# THE CURRENT AND POTENTIAL ROLES FOR NUTRITION EDUCATION IN CANCER SUPPORT GROUPS IN SASKATOON

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# ABSTRACT

The purpose of this study was to identify and describe the role of nutrition education in support groups for people with cancer. Four research questions guided the research study; 1) What factors, if any, do facilitators observe that affect the nutritional status of the cancer patient? 2) What, if any, nutrition education, either formal or informal, currently takes place in cancer support groups in Saskatoon? 3) What factors do facilitators see as enhancing or detracting from nutrition education, either formal or informal, in cancer support groups in Saskatoon? 4) What role may the facilitators of the support programs for cancer patients identify for nutrition education, either formal or informal, within their groups? Using qualitative methodology in the form of interview inquiry, in – depth personal interviews were conducted with fourteen facilitators of cancer support groups. Cancer impacted their lives and the lives of their group members both physically and emotionally. Social support groups were considered beneficial in improving health and well being. However, support groups varied in organization and function. The functioning of the group was affected by group dynamics, individual characteristics of the group members, attendance issues, and the type of facilitator in the group. Nutrition education occurs both formally and informally in the groups. Formal nutrition education usually occurs in the format of a presentation by a nutrition professional on a topic of interest to the groups. Informal nutrition education occurs in the form of a group member raising a nutrition related concern, and other group members providing advice on how they dealt with that concern. There is potential for nutrition education in support groups for people with cancer. Barriers to further nutrition education in the support groups included the drop-in nature of the groups, the competing priorities of the group members, the timing of nutrition education, the availability of resources, and the characteristics of group members and facilitators. Enhancers of nutrition education included the format, importance and timeliness of nutrition education in the group. Several recommendations can be made for organizations with support groups and nutrition educators in order to enhance nutrition education.

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# Chapter 1 - Introduction

## 1.1 Introduction

Recent developments in the diagnosis and treatment of cancer have rendered it a more chronic disease with associated morbidity than an acute one (Smigel, 1995). Therefore, people with cancer must learn to integrate the disease, and all of its ramifications, into all aspects of their lives. One such aspect is a person's dietary habits.

Cancer is related to nutrition in several ways. First, diet may have substantial links to the development of cancer, such as a low intake of fruits and vegetables contributing to colon cancer (Voorrips, Goldbohm, van Poppel, Sturmans, Hermus, & van den Brandt, 2000), and a high intake of fat contributing to breast cancer (Kesteloot, Sasaki, Verbeke, & Joossens, 1994). Second, nutrition and diet are affected by the treatments for cancer. For example, chemotherapy is often accompanied by side effects such as nausea, vomiting, stomatitis, diarrhea, and weight gain, all of which may impact a patient's eating behavior (Shapiro & Recht, 2001). Third, cancer patients often make dietary changes after diagnosis and treatment in order to lessen the chance of disease recurrence (Salminen, Lagstrom, Heikkila, & Salminen, 2000). These issues suggest the need for nutrition education for cancer patients.

Support groups often address the issues that are important to people with cancer, such as treatment options, side effects, and fears (Heiney & Wells, 1989). These types of programs typically provide both information and emotional support for the people who attend the groups

(Everett, Martin, & Moore, 1995). The availability of information that helps improve the quality of life for people with cancer is important. Participation in support groups is known to increase quality of life in many general ways. Support groups may be one setting in which to offer nutrition education to people with cancer.

Nutrition education for people with cancer has been shown to be effective, however, very little has been written on the nutrition education that takes place in support groups for people with cancer. Nutrition education may have a role in a support group for people with cancer for two reasons. First, education of any kind is a vital part of a support group (Harris, 1988; Rootes & Aanes, 1992; Wilson, 1992). Second, social support is also vital in making behaviour change, since knowledge alone doesn't lead to behaviour change (Chapman, Toma, Tuveson, & Jacob, 1997; Sorensen, Stoddard, & Macario, 1998).

In order to provide effective nutrition education for people with cancer who participate in support groups, nutrition educators, group organizers, and group facilitators must have a good understanding of the current nature of nutrition education in the support groups.

## 1.2 Study Purpose

The purpose of this study was to identify and describe current formal and informal nutrition education takes place in support groups for people with cancer, and to examine the potential role for incorporating formal and informal nutrition education into these groups.

## 1.3 Research Questions

1. What factors, if any, do facilitators of cancer support groups observe that affect the nutritional status of people with cancer?
2. What, if any, nutrition education, either formal or informal, currently takes place in cancer support groups in Saskatoon?
3. What factors do facilitators see as enhancing or detracting from nutrition education, either formal or informal, in cancer support groups in Saskatoon?
4. What role may the facilitators of the support groups for cancer patients identify for nutrition education, either formal or informal, within their cancer support groups?

## 1.4 Definitions

The concepts of social support, support group, facilitator, nutrition education, and what constitutes formal and informal nutrition education for the purposes of this study are outlined below.

### Social Support

"An interpersonal transaction involving one or more of the following: emotional concern, instrumental aid, information, or appraisal that can come from a spouse or partner, from children or other family members, from friends or professional caregivers, from social or community ties, or from a social support group" (Taylor, Falke, Shoptaw, & Lichtman, 1986, p. 608).

### Support Group

Any form of group that brings people together whose aim is to solve and seek support for a personal problem (Lavoie & Stewart, 1995). For the purposes of this research, support groups were those groups whose aim was to solve and seek support for the problems related to having cancer.

### Facilitator

Group facilitators were identified by each of the organizations. Facilitators were people who were identified by the group as the leaders of the group.

### Nutrition Education

Any set of learning experiences designed to facilitate the voluntary adoption of eating and other nutrition related behaviors conducive to health and well being (Shafer, Gillespie, Wilkins, & Borra, 1996).

### Formal Nutrition Education

For the purposes of this research, formal nutrition education was defined as any nutrition education that was formally organized for the benefit of the support group, such as a guest speaker on a nutrition topic.

### Informal Nutrition Education

Informal nutrition education was defined as the sharing of information about nutrition related topics that is not part of a formal nutrition education program, such as one group member seeking information from other group members about a nutrition issue.

## 1.5 Summary

Nutrition plays a substantial role in both the development and the treatment of cancer. People with cancer need accurate and pertinent nutrition information. One place people with cancer may seek nutrition information is through a support group. Support groups may call on nutrition educators to present nutrition information to group members. The aim of this research is to identify and describe the current and future roles of nutrition education in support groups for people with cancer.

# Chapter 2 - Literature Review

## 2.1 Introduction

This review will begin with a short overview on cancer and nutrition before examining the issues surrounding social support, support groups, and support groups for people with cancer. The discussion then proceeds to examine the current relationship between nutrition education and cancer, including the potential for nutrition education in support groups for cancer patients, as well as several models and theories of change on which a nutrition education program for cancer patients in support groups could be based.

## 2.2 Cancer and Nutrition

### 2.2.1 Etiology of Cancer

Cancer occurs when the cells of the body do not respond normally to growth control mechanisms (Zeman, 1991). Cancer can affect most systems of the body, either directly through cancer growth, or indirectly through metastases, obstruction, or atrophy of adjacent tissues. The patient is alerted to the malignant process by the onset of symptoms (Cleary & Carbone, 1997; Pugliano, et al., 1999). For example, fatigue is reported by up to 90% of cancer patients (Berger & Farr, 1999; Owen, Parker, & McGuire, 1999).

### 2.2.2 Diet and Cancer

There are several strong links between diet and the development of cancer (Armstrong & Doll, 1975). A high intake of dietary fat has been linked to several types of cancer (Carroll, Gammal, & Plunkett, 1973; Kesteloot, et al., 1994), and a high fibre diet has been shown to reduce the risk of developing cancer, specifically intestinal cancers (Voorrips, et al., 2000; Weisburger, et al., 1993).

A person's nutritional status can be affected by cancer before and after the diagnosis of the disease (Kelly, 1986). The major symptom complex associated with cancer is cachexia, which includes anorexia, tissue wasting, apathy, impaired function, electrolyte imbalance and decreased resistance to infection (DeWys, 1977; Warnold, Lundholm, & Schersten, 1978). While decreased food intake is a common symptom of a cancer patient, it does not account for the dramatic weight loss usually seen (Cravo, Gloria, & Claro, 2000). In the cancer patient there is altered metabolic states as the tumour and the person compete for the nutrients that are consumed (Buzby, et al., 1980).

