and how much you would like to participate. If you choose to complete the questionnaires we send from time to time, these will likely approximately take 10-15 minutes every 2 weeks.

Again, you may choose to not participate or you may change your mind and withdraw at any time, and this will not affect your medical treatment or access to supportive care services.

All the information you provide will be recorded in a confidential way. The information will be kept for 7 years, as is recommended. Your name, or other identifying information, will not be revealed in any published materials.

This project was reviewed by and received ethics clearance through the Office of Research Ethics at Lakehead University and the Thunder Bay Regional Health Sciences Centre Research Ethics Board. **The final decision to participate is yours.** If you have any questions about your rights as a research participant, you may contact Lakehead University's Research Ethics Board at 807-343-8283, or Heather Poulter, a member of Thunder Bay Regional Health Sciences Centre Research Ethics Team, at 807-684-6422.

If you have any questions about the website, you can contact Liane Kandler, Supportive Care, at 807-684-7308 or toll free at 1-877-696-7223, by email at [kandlerl@tbh.net](mailto:kandlerl@tbh.net) You can also reach Dr. Scott Sellick, Director of the Supportive Care Program at the Thunder Bay Regional, at the toll free number as well.

Thank you!



Liane S. Kandler, BA (Hons.)  
MA Candidate (2010)



Scott M. Sellick, PhD., C. Psych.  
Director, Supportive Care



Appendix K: Consent form for Online Group

Lakehead  
UNIVERSITY



CONSENT FORM FOR ONLINE GROUP

I, \_\_\_\_\_ (your name), agree to be contacted so I can participate in the online group for young adult cancer patients and survivors.

I know that although this is a two part study, I may choose to participate in either, both, or neither parts. I know that the online group will not begin until February 15<sup>th</sup>, 2010.

I have read and understand the information on the study that was provided, and I understand and agree to the following:

- To be contacted by a researcher who will provide me with the information I need to access the online group
- To access the group as often as I am comfortable with
- That I will be asked to fill out questionnaires from time to time, about myself, how I am doing, and about my opinions on the website

I know that I am a volunteer and can withdraw at any time, without penalty, and without any impact on my medical care or access to supportive care services. To withdraw, I would contact Supportive Care by telephone or email and indicate that I no longer wish to participate.

I understand that all communication on the website will be monitored, but that my name or identifying information will not be associated with it. I understand that the data will be stored securely at the Thunder Bay Regional for 7 years and that I will remain anonymous in any publications or presentations of research findings. If I choose to withdraw, I know that data up to the point of withdrawal will be used for research purposes. I will be mailed or e-mailed a summary of the research when it is complete.

I know that the goal of this website is to connect patients, to help decrease distress, and to assess provision of services. I know that outside of these potential effects and the chance prize draws for Chapers/Indigo, there will be no direct benefit to me for participating.

I know that there is no apparent physical danger or harm, but that it may be emotionally difficult to talk about certain things. If ever I am too overwhelmed and need to talk to someone I know that I can contact Supportive Care.  
Supportive Care: 807-684-7310 or toll free at 1-877-696-7223

Questions?

Contact Liane Kandler  
Supportive Care

Tel: 807-684-7308  
Toll Free: 1-877-696-7223  
kandlerl@tbh.net

\_\_\_\_\_  
Name (please print)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Telephone number where I can be reached

\_\_\_\_\_  
Email address where I can be reached

**If you do NOT agree to participate, please fill in your name, check the NO circle below, and return this form in the addressed and stamped envelope.**

No, I do not want to participate in the online group.

**Appendix L: Schedule of Questionnaire Administration**

Study Week	Questionnaires Administered
1	
2	<ul style="list-style-type: none"> <li>a. Distress Battery: HADS, PWC, ESAS, Canadian Problem Checklist</li> <li>b. BSSS</li> <li>c. Qualitative Questions</li> </ul>
3	
4	
5	
6	<ul style="list-style-type: none"> <li>a. Distress Battery: HADS, PWC, ESAS, Canadian Problem Checklist</li> <li>b. BSSS</li> </ul>
7	
8	
9	
10	<ul style="list-style-type: none"> <li>a. Distress Battery: HADS, PWC, ESAS, Canadian Problem Checklist</li> <li>b. BSSS</li> <li>c. Post-Study Qualitative Questionnaire</li> </ul>

Appendix M: Qualitative Questions

Qualitative Questions

**QUESTIONS ABOUT YOUR PARTICIPATION**

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**These questions are just to give us an idea about why you agreed to participate, and your thoughts about participating. We are really interested in hearing what you think, in your own words, so please share your thoughts with us!**

Why did you agree to participate in this study?

Are you hoping to benefit? How?

How involved in the online group do you think you will be?

How often do you plan on going to the website?

1	2	3	4	5
Rarely		Sometimes		Very Often

Are there any barriers or difficulties that might make participating difficult for you, such as limited access to a computer, a busy schedule, or something else?

Any comments you would like to share?

Appendix N: Post-study Qualitative Questions

Post-Study Qualitative Questions

**QUESTIONS ABOUT YOUR PARTICIPATION**

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**These questions are just to give us an idea about what you liked or disliked about this study and website, and how we could improve it. We really appreciate your feedback!**

Did you enjoy participating in this study? Why or why not?

Have you ever participated in another online support group?

IF YES, How did this online group compare? Better? Worse?

If we could offer this website as a permanent place to get information and chat with peers and professionals, would you continue to participate? Why or why not?

Any suggestions on how we could improve the website, and the online experience for you?

What did you enjoy the most? Why?

What helped you the most? Why?

What did you enjoy the least? Why?

Any other comments you would like to share?



**Appendix O: Website Specifications**

## 1. Project Overview – care2talk: A Website for Young Adults with Cancer

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### *What is our goal?*

It is our vision to produce an interactive website for young cancer patient (aged 18-44) in Northwestern Ontario. The website will feature “social networking” experiences for the user such as asynchronous messaging or “Mailboxes” and real-time chat components that will foster positive and safe communications between cancer patients who need a support network. The website will also house a list of resources and news-like documents that will inform the community of new and exciting opportunities for patients with cancer.

Security will drive most of the decisions made throughout the development process to ensure that users feel completely confident using this system as an alternative social/support network. These ends are described in section 3 of this document.

### *Will the site be simple to use?*

It is our intent to ensure that the user's experience will be comfortable. This philosophy extends beyond the end user; it will also include the people in charge of content creation. Through the implementation of WordPress, a free content management system, we will discover how easy and timely web publishing can be.

## 2. Technologies

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### *What experiences can the user enjoy?*

The system will support the following technologies:

- ❖ Real-time chat
- ❖ Mailboxes
- ❖ Blogging / Forums
- ❖ Online Status for currently connected users.
- ❖ A contact form that will email the stakeholders with users' requests.
- ❖ Weekly topics hosted in a blog format.
- ❖ Information pages describing the project and other critical topics.
- ❖ A resource pool of outbound hyperlinks.
- ❖ Disclaimer / Privacy policy page.
- ❖ A back-end administration website for content creators and managers.
- ❖ An email system that will send updates to all stakeholders when posts are made on blog pages and/or when users log into the chat room.
- ❖ Image gallery and video streaming from popular media providers such as YouTube.

*What is the specific technology in use?*

Since the advent of on-line systems, most developers have had to create custom Internet applications for clients. In recent history, web developers have agreed to put their skills together to produce free "Open-Source" technologies that remove the need to reinvent the core tools every time a new site is designed. Some of these pioneers have spent over 6 years developing one of the most robust, user-friendly and secure web solutions called "WordPress".

WordPress is a Content Management System, or CMS. It can be best described as two websites, one for the public to consume (the front-end) and a private website (the back-end) for content creators and managers to rapidly publish and manage all of the sites textual and visual assets. There are now 250 programmers worldwide who are working on WordPress and extensions to it, called plug-ins. These plug-ins extend the core framework to perform innovative tasks such as live chat and video streaming.

In order for the WordPress solution to be realized by your organization, we intend to do a soft-launch of the system in a private space so you may assess for yourselves the usability and security of the website.

Please visit [www.wordpress.org](http://www.wordpress.org) to learn more about the wide variety of organizations currently using the system.

*What does the care2talk technology landscape include?*

## Server Technologies:

- ❖ Linux operating system
- ❖ Apache web server
- ❖ MySQL database server
- ❖ PHP server side scripting engine

## Software Technologies:

- ❖ WordPress core CMS.
- ❖ "Live Chat" plug-in: extends WordPress to include real-time dialogue.
- ❖ "Online Status" plug-in: shows who is currently logged into the website.
- ❖ "Contact form" plug-in: allows instant messaging to email from the website.
- ❖ "Group Management" plug-in: hides and shows sections of the site to people with different access requirements.
- ❖ "File Management" plug-in: manages and organizes related files like PDFs, Word files and images.