There are three main types of medical treatments for cancer: surgery, radiation, and chemotherapy, and each treatment option can have nutritional consequences (Copeland, Daly, & Dudrick, 1977; Costa & Donaldson, 1979; Yen, 1999). Surgery may result in a direct impairment on food intake, as in head, neck, and intestinal cancers, or the effects of surgery may affect intake, as in decreased appetite or increased protein needs (Costa & Donaldson, 1979). Radiation can cause anorexia, nausea, and vomiting, as well as localized effects such as changes in taste and smell for head and neck cancers to changes in intestinal villi in intestinal cancers (Parker & Withers, 1995). Drugs used in chemotherapy treatment have severe side effects on the nutritional status of the person with cancer. Side effects that can influence nutritional status include nausea, vomiting, fatigue, infections, and weight gain (Beisecker et al., 1997; Demark - Wahnefried et al., 1997; Haskell, 1995; Ovesen, Allingstrup, Hannibal, Mortensen, & Hansen, 1993).

## 2.3 The Role of Social Support in Health

### 2.3.1 Definitions of Health

The contribution of social support to health traces back to early definitions of health. In 1948, the World Health Organization defined health as "a state of complete physical, mental, and social wellbeing, and not merely the absence of disease and infirmity" (World Health Organization Website, 2002).

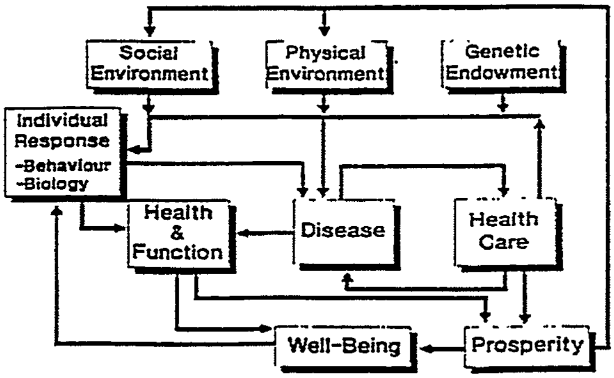
In 1996, the Saskatchewan Provincial Health Council defined health as "a dynamic process involving the harmony of physical, mental, emotional, social, and spiritual well-being. Health enables individuals, families, and communities to function to the best of their ability within their environment" (Bailey, 1996, p. 1). Social support is critical to promoting harmony, and allows people to function to the best of their ability.

### 2.3.2 Determinants of Health

Health researchers have suggested that there are certain factors that help to determine the health of both individuals and populations. These factors encompass physical, environmental, social, spiritual, and political aspects of health, and are referred to as the determinants of health.

Evans and Stoddart (1990) conceptualized a framework for the interaction between the various determinants of health. Factors that help to determine health include the physical and social environments, the genetic endowment of the individual, the biologic and behavioural responses of the individual, diseases, and the health care system. The possible interactions between the various determinants are shown in Figure 1.

**FIGURE I: Conceptual Framework for Patterns of Determinants of Health**



Source: Robert G. Evans and Gregory L. Stoddart, Producing Health, Consuming Health Care. *Social Science and Medicine*, 31, 12, 1990: 1352.

Figure 1. Conceptual Framework for Patterns of Determinants of Health.

Interactions between the environments and each individual, in conjunction with diseases that are present in the population, determine the health and function of the population. The health and function of the population can then influence the well being and prosperity of the population, and a well and prosperous population can then effect change on the physical environment, the social environment, and the responses of individuals. The framework suggests that interventions designed to improve health can be effective when aimed at any of the determinants, not just change at the individual level. For example, an intervention implemented in a social setting may still impact on the behaviours of individuals in the setting. This, in turn, may impact on the health and function of the population, which may foster an increased sense of well being. Frank (1995) echoes these thoughts, highlighting that a person's "immediate social and economic environment and the way that this environment interacts with his or her psychological resources and coping skills may influence the determination of health status" (p. 35) much more than was earlier thought.

The availability of social support is one aspect of an individual's social environment, and an individual's social environment can be a determinant of health, thus health and social support are intertwined. Labonte (1993), in his framework for health promotion, outlines the experience of health (See Figure 2). He maintains that health includes such qualities as being loved, being in control, being stress free, being able to do enjoyable things, and experiencing happiness.

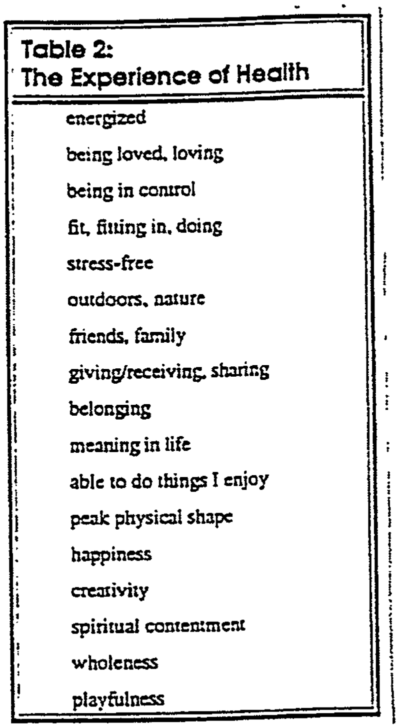


**Table 2:**
**The Experience of Health**

energized
being loved, loving
being in control
fit, fitting in, doing
stress-free
outdoors, nature
friends, family
giving/receiving, sharing
belonging
meaning in life
able to do things I enjoy
peak physical shape
happiness
creativity
spiritual contentment
wholeness
playfulness

Figure 2. The experience of health.

Various parts of the descriptive experience of health are similar to aspects of social support, in that individuals seek social support to feel an emotional connection with others, relieve stress, and increase feelings of control by increasing knowledge and learning of the experiences of others in similar situations. Social support is an influencing factor in the dimensions of health and wellbeing. This view is supported by Stevenson and Coles (1993) who contend that support groups function in the belief that many of our physical and mental health needs go beyond the bounds of traditional health care.

## 2.4 Social Support

### 2.4.1 Definitions of Social Support

Although there are many types of support available, the interest for this research is in the arena of social support. Lavoie and Stewart (1995) define social support as a process wherein people who share common experiences, situations, or problems can offer each other a unique perspective that is not available from those who have not shared those experiences.

Social support has also been defined as "an interpersonal transaction involving one or more of the following - emotional concern, instrumental aid, information, or appraisal, and can come from a spouse or partner, from children or other family members, from friends or professional caregivers, from social or community ties, or from a social support group" (Taylor et al., 1986; p. 608).

Other researchers define social support as those social interactions or relationships that provide individuals with actual assistance or embed individuals within a social system believed to provide love, caring, or a sense of attachment to a valued group or dyad (Fine, Hammett, Sernick, & Steinhouse, 1995; Norris, Davey, Davey, & Weiler 1995). Social support networks can be either formal or informal in nature (Guidry, Aday, Zhang, & Winn, 1997). Guidry et al. (1997) define formal social support networks as "relationships that are agency based, such as hospital and community sponsored social support programs" (p. 241) and informal social support networks as relationships with family and friends.

Social support has also been defined according to the type of support obtained. Received support is the naturally occurring helping behaviours that are provided whereas perceived support is the belief that such helping behaviours would be provided when needed (Norris & Kaniasty, 1996).

### 2.4.2 Support Groups

Many people seek social support from support groups. The term support group is most commonly used by the general public to describe any form of group that brings people together whose aim is to solve and seek support for a personal problem (Lavoie & Stewart, 1995). It is used universally to describe the work of self help groups, mutual aid groups, and support groups. These three types of groups are built on many of the same guiding principles, but there are subtle differences (Constantino & Nelson, 1995; Everett, Martin, & Moore, 1995; Heiney & Wells, 1989). For example, self help and mutual aid groups tend to focus more on a single issue, and their goal is to increase the personal growth of the members, whereas support groups may have to deal with several issues that arise from the common problem, and increased personal growth is a bonus (Rootes & Aanes, 1992). For the purposes of this research, support group is the term that will be used.