### 3. Security

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#### *Are these technologies secure?*

The WordPress system is built on three pervasive web technologies: Apache, PHP and MySQL. Apache is an Open Source Web server that was originally designed to operate on Unix systems. Unix and its Open Source relative Linux are both operating systems that are used on over 50% of Internet Web Servers today. These two environments are considered to be the most secure of all web server technologies when configured with top security in mind. It is the intent of this author to utilize the power of these operating systems to ensure that no data be lost and that user information be managed in a safe manner. No individuals with ill-intent will be able to access sensitive information.

MySQL is the open source database server system that houses all information for the WordPress environment. It supports all of the functionality commonly expected from other highly priced databases, including the opportunity to encrypt any or all data in the system. Out of the box, WordPress uses MD5 encryption to ensure that even the most astute hacker attempting to steal datum will only obtain passwords that are encrypted. This method cripples the attempt of the data miner who wishes to use the information to break into the system.

PHP is another open source technology that is required to run the WordPress software. PHP is a programming language and server technology used in conjunction with Apache to render all systemic logic (code) as meaningful webpage output to the viewer. Since the WordPress PHP code is housed on the server in a safe and secure manner, the logic is kept safe from prying eyes.

To ensure that these 3 technologies are "locked down" in the safest ways, it is the opinion of this author that the care2talk system be hosted by a third party provider such as GoDaddy, 1&1, or Host Papa. These affordable solutions are managed by some of the industry's top security specialists and all offer the flexibility to create the most secure environments for the software.

#### *To What Extent can the privacy of participants be guaranteed?*

Managing user information is a sophisticated and often misunderstood process. The popular misconception is that technology alone can protect sensitive information. Hackers and data miners will, if so inclined, break into any system. Knowing this, there is no need to create complicated security measures, but instead only capture data that is absolutely required and destroy the rest. For instance, it is unnecessary to store a credit card number in a database when that information can be destroyed after an ecommerce transaction occurs.

In the case of care2talk we will define what datum is critical to store on the server, assess what information can be deleted and avoid storing any sensitive information from the outset. This approach will become clear during the “User Needs Assessment” phase of the project.

Some early ideas that will help to keep the user safe include:

- ❖ Only storing custom user names and not using full names. Full names can be stored in an offline data file on a system managed by the care2talk team, so relation can be made between a user nickname and a real identity.
- ❖ Chat conversations can be encrypted through SSL (secure socket layer) at the moment of creation. The resulting data files remain encrypted on the server for later review.
- ❖ Internal messaging or mail can be encrypted as well to ensure that no one attempting to illegally access the database could read the contents.

**4. Timelines**

As mentioned earlier in this proposal, it is our intent to provide access to the system as early as September 15<sup>th</sup> to provide your security specialists with a functional testing platform. We call this preview the “soft-launch”.

Work Description	September	October	November	December	January
Soft-Launch					
Needs Assessment					
Programming					
Testing					
Training					
Public-Launch					
Re-Testing					
Project Completion					

Please do understand that timelines may shift based on client availability or unforeseen issues with vendors.

**5. Budget**

This proposal is focused on saving as much financial resource as possible. The technologies described in section 2 are Open Source, meaning that a vendor cannot charge for the software itself, but can only sell services relating to the implementation of the software. The following spreadsheet shows a breakdown of the hard and soft costs associated with the implementation of this website.

**NOTE:** This budget is broken down into ongoing costs and upfront costs. The ongoing costs will not be a recursive fee owing to Kevin Element, but rather with the vendors that offer the solutions. This puts the client in control over the company they choose to host with and how much they are willing to pay for these services.

Most importantly, this approach removes my organization from any ongoing work after the sunset of this project.

Ongoing costs:

Description of Service	Rate (per annum)
Secure Web Hosting	90.00
Domain Registration	Free (if using Host Papa)
SSL (Secure Socket Layer)	Free (if using Host Papa)
<b>TOTAL</b>	<b>90.00</b>

(Note: pricing represents the current cost at HostPapa. Pricing may change)

Upfront costs:

Description of Service	Time (hours)	Hourly Rate	Rate (one time)
Soft Launch Implementation	4	40.00	160.00
Graphic Design	12	25.00	300.00
Integration	4	40.00	160.00
Programming	8	40.00	320.00
Testing	8	25.00	200.00
Training	4	25.00	100.00
Public Launch	4	40.00	160.00
Re-Testing	4	25.00	100.00
<b>TOTAL</b>			<b>1500.00</b>

(Note: Kevin Element's fees are reduced for this project)

## 6. Conclusion

It is with great pleasure that I offer this quotation. After meeting with Liane, I feel very comfortable that the requirements have been considered and that the expectations are realistic. It is my intent as a small local business to focus my energies on projects that serve the greater social good. Therefore, I am very excited to work with your team to create what will become a positive space for young adults needing support.

Appendix P: TBRHSC Ethics Approval



Thunder Bay Regional Health Sciences Centre  
Research Ethics Board  
Level 1 ~ Rm 1534

980 Oliver Road, Thunder Bay, ON, Canada P7B 6V4  
Tel.: (807) 684-6422 Fax: (807) 684-5904

December 14, 2009

Ms. Liane Kandler  
980 Oliver Road Room 3132  
Regional Cancer Program-Supportive Care  
Thunder Bay Regional Health Sciences Centre  
Thunder Bay, ON P7B 6V4

Dear Ms. Kandler:

**Re: REB # 2009128**  
**Project: Do you care2talk? Examining an online approach to psychosocial support for young adults living with cancer**

The Thunder Bay Regional Health Sciences Centre Research Ethics Board (TBRHSC REB) conducted a full board review of the research study referenced above on October 26, 2009. The views of the TBRHSC REB have been documented and resolved. The following documents have been received, reviewed, and approved:

- TBRHSC REB application FORM A dated October 5, 2009.
- Research Protocol including all appendices (version 1)
- Information letter and consent form revised & dated December 14, 2009

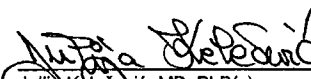
Quorum for approval was free from conflict and did not involve any member associated with this project.

The TBRHSC REB approval is granted for one year from the date of your last presentation to the full Board; your approval expires on November 23, 2010. REB approval is required should your project extend beyond this approval period.

Please ensure you are aware of your responsibilities for continuing ethics review. During the course of your research, any serious adverse events, changes in the approved protocol, consent form or other information needs to be reported to the REB using the appropriate forms. Upon completion/termination of the study you are required to submit a Study Completion Report.

All forms are available at [http://www.tbrhsc.net/about\\_TBRHSC/research\\_ethics/forms.asp](http://www.tbrhsc.net/about_TBRHSC/research_ethics/forms.asp)

Yours Sincerely,

  
Julija Kelecevic, MD, PhD(c)  
Chair, TBRHSC REB



TBRHSC REB is guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Subjects & ICH: Good Clinical Practice (GCP) guidelines.



Appendix Q: Lakehead University Ethics Approval

# Lakehead

UNIVERSITY

Office of Research

Tel (807) 343-8283

Fax (807) 346-7749

December 2, 2009

**Principal Investigator:** Dr. Scott M. Sellick  
**Co-Investigator:** John Jamieson  
**Student Investigator:** Liane S. Kandler  
Psychology  
Lakehead University  
955 Oliver Road  
Thunder Bay, ON P7B 5E1

Dear Researchers:

**Re: REB Project #: 013 09-10**  
**Granting Agency name: N/A**  
**Granting Agency Project #: N/A**

On behalf of the Research Ethics Board, I am pleased to grant ethical approval to your research project entitled, "Do you care2talk? Examining an online approach to psychosocial care for young adults living with cancer".

Ethics approval is valid until **December 2, 2010**. Please submit a Request for Renewal form to the Office of Research by November 2, 2010 if your research involving human subjects will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Research Ethics Board forms are available at:

[http://research.lakeheadu.ca/ethics\\_resources.html](http://research.lakeheadu.ca/ethics_resources.html)

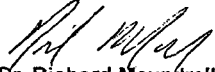
During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Completed reports and correspondence may be directed to:

Research Ethics Board  
c/o Office of Research  
Lakehead University  
955 Oliver Road  
Thunder Bay, ON P7B 5E1  
Fax: (807) 346-7749

Best wishes for a successful research project.

Sincerely,



**Dr. Richard Maundrell**  
Chair, Research Ethics Board

/scw

cc: Office of Research  
Office of Graduate Studies