#### 2.4.2.1 Benefits of Support Groups

The benefits of support groups for people who share common stresses are widely publicized and are seldom questioned. Both literature and popular media frequently report the relief, reassurance, practical information, guidance, and enhanced coping skills that members of support groups gain as they share experiences (Galinsky & Schopler, 1994). According to Norris and Kaniasty (1996) the general idea behind support groups is that coping can be facilitated through interaction with like minded individuals, and support, information, and tangible help can be exchanged among those with shared experiences. Everett et al. (1995) maintain that one of the reasons that support groups are so successful is the immense sense of relief people experience when they discover that they are not alone.

In his discussion of mutual aid groups, Farquharson (1990) identifies a benefit common to both mutual aid groups and support groups. This is the usefulness of groups, in that they are based on the experiential knowledge of the members. He says : "I believe it is the day to day experience of learning to live with and to manage profound personal concerns that builds an important base of knowledge that can benefit others who confront similar issues" (p. 115) Lavoie and Stewart (1995) echo this viewpoint when they say that the benefits of participating in support groups include alleviating the problem, expanding a support network, increasing feelings of control and satisfaction, gaining a new perspective, learning new skills, increasing feelings of hope, decreasing feelings of isolation, and procuring new resources. McLean (1995) writes that : "Sharing mutual experiences in a support group can minimize feelings of depression, isolation, and alienation. Membership in a support group may lead to quantifiable benefits in quality and quantity of life" (p. 212). Support groups play a significant role in the rehabilitation of a person with cancer by providing a unique opportunity for people with similar experiences to meet, share feelings, and learn alternative means of dealing with difficulties

(Cella & Yellen, 1993; Cope, 1995; Lavoie & Stewart, 1995; Paice, 1990; Stevenson & Coles, 1993).

#### 2.4.2.2 Components and Functions of Support Groups

Levine and Perkins (1987) describe the functions of support groups. These include "promoting a psychological sense of community, providing an ideology that serves as a philosophical antidote, providing an opportunity for confession, catharsis, and mutual criticism, providing role models, teaching effective coping strategies for day to day problems, and providing a network of social relationships" (p. 243). Some of these functions, particularly the provision of role models, the teaching of effective coping strategies, and the provision of a social network, are used in the support groups used by cancer patients (Cella & Yellen, 1993; Cope, 1995). Stevens and Duttlinger (1998) studied the perceived benefits of people attending a support group for breast cancer patients. Thirty – eight breast cancer patients were classified as either new members, established members or non members of the support group, based on the length of time they have been attending the group. Established members were those members who had attended more than six meetings, while new members were those members who had attended less than six meetings. Established members perceived the group as more supportive than did new members. Established members identified coping skills and sense of community as the most helpful features of the group, whereas new members identified medical information as the most helpful feature of the group.

Characteristics of successful groups include cohesiveness, uniqueness, and diversity (Lieberman, 1990). However, as Norris and Kaniasty (1996) suggest, the support people receive is not universal, in that people with equal needs do not always receive equal amounts or calibre of support.

## 2.5. Social Support and Health Outcomes

### 2.5.1 Social Support and Stress

Williams and House (1991) reviewed the relationship between stress, social support and coping strategies. They suggested that having social relationships and support, having a sense of personal control, and having strategies to cope with stress all buffered the effects of stress. Norris and Kaniasty (1996) evaluated the impact of receiving social support on the subsequent levels of perceived social support in two independent samples of victims of natural disasters. Victims of Hurricane Hugo (n = 498) and Hurricane Andrew (n = 404) were interviewed with regards to the supportive activities they had received in the two months directly following the hurricane, as well as their perceived levels of social support and psychological distress. Participants were re-interviewed at six months and again at one year after the initial interview. Analysis of the data supported the hypothesis that perceived support mediated the long term effects of distress on both scope of disaster exposure and post disaster received support.

One of the most frequent side effects of having cancer is the amount of stress it creates, not only for the patient, but also for the patients' loved ones (Benson et al., 1996). Some of the stressful effects families experience include loss of social contacts and leisure time, depleted energy, increased financial difficulties, and feelings of anxiety, guilt, shame, anger, and resentment. Having social support systems available reduces that stress (Mesters et al., 1997; Sorensen, et al., 1998).

### 2.5.2 Social Support and Dietary Change

Social support can be seen as an enabling factor for dietary change, and therefore can be an important target for nutrition intervention programs (Baranowski, Cullen, & Baranowski, 1999; Kristal, Glanz, Tilley, & Li, 2000). A review of the literature showed that there was very little written on the effect of social support from support groups on dietary changes. Studies had evaluated the effect of social support in the workplace on dietary change. Kristal and colleagues (2000) examined whether a worksite dietary intervention program increased enabling factors, such as social support, in making dietary changes. Their definition of social support was encouragement from co-workers to effect and maintain dietary changes. A total of 1795 participants from 28 worksites were randomised into intervention and control groups. The intervention consisted of a series of nutrition classes, as well as self help nutrition materials that were mailed to employees' homes. The intervention was designed to decrease fat intake and increase consumption of fibre, fruits, and vegetables, Participants completed food frequency questionnaires and surveys that assessed their knowledge, attitudes, and beliefs about cancer screening and nutrition. Significant dietary changes were found to be associated with the amount of social support participants received from their co-workers.

Also using worksites as a research setting, Sorensen et al. (1998) examined the relationship between support and increased fruit and vegetable consumption. In all, 22 worksites were randomised into one of three conditions; minimal intervention, worksite intervention, or worksite and family intervention. Baseline data was collected from 1,359 workers at the 22 sites. Participants completed surveys assessing fruit and vegetable intake, readiness for dietary change, co-worker support for healthy eating, household support for healthy eating, and demographics. An assessment of the baseline data indicated that family and co-worker support influenced readiness to change.

## 2.6 Social Support and Cancer

### 2.6.1 Need for Social Support for Cancer Patients

Since cancer affects many aspects of life, the support of family and friends is not always enough (McLean, 1995). Survivors must cope not only with physical disabilities from surgery, but also with psychological trauma from fear of recurrence, disappointment from reduced career possibilities, and changes in relationships with those around them (Muzzin, Anderson, Figueredo, & Gudelis, 1994). Cancer patients often encounter difficulties in talking about cancer within their families because family members often have contradictory feelings about cancer, and the patient does not want to cause the other family members more worry (Mesters et al., 1997).

Even when serious physical issues do not arise, many cancer patients continue to be concerned about their health (Andersen, 1994). Part of the cancer experience is the change in self esteem and self image as the feelings of security, integrity, wholeness, and confidence of the person with cancer are compromised, and feelings of fear, anger and embarrassment surface (Anderson & Johnson, 1994). Sometimes these feelings appear as a result of side effects from treatment for breast cancer, such as lymphedema. Carter (1997) conducted a qualitative study examining breast cancer patients' experiences with lymphedema. Two in – depth interviews were conducted with each of 10 women who had suffered from lymphedema as a result of having breast cancer. While most women were able to return to normal life, some of the women felt that their physicians generally had little knowledge of the effects of lymphedema, which led to the women feeling abandoned by the medical field. Some women also felt that having lymphedema impaired their intimate, work and social relationships as the women experienced changes in their body image and self esteem. Changes in body image can have effects on eating behaviours (Cash & Hicks, 1990). Feelings of isolation, stigmatization, and alienation may have an effect on nutrition. Having a support system available to a cancer patient helps to alleviate the alienation that cancer patients feel in their fight against the disease (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998).

Friendships change for breast cancer patients and so they seek the help of health care professionals, however, sometimes this help is not enough and there may be a need for greater support (Dunkel - Schetter, 1984; McLean, 1995). Zemore and Shepel (1989) assessed the effects of breast cancer and mastectomy on emotional support and adjustment. Social and emotional adjustment inventories were administered to 301 women who had undergone a mastectomy as treatment for breast cancer and 100 women diagnosed with benign breast lumps who acted as controls. The hypothesis was that breast cancer patients would perceive less support than controls, however, cancer patients perceived greater emotional support than did the controls.

Ell, Mantell, Hamovitch, and Nishimoto (1989) examined the role of social support in the psychological and functional adaptation of patients with breast, lung, and colorectal cancers. Assessments of the relationships between the constructs of social interactions, sense of control, reliance of religion, cognitive restructuring, and psychological functioning were conducted in 369 patients with breast, lung or colorectal cancer. Strong associations between social support and psychological and functional status existed.

Roberts, Cox, Shannon, and Wells (1994) examined how breast cancer patients perceived the effects of emotional support they received from family, friends and spouses. Questionnaires were completed by 135 newly diagnosed breast cancer patients. The questionnaires measured the patients' current psychological status, the amount of distress the patients perceived, and the degree of support patients received from family, friends, and spouses. There was a significant, though moderate, relationship between the perceived social support and the psychological well being of the breast cancer patients.

### 2.6.2 Social Support and Cancer Survival

Based on a review of the literature, McLean (1995) found that social support can have an effect on survival rates. For example, life stress and social support have independent significant effects on breast cancer survival.

Waxler –Morrison, Hislop, Mears, and Kan (1991) examined the relationships between social networks, family and friends, and work experiences on survival from breast cancer by following 133 breast cancer patients for four years. They assessed the impact of the women's social context at the time of diagnosis on the women's survival four years later. Large, strong social networks of friends were associated with survival, in that the issues that the patients identified needing assistance for were practical concerns such as cooking, child care, and shopping, and the women perceived friends as more willing to do those tasks without any obligation. A woman's marital status and employment status were also significantly related to survival, in that single and working women were more likely to survive.

### 2.6.3 Social Support and Coping with Cancer

Graham and Martin (1997) summarize the emotional phases a person traverses when they receive a diagnosis of cancer. The person first goes through a period of denial, followed by a period of turmoil as the reality of the situation sets in. Finally, the person begins to adapt to their new reality and returns to normal routines, however part of the person's ability to adapt is their coping skills. Coping skills can include previous experiences, personality traits, defense mechanisms, religious values, and social support networks. Social support influences coping responses, self concept, and psychological distress in women with breast cancer (Bloom, 1982). Satisfaction with support enables a person to better cope with having cancer by lowering anxiety, increasing self esteem, and decreasing levels of depression (Neuling & Winefield, 1988). Gore-Felton and Speigel (1999) also found that attendance at a support group helped people with cancer to cope with their disease by alleviating anxiety and reducing mood disturbances.

Fredette (1995) also studied the coping mechanisms employed by breast cancer survivors. Semi – structured interviews were conducted with 14 women who had lived with cancer for at least five years. Gathering as much information about the disease as possible, returning to work, exploring various aspects of spirituality, and turning to family and friends for support were the predominant coping strategies used. Support groups were also used as a coping strategy, but to a lesser extent than the others.

Stevenson and Coles (1993) surveyed the reasons why women attend support groups and the benefits they perceive from attending. Questionnaires were mailed to 106 women who had attended more than one meeting of the breast cancer support group. The questionnaires assessed the women's perceptions of the group. The questions addressed the reasons the women chose to attend the group, which meetings they enjoyed the most or the least, what information was of most use to them, and positive and negative outcomes of attending the group. The questionnaire was completed by 36 women. Reasons for attending included that the women wanted the information and emotional support. The women also felt that the group provided needed information and assistance in coping with the psychological effects of cancer.

## 2.7 Characteristics of Support Groups for Cancer Patients

Support groups for cancer patients are formed for several purposes. These include sharing feelings, building coping skills, and providing timely and relevant information about cancer (Bottomley, 1997; Zimpfer, 1989). Support groups for cancer patients often focus on wellness and enhancing self esteem (Kelly, 1998). Speigel, Bloom, and Yalom (1981) found that group support for cancer patients has several advantages over individual counselling in that group members can increase the effectiveness of their coping skills, can give as well as receive, and can gain a sense of community, which can help to overcome feelings of isolation. It was also noted that group members learned to focus on and identify specific problems, which lessened confusion and anxiety, and increased feelings of control. Instead of the cancer separating them, as they thought it did in families, it unified them, and discussions of death and similar issues was comforting, not destructive.

### 2.7.1 Participants of Support Groups for Cancer Patients

Demographic surveys of support groups for cancer patients have delineated characteristics of members (Bauman, Gervey, & Siegel, 1992; Caulton, 1996; Deans, Bennett –

Emslie, Weir, Smith, & Kaye, 1988; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999; Montazeri, 1996; Stevens & Duttlinger, 1998). Deans et al. (1988) conducted a descriptive survey of the support groups in Tak Tent, a Scottish cancer support organization. Questionnaires were completed by 146 patients attending 11 various groups in the organization. Cancer patients, relatives of patients, and cancer care professionals attended support groups for cancer patients. Women outnumbered men three to one. Montazeri (1996) conducted a descriptive study of six support groups for cancer patients in Scotland. Interviews were conducted with the 31 patients attending these groups. The majority of participants were female, married, aged 50 – 65, and post treatment. Bauman et al. (1992) examined the factors associated with cancer patients' participation in two support groups at a large cancer centre. One group, led by a physician, was for leukaemia patients. The second group, run by a social worker, was for lymphoma patients. Questionnaires were mailed to the 106 patients in the leukaemia group, and the 128 patients in the lymphoma group. Of the 234 eligible study participants, 154 returned the completed questionnaire. The study hypothesized that five factors would influence attendance at the support groups, namely demographic characteristics, tendency to join voluntary organizations, experience with mental health counselling, availability of social support from family and friends, and geographical distance from the hospital. Demographic factors that influenced participation were that participants in support groups were likely to be younger, educated, and unmarried. Participants in the support groups were also likely to join other voluntary organizations, and were likely to seek help from other health professionals. Krizek et al. (1999) examined the gender differences in response to an invitation to participate in a support group. Structured telephone interviews regarding patient choice about support group participation were conducted with 130 women with breast cancer, and 87 men with prostate cancer. Men were less likely to join a support group, but both men and women who join usually attend the group for about a year. Both men and women joined support groups to learn more about cancer, to share their concerns, and to compare their progress with other individuals. Caulton (1996) recommended that support groups for breast cancer patients should be homogenous in terms of providing the best support for participants.

### 2.7.2 Types of Support Groups for People with Cancer

There are support groups for all types of cancers, including soft tissue sarcoma (Payne, Lundberg, Brennan, & Holland, 1997), ovarian cancer (Sivesind, & Baile, 1997), leukemia (McGrath, 1999), and for families of children with cancer (Last & Grootenhuis, 1998). Groups for people with breast cancer and prostate cancer are the groups of predominant interest to this research.

#### 2.7.2.1 Prostate Cancer Support Groups

Men diagnosed with prostate cancer feel that there is a need for a specific group for prostate cancer patients (Anderson, Dowell, Fairbrother, & Louey, 1998; Crawford et al., 1997). In a descriptive study of a group for men with prostate cancer, Coreil and Behal (1999) report that the participants in groups for men with prostate cancer are mainly white males, aged 60 – 70 years, who attend the monthly meetings for support and education.

Some groups for men with prostate cancer are professionally led. Gregoire, Kalogeropoulos, and Corcos (1997) examined the effectiveness of a professionally led support group for men with prostate cancer. The groups consisted of 10 sessions, each 90 minutes long, and led by a nurse and a psychologist. The goals of the group were to provide information about prostate cancer and promote healthy coping strategies. Study participants revealed that they felt they had a better understanding of the disease, and that participation in the group offered reassurance, alleviated anxiety, and helped them attain a more positive outlook.

#### 2.7.2.2 Breast Cancer Support Groups

Many breast cancer patients seek the support available from a support group. While there are many general groups for breast cancer patients, there are groups targeted at various aspects of the disease process, including women undergoing genetic testing for the genes thought to play a role in the development of breast cancer (Di Prospero et al., 2001); women undergoing the rigorous autologous stem cell transplant as part of their cancer treatment (Feigin et al., 2000); and women who have had their cancer metastasise to other sites (Cunningham et al., 1998).

Veronesi et al. (1999) conducted a survey of European women's experiences with female cancers. Questionnaires were completed by 13,136 women in 15 countries in Europe. They evaluated the women's pre-diagnosis knowledge, how they received the diagnosis, their treatment experiences, the quantity and quality of emotional and practical support they received, and the impact of cancer on their relationships and lifestyles. Social support came from the women's families and from professionals. Gaps existed in the provision of information and education for cancer patients and in the provision of support services.

Samarel et al. (1998) evaluated differences women's adaptation to breast cancer and their participation in support groups. Structured telephone interviews were conducted with 70 women who had participated in one of two support groups for cancer patients. In one group the participants were also individually coached by their significant other, while in the other group, only participants attended. Both groups were eight sessions in total, and the content of both groups was identical. Each session examined different stresses in the participants lives, and helped the participants to develop strategies to deal with the stresses. Differences between the two groups were not discussed. In both groups, about 75% of women expressed positive attitude changes as a result of participating in the groups, especially with regards to self concept.

## 2.8 Dietary Behaviour Change and Cancer

Aside from the specific dietary regimens offered to offset particular side effects, there are very few dietary recommendations for people with cancer (Lerner, 1994). However, malnutrition is a major cause of mortality and morbidity among people with cancer (Bass & Cox, 1995). People with cancer present unique problems that have nutritional ramifications, including treatment side effects such as nausea, vomiting, food aversions, and weight changes (Monnin & Schiller, 1993). These problems indicate that people with cancer may have a need for nutrition education.

A review of current literature shows that there is very little written on nutrition education for people participating in cancer support groups, however, several studies have evaluated the efficacy of various diet regimens for people with cancer. Areas of study include the need for nutrition counselling for people with cancer, patient directed dietary changes, and dietary intervention programs aimed at people with cancer.

### 2.8.1 Need For Nutrition Counselling of People with Cancer

People with cancer sometimes subscribe to poor nutrition practices, such as excess consumption of foods, elimination of one or more nutrients, or ingesting megadoses of various supplements, which may result in malnutrition (Monnin & Schiller, 1993). As a result, some people with cancer may want to consult with a nutrition professional in order to treat the malnutrition.

Monnin and Schiller (1993) assessed the desire of breast cancer patients for nutrition counselling. Questionnaires seeking information on the nutritional concerns of women with breast cancer were mailed to 143 women who had had surgery for breast cancer, and 103 questionnaires were completed and returned. The patients expressed an interest in learning about dietary recommendations for cancer prevention, losing weight, low fat diets, and using vitamin and mineral supplements. The patients also suggested that the best time to speak with a dietitian would be shortly after surgery. Inpatient counselling was preferred over outpatient counselling or classes.

Bass and Cox (1995) also assessed the need for dietary counselling of cancer patients by evaluating their nutrient and supplement intake. Interviews were conducted with 106 adults with cancer who were asked about their diagnosis, treatment, side effects and experiences with dietary counselling. Patients were asked to keep three day food records, and 62 patients did so. For both male and female cancer patients, the intake of many nutrients was significantly below that of the general population, as well as being below recommended dietary allowances, suggesting that cancer patients may have substantial dietary deficiencies and are in need of dietary counselling.

### 2.8.2 Patient Directed Diet Changes

Some people who are diagnosed with cancer make self directed changes to their dietary practices in the interest of preventing a recurrence or feeling better through the treatment process. Salminen and colleagues (2000) examined the diet change behaviour of breast cancer patients. Questionnaires examining issues related to diet were given to 123 breast cancer patients. Almost all of the patients (86%) ate a normal diet, while 5.3% were vegetarians and 8.1% were vegetarians who consumed fish and chicken occasionally. A total of 38 patients had changed their dietary habits after their diagnosis of breast cancer. Of those patients that changed their diets, most (53%) changed their diet behaviours due to the desire to be cured of cancer, 12% of patients changed their diet to alleviate side effects, and 12% pf patients changed their diet because of a recommendation by a health professional. The main changes patients made included reductions in intake of animal fats, sugar, and red meats, and increases in intake of fruit and vegetables.

Auld et al. (2000) assessed the adoption of dietary fat and fibre recommendations among consumers, including a sample of heart attack and cancer patients. A general population sample of 6,206 yielded a subset of 2,682 respondents who said that they would adopt a dietary recommendation if they felt it was good for them. Subsets of the general population were matched, by selected demographic variables, to 362 registered dietitians and 147 people with either heart disease or cancer. More than 60% of the general population reported consuming whole grains, but only 15% reported eating fruits and vegetables. In the general population sample, certain people were more likely to practice a health behaviour, such as eating the recommended amount of fibre. These people were female, college educated, older, white, had higher incomes, and were not suffering from a chronic disease. Those with a chronic disease were more likely to follow dietary fat and fibre recommendations than the general population.

### 2.8.3 Dietary Interventions for People with Cancer

Recent research has discovered more information about the links between various aspects of the diet and the development and treatment for cancer. Studies have shown the influence of dietary fat, fibre, and antioxidants in reducing the risk of developing cancer. As a result, researchers have also started to evaluate the effects of specific dietary changes for people with cancer. In most studies, the purpose of the dietary changes is to reduce the risk of recurrence of cancer.

Gorbach and colleagues (1990) studied the effects of a dietary intervention aimed at lowering the dietary fat intakes of women at elevated risk for developing breast cancer in hopes of reducing the incidence of breast cancer among those women. A total of 173 women participated in the dietary intervention, which consisted of group sessions to teach nutrition information and behavioural skills necessary to make dietary changes. Participants completed four day food records at baseline and again at 12 months. An assessment of the changes made by the women showed a decrease in mean fat intake, achieved mostly through reductions in intake of red meats, dairy products and fats and oils, and increases in fruits and skim milk.

Similarly, Chlebowski et al. (1993) examined the feasibility of a low fat dietary intervention for breast cancer patients. A total of 290 women with breast cancer were randomised into either the intervention group or the control group. The intervention group received individual dietary instructions for reducing fat intake while controls received minimal dietary counselling. A 50% reduction in daily fat intake was observed in the intervention group, a change that was maintained over 24 months of observation.

Hebert and colleagues (2001) assessed changes in women's diet and body mass following treatment for early stage breast cancer. The participants were 172 women randomised to receive one of three conditions; a dietary intervention, a mindfulness stress reduction program, or usual supportive care. Dietary data was collected at baseline, postintervention (4 months) and at one year. A total of 146 women had complete data at one year. The intervention was a 15 session, group based, dietitian led, nutrition education program. The researchers assessed dietary intakes of fat, carbohydrates, and fibre, and tracked body mass over the intervention period. The intervention group (n = 50) reduced fat intake and had a reduction in mean body mass, findings that were stable at one year post intervention.

McTiernan et al. (1998) conducted a pilot study to evaluate the anthropometric and hormone effects of an exercise and diet intervention for women with breast cancer. Ten participants followed an eight week protocol of supervised aerobic exercise three times a week, and a diet with 20% of total calories coming from fat. While there were no significant serum hormone changes, significant reductions in body weight, waist circumference, hip circumference, body fat, blood pressure, and heart rate were noted.

Ovesen et al. (1993) examined the effect of nutritional counselling on food intake, body weight, survival, and quality of life in lung, ovary, and breast cancer patients undergoing chemotherapy. A total of 105 patients were randomised into an intervention group (n = 57) or a control group (n = 48). The intervention group received counselling by a trained dietitian twice a month for a five month period following the start of chemotherapy. Although there was a significant difference in triceps skinfold measurements in the intervention group, no significant differences were found between the intervention and control groups with regards to weight, survival rates, energy intake, and quality of life.

Nordevang, Callmer, Marmur, and Holm (1992) examined the effect of a dietary intervention on the food choices of breast cancer patients. A total of 240 women with breast cancer were interviewed to obtain a diet history and then they were randomised into two groups. The intervention group (n = 121) received individual dietary counselling aimed at reducing dietary fat intake to 20-25% of energy, while the control group (n = 119) received no dietary advice. There were significant reductions in high fat food choices, and increases in the consumption of vegetables and high fibre carbohydrates. The participants level of formal education influenced their dietary changes, therefore dietary counselling should be adapted to education level.

The findings from these research studies have several implications for nutrition education for people with cancer. First, nutrition education which instructs people with cancer on how to make dietary behaviour changes is well received, in that the participants in the studies were able to make the recommended changes. Secondly, these findings also suggest that nutrition education for people with cancer is effective, in that the people are able to maintain dietary behaviour changes for sustained periods of time (Chlebowski et al., 1993; Hebert et al., 2001).

### 2.8.4 Diet Changes and Side Effects of Cancer Treatment

Some of the side effects of cancer treatment have implications for the nutritional status of the person with cancer. Nausea, vomiting, and food aversions may all impact on food intake, and fatigue may impact on activity levels. Changes in food intake and activity levels may result in changes in body weight. Researchers have begun to examine the various roles of nutrition in coping with the side effects of cancer treatment.

Mattes (1994) developed a dietary intervention program for the prevention of chemotherapy related food aversions. In all, 209 patients were exposed to a sensory stimulus, such as a beverage or an odour, before treatment. As a result, if the patient developed an aversion after treatment, the aversion was more likely to be to the stimulus, instead of to a particular food. The sensory stimulus became a scapegoat for alternate aversion. The resultant aversion to the scapegoat stimulus led to a 30% decrease in aversions to dietary items.

Goodwin et al. (1998) conducted a psychosocial, dietary, and exercise intervention for 61 women with breast cancer aimed at managing weight while undergoing chemotherapy. Women who had a Body Mass Index (BMI) of less than 25 were asked to use the intervention to maintain their weight, while women who had a BMI of 25-35 were asked to use the intervention to lose up to 10kg. The intervention was 20 group sessions, led by a psychologist and nutritionist. The nutrition component of the program followed Canada's Food Guide to Healthy Eating, while the exercise component of the program stressed long term changes in everyday activities and moderate aerobic activity. Weight loss was greatest in women who were initially overweight, and women who were initially normal weight did not gain weight.

### 2.8.5 Proposed Dietary Interventions

Wynder, Rose, and Cohen (1994) reviewed geographical and metabolic epidemiological evidence from laboratory studies examining prostate cancer. They proposed the development and implementation of a dietary intervention trial for men with prostate cancer which would include a reduction in total fat consumption to 15% of total calories and supplementation of selenium, Vitamin E, and soy.

Cohen, Rose, and Wynder (1993) also revisited a proposed dietary intervention for women with breast cancer where they had suggested that lowering fat intake to 20% of total calories would increase the disease free interval for breast cancer patients. They now suggest that, based on epidemiological and laboratory findings, the fat intake of such an intervention can be lowered to 15% of total calories.

### 2.8.6 Diet Changes and Survival

One of the reasons a person with cancer might make dietary changes is to improve his or her chances of survival. Carter et al. (1993) examined 18 prostate and 23 pancreatic cancer patients to evaluate whether or not dietary management improved survival. One year survival rates were higher for pancreatic cancer patients who modified their diets. There was also a statistical association between diet modification, survival, and improved quality of life in metastatic prostate cancer patients.

Rohan, Hiller, and McMichael (1993) examined the correlations of several dietary factors to survival rates from breast cancer, including energy intake, protein intake, fat intake, alcohol, beta carotene, and Vitamin C. A total of 412 patients were followed for a median of 5.5 years. For patients whose energy and protein intakes remained at or above baseline, a 25- 40% decrease in the risk of death was noted, as was up to a 40% increase in the risk of death if the intake of fat was in the uppermost quintile.

## 2.9 Nutrition Education Strategies for People with Cancer

There are several factors to consider with regards to nutrition education for people with cancer. The first is that, to date, most cancer related nutrition education is aimed at preventing cancer. The second is the role of information and knowledge in nutrition education aimed at changing behaviours. The third is the strategies that can be used for targeting nutrition education programs for specific groups, such as people with cancer.

### 2.9.1 Nutrition Education for Cancer Prevention

A review of the literature indicates that most cancer related nutrition education is aimed at dietary change to reduce the risk of developing cancer. Research has provided more information regarding the links between diet and the development of cancer. Using this information, cancer prevention nutrition education programs have aimed to increase individual's dietary fibre intake and fruit and vegetable consumption, and decrease fat intake. Various nutrition education techniques used include supermarket tours, which are used to promote fruit and vegetable consumption (Patterson et al., 1992; Rodgers et al., 1994), community programs (Boeckner, Kohn, & Rockwell, 1990; Lanza et al., 2001), and consultations with health professionals (Hunt et al., 2001).

Community based nutrition education programs typically focus on the entire eating pattern. For example, Navarro, Rock, McNicholas, Senn, and Moreno (2000) describe how their 12 session program includes increasing both the variety and the quality of fruits and vegetables consumed by participants, as well as addressing the importance of balance between energy intake and physical activity, with special attention paid to intake of both fat and fibre.

Hunt et al. (2001) evaluated a nutrition intervention designed to increase intake of fruits and vegetables, to decrease intake of red and processed meats, and to increase the substitution of low fat milk products for whole fat milk products, in the hopes of decreasing the participants' risk for cancer and other diseases. Six medical offices were randomised into intervention or control conditions. A total of 230 patients from the intervention sites and 274 patients from the control sites enrolled in the study. The intervention consisted of a detailed feedback letter on the participants' consumption of target foods, recommendations for how to improve intake, stage matched nutrition booklets, a diet endorsement from their primary care provider, and two motivational counselling phone calls. Significant changes were made by the participants in the intervention sites with regards to fruit and vegetable consumption, but not with regards to changing their intake of red meats and milk products.

### 2.9.2 Providing Nutrition Information in Nutrition Education

Providing knowledge about nutrition is an important aspect of nutrition education. Wardle, Parmenter, and Waller (2000) questioned the efficacy of nutrition education by investigating the relationship between nutrition knowledge and dietary intake. Participants (n = 1040), selected at random from general practitioner's patient lists, were mailed a survey assessing their nutrition knowledge. Knowledge was significantly related to healthy eating, and knowledge is an important factor in explaining variations in food intake, therefore knowledge is still an important component of nutrition education programs.

Kristal, Bowen, Curry, Shattuck, and Henry (1990) examined perceived knowledge and attitudes as factors in selecting low fat diets. A total of 97 women completed questionnaires over several weeks. Demographic data was collected at baseline, a four day food record after one week; a food frequency questionnaire, a diet behavior questionnaire, and a questionnaire on diet attitudes, beliefs, and knowledge at six weeks; and a repeat four day food record at 13 weeks. Factors associated with low fat diets were related to perceived norms and knowledge about fats in foods. This suggests that effective nutrition education programs should include components that enhance practical food knowledge and support people in changing their dietary behavior.

### 2.9.3 Targeting Nutrition Education for Specific Groups

Nutrition education strategies need to be tailored to the specific population group being targeted. The most effective nutrition education programs are those that are behaviourally focussed. That is, the intended behaviours are identified from the needs, perceptions, motivations, and desires of the target audience (Contento, et al., 1995).

In order to provide the most effective nutrition education, it is crucial to understand the needs of the population group being served by the education. Conducting a needs assessment is one way to determine the needs of a population group. It is also important to obtain information on the potential impact of nutrition education on a variety of mediating and enabling factors, such as personal factors, cognitive and affective skills, and environmental supports (Contento, et al., 1995). This way, both the content of the nutrition education and the most appropriate delivery of these programs can be determined. In order to provide effective nutrition education and promote healthy food habits, creative and innovative nutrition education strategies are needed (Anderson, 1994).

The most successful nutrition education programs have used combinations of several different strategies, aimed at individual, social and environmental change (Contento, et al., 1995). Some strategies enhance personal awareness and motivation, such as self evaluation and active participation. Other strategies target behaviour change through systematic change processes and the use of social support. Finally, some strategies are environmental interventions, such as point of sale displays, and community activism. Successful nutrition education programs are also based on models and theories of behaviour change, such as the knowledge, attitude, and behaviour model, and other value based models, such as the health belief model, the stages of change model, and consumer information processing models (Contento, et al., 1995).

#### 2.9.3.1 Health Behaviour Change Models and Theories

Nutrition education involves understanding the beliefs, attitudes and behaviour towards food and nutrition. An individual's values and behaviours can be influenced by disease occurrence, which may subsequently influence the health behaviours of the individuals (Lerman & Glanz, 1997). Health behaviour models and theories provide guidelines to help nutrition educators learn and understand human behaviour so that they can develop appropriate nutrition education programs. There are many such theories and models, including the health belief model, the stages of change model, the theory of reasoned action, the social learning theory, and its offshoot, the locus of control model (McLeroy et al.,1993).

Some models and theories have been used as a basis for dietary interventions. Kristal, Glanz, Curry, and Patterson (1999) reviewed how the stages of change model has been used in dietary interventions. They recommend that the stages of change model be used as a way of changing thinking about eating behaviours, and not as a measure of changing particular eating behaviours.

Schapira, Kumar, Lyman, and Baile (1991) assessed the effect of the locus of control model on the effectiveness of a dietary intervention aimed at reducing the risk of developing cancer. The interventions produced significant changes in dietary intake and weight, but the participants who had an internal locus of control did not demonstrate as big of a change as the participants who had an external locus of control.

An examination of the various models and theories showed that two of them could best be applied to nutrition education programs to be used in support groups for people with cancer. These are the health belief model and the social learning theory.

##### 2.9.3.1.1 Health Belief Model

The main constructs in the health belief model centre around an individual's perceptions about being able to make changes within the realm of preventative health behaviour (Strecher & Rosenstock, 1997). The amount of susceptibility a person feels towards a particular outcome, and how severe a person thinks a particular outcome will be, will affect their thinking about the need to make a change. For example, a person might not think they are at high risk for developing cancer, so they might not lower their fat intake, or a person might not view cancer as a severe disease, thereby lessening the chances that they will make changes to decrease their risk of developing cancer. Also, how an individual views the potential benefits of making a change to avoid a potential outcome will influence the individual's decision to make a change. For example, a person may view eating more fruits and vegetables as helping to lower risk of not just cancer, but of heart disease and diabetes as well, and therefore may make dietary changes.

There are usually barriers that individuals face in making changes, and how limiting an individual perceives the barriers to making changes is part of the health belief model (Strecher & Rosenstock, 1997). For example, if a person thinks that eating more fruits and vegetables is good for lowering the risk of developing cancer, but doesn't think that he or she can afford to buy more fruits and vegetables, then that individual's perception of the barrier to making changes is high. But there are also influences exerted by the various cues that prompt an individual to make changes. For example, having been diagnosed with cancer may make an individual rethink his or her situation. Finally, an individual's self efficacy, or belief in his or her ability to make the changes, will affect the likelihood of the individual making changes. An individuals ability to make changes can be affected by his or her ethnic origin, age, gender, personality, knowledge level, and socioeconomic status. These constructs are recognized within the health belief model as modifying factors.

The health belief model has been used to explain or predict the cancer screening measures of populations, including those for skin cancer (Marlenga, 1995), cervical cancer (Burak & Meyer, 1997; Gillam, 1991), and breast cancer (Holm, Frank, & Curtin, 1999; Yarbrough & Braden, 2001). The health belief model has also been used to evaluate dietary changes in conditions such as renal disease (Katz et al., 1998), heart disease (Bennett, Milgrom, Champion, & Huster, 1997), and diabetes (Pham, Fortin, & Thibaudeau, 1996). Therefore, it is logical to propose the use of the health belief model when considering providing nutrition education for cancer patients.

##### 2.9.3.1.2 Social Learning Theory

The main construct in social learning theory is that people make changes based on the person's expectancy that the changes will lead to a particular outcome and that the outcome is valuable to the person (Wallston, 1992). The health related version of the social learning theory argues that the potential for a person to engage in a set of health promoting behaviours is a function of that person's health values and perceived control over his or her health. In order for people to engage in health directed action, people must believe that their actions influence their health status and that they are capable of completing the action.

Baranowski, Perry, and Parcel (1997) outline the major concepts in social learning theory. These include the environment, the situation, behavioural capability, expectations and expectancies, self control, observational learning, reinforcements, self efficacy, and emotional coping responses. Several of these concepts would lend themselves well to facilitating nutrition education in a support group for people with cancer. For example, since strengthening emotional coping skills is frequently part of a support group, these skills could be put to practice with regards to nutritional decision making. Also, since new members of support groups frequently look to older members for help, observational learning could be utilized to help new members make dietary changes.

Social learning theory has been used in cancer related health situations such as measuring women's screening behaviours for breast cancer (Lu, 1995), cervical cancer (Hodge, Fredericks, & Rodriguez, 1996), and as a model for a dietary cancer prevention program for adolescents (Wallin, Bremberg, Haglund, & Holm, 1993)

## 2.10 Potential for Nutrition Education in Support Groups

There is some evidence that a support group may be an appropriate place to conduct nutrition education for cancer patients (Carlsson, Stang, & Nygren, 1999; Dwyer, 1986; Glanz, 1985). Carlsson et al. (1999) conducted a study examining the questions asked by cancer patients at an educational support group. Out of a total of 329 questions during the 40 group sessions, there were 48 nutrition questions. Most of the questions referred to the need for dietary changes to combat treatment side effects.

Dwyer (1986) addresses some myths and misconceptions about nutrition education for the cancer patient. One of the misconceptions addressed is cancer patients' misconception that the best source of nutrition advice for cancer patients is other cancer patients. She maintains that while other patients are helpful as supporters and encouragers of dietary change, dietitians provide the best information, and other health professionals should also reinforce good nutrition.

Glanz (1985) reviewed studies of nutrition education for adults with various diseases, including cancer, and found that nutrition education for people with cancer should account for individual needs and preferences. She suggests that "nutrition education can be offered in the community, where people convene for social, religious, and educational purposes" (p. 745) because these settings take advantage of the mutual interests of the group and make use of the benefits and mechanisms of social support.

## 2.11 Summary

Cancer is a disease of uncontrolled cell differentiation. Cancer is related to nutrition in terms of disease onset, treatment, and post treatment issues. Having a social support system is a part of being healthy, and is no less important when diagnosed with a disease such as cancer.

Some people with cancer obtain social support through the use of support groups. There are specialised groups for various types of cancers, but groups for men with prostate cancer and groups for women with breast cancer are of the most interest to this research. Research on support groups for people with cancer has found that people with cancer participate in the support groups to obtain information about cancer, and to deal with the emotional aspects of having cancer, such as feelings of fear and anger.

There has been some research on the dietary changes that people with cancer make after they are diagnosed with cancer. Some research has evaluated the need for nutrition counselling for people with cancer, as well as the effectiveness of low fat dietary interventions on the recurrence of breast cancer. Researchers have also examined the relationships between diet changes and the effects of cancer treatment, and diet changes and surviving cancer.

Currently, most nutrition education is aimed at preventing cancer. Nutrition education of people with cancer needs to be tailored to the needs of the people in order to be effective. The health belief model and the social learning theory are potential models for eliciting health behaviour change in people with cancer. There is some evidence of a potential role for nutrition education in support groups for people with cancer.

# Chapter 3 - Methodology

## 3.1 Introduction

The chapter outlines the methodology used in conducting this research study. This chapter begins with descriptions of the research framework as well as some insight into various aspects of qualitative research methodology. It then outlines the steps that were taken to complete the research.

## 3.2 Research Framework - Needs Assessment

Witkin and Altschuld (1995) define a needs assessment as a process of information finding that "seeks to involve service recipients and providers in providing information and having an integral part in the decision making process" (p. 5).

The basic premise of needs assessment is that changes are most effective when they are determined by the people in the situation as being needed, not just arbitrarily brought about. In this research, what was assessed was what the facilitators of the groups saw as being needed. The focus of this study was not on the support groups themselves, but rather it was to examine the current extent of nutrition education in the groups, and to assess the group facilitators' views on the possibility of incorporating nutrition education into the groups.

There are three phases of needs assessment: pre-assessment, assessment, and post-assessment (Witkin & Altschuld, 1995). The pre-assessment stage specifies the purpose of the assessment, and in this study, it was accomplished through the review of the current literature, and through preliminary meetings with group facilitators. As a result of this stage, the research methods were determined. The decision was made to use qualitative research methods. It was also decided to use in – depth interviewing as the data collection tool. The necessary written documents were developed. An informed consent form (Appendix A) for the participants was adapted from a general guideline for consent forms from the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research. The interview guide (Appendix B) was developed in conjunction with the research supervisor, and submitted for ethical approval. Numerous practice interviews were conducted with the research supervisor and other graduate students in the department to prepare the researcher for conducting the interviews.

The assessment stage is when the actual data collection process occurs (Witkin & Altschuld, 1995). This was accomplished through conducting interviews with group facilitators and subsequently transcribing the interviews into verbatim hard copies. The assessment stage is completed when the data has been analysed sufficiently to answer the research questions. The data was themes that emerged as a result of content analysis of the transcripts. These themes were then compared between participants to develop a complete picture of the nutrition education currently ongoing in the groups, and to formulate possible future roles for nutrition education within the groups.

In the post assessment stage the current status is typically compared to the desired result (Witkin & Altschuld, 1995). However, the aim of this research was to take the first step in analysing the potential role of nutrition education in cancer support groups by obtaining the views of the people who currently facilitate the groups. Thus, no final comparisons or recommendations were made on the basis of the data collected. The data was the result of the assessment of one stakeholder in a multistakeholder situation. To that end, the findings were based on the themes that emerged from the discussions with group facilitators, and the findings were reported both to the individual facilitators and to the staff of the parent organizations so that either may use the information as they see fit.

## 3.3 Qualitative Research Methods

### 3.3.1 Introduction to Qualitative Research Methodology

Qualitative research describes the effects of a phenomena (Lakshman, Sinha, Biswas, Charles, & Arora, 2000). For example, while quantitative research might look at the causes, treatments and potential cures for cancer, qualitative research might examine how having cancer has affected a person's life. The support groups offered for people with cancer in the city of Saskatoon, for example, are an obvious context with which to frame qualitative research that aims to find out how a person has been affected by a diagnosis of cancer. In this case, the research aim was to evaluate the suitability of incorporating nutrition education in support groups because nutrition and cancer are interrelated with regards to both diagnosis and treatment.

Qualitative methods describe the meaning that people assign to the life events they experience, and they help to relate these meanings to the context of the lives of the people being studied (Rice & Ezzy, 1999). In this case, the life events are the diagnosis and treatment of people with cancer, and the meanings are how the facilitators feel nutrition education would benefit the people that participate in the support groups. The use of a qualitative study design allowed the researcher to understand and describe the meanings of these experiences and their context in depth.

### 3.3.2 Specific Elements of Qualitative Research Methods

Lincoln and Guba (1985) outline the main elements of qualitative research. Those most relevant to this study included the use of purposive sampling, inductive analysis, and idiographic interpretation.

Purposive sampling is choosing subjects based on the fact that they can provide the researcher with the most complete data (Lincoln & Guba, 1985). Those who are best able to provide complete data are those who are in the situation. For this study, the group facilitators were looked to as the best subjects because they would have information on the nutrition education that had taken place in the groups. Based on their experiences, the group facilitators might also have opinions and thoughts on how nutrition education could be further incorporated into their groups.

Inductive analysis tries to find hidden meanings and other meanings people attach to their experiences through categorization of the data (Lincoln & Guba, 1985). Since this was the goal of this study, inductive analysis was used to analyse the collected data. The data analysis was content analysis that arose from categorizing the data into various themes and then relating it to other themes.

Idiographic interpretation is the interpretation of findings is a case related way, not in a general way (Lincoln & Guba, 1985). This study made use of idiographic interpretation in that the findings were not generalizable to the general public, and perhaps not even to other groups.

This study was concerned with describing the views given by the particular participants at this point in time, not in comparing those perceptions to perceptions of other subject groups.

### 3.3.3 Methods of Verification

Lincoln and Guba (1985) suggest four criteria parallel to those used in positivist research that can be used to help establish the trustworthiness of qualitative research. These are the parallel criteria of credibility, transferability, dependability, and confirmability. They also describe a number of methodological techniques that naturalistic researchers can employ in trying to ensure that these criteria are met, such as prolonged engagement, member checking, the use of thick description, and an external audit. Several of these techniques were used throughout this study, as described below.

Guba and Lincoln (1989) later proposed that there are several measures of authenticity of naturalistic inquiry that are not derived as parallels to positivist measures, but which arise from constructivist principles. These are the authenticity criteria of fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. These measures of authenticity were not operationalized in this research study.

#### 3.3.3.1 Credibility

Credibility in naturalistic inquiry is a measure of the "truth value" of the data, not of the researcher in particular (Lincoln & Guba, 1985). In determining the credibility of the data, the "researcher must show that he has represented the multiple constructions adequately" (p. 213). There are several ways of enhancing credibility. The first is by using the right research method. Using the right method increases the probability that the findings are credible. Using the right method generally incorporates the use of three actions. These are prolonged engagement, persistent observation, and triangulation.

Prolonged engagement involves the researcher investing sufficient time in the collection of data so that there is trust built with the participants, distortions are minimized, and the constructed reality is understood (Lincoln & Guba, 1985). Prolonged engagement with the parent organizations was used throughout this study. Through a review of the programs offered by several disease based charitable organizations in Saskatoon, the decision was made to approach three cancer based organizations and request their participation in the research study. The researcher contacted the first organization and gathered information about the groups currently running in the organization. The researcher was given the names of several group facilitators to contact. The researcher then contacted several facilitators and requested their participation in gathering contextual data about the groups they facilitated. Six facilitators agreed to participate. Individual in – depth interviews were conducted with these participants from May to October of 1999. Three of these facilitators were re - interviewed between January and June of 2001 in order to gather more nutrition related data.

When the researcher approached the second organization about the facilitators of its groups participating in the research, the researcher was given permission to approach three facilitators of support groups. The researcher met with each of these facilitators twice, once to introduce herself, and once to conduct the interview. These facilitators were interviewed between January and June 2001.

When the researcher approached the third organization, the first contact was made with a group member at a seminar. This contact gave the researcher the name of the office person at the organization, who then directed the researcher to contact the organization's governing body for permission to request the members of the organization to participate in the study. The organization's governing body forwarded a list of names for the researcher to contact. Upon contacting the people on that list, six facilitators from the organization agreed to participate in the study. In - depth personal interviews were conducted with the six facilitators between January and June 2001.

Persistent observation involves sorting out the important data from the unimportant, always revising the relevant issues (Lincoln & Guba, 1985). This strategy was employed from the initial contact through to the final analysis. Because the data collection occurred over a period of time, the data was preliminarily analysed as it was collected, and then presented to the participants for feedback.

Triangulation was not used as a verification method in this study, however, a checking system was used to increase credibility. An external checking system is most often accomplished through peer debriefing (Lincoln & Guba, 1985). The external checking system in use for this study was the numerous debriefings with the research supervisor. As well, debriefings with an advisory committee were held regularly throughout the duration of the study.

A system of member checking (Lincoln & Guba, 1985) was also used to increase credibility. This is similar to the external checking, except that in this system, the findings are approved by the very people who constructed the reality. If the group facilitators confirm that the findings reflect their reality, then the credibility of the findings is increased. This method was employed in this study, in that each facilitator received a copy of his or her transcript to review and offer any elaboration, clarification, or additional thoughts.

### 3.3.3.2 Transferability

Transferability is also known as the applicability of the research. The "degree of transferability is a direct function of the similarity between the two contexts" (Lincoln & Guba, 1985, p. 124). Transferability can be assessed by examining how easy it would be for another researcher to take the information given in the research and apply it to another situation. In order to do this, the researcher must use thick description so that other researchers are fully able to assess the results. In this study two measures of "thick description" were undertaken to ensure that transferability was a viable option. Thick description is detailed descriptions of the situation, the participants, and the resultant data. Thick description was used in this study by providing the participants with an opportunity to review the transcript of their discussion with the researcher and provide any necessary clarification or elaboration. The second method that was used to increase the transferability of the data was the detailed thick description of the context of the situation. In order to accurately frame the participant data, the program data must also be described. This way, a subsequent researcher has two vehicles by which to assess the transferability of the data. Both types of thick description were applied in this research.

### 3.3.3.3 Dependability

Because the design of a qualitative study is inherently emergent as the study continues, the researcher is always vulnerable to external factors that cause instability, as well as the influence of design induced change (Lincoln & Guba, 1985). Dependability is the characteristic of the data that accounts for how well the researcher was able to control for these factors. Dependability is the assessment of how well the data stands up on its own, and this is most usually measured through an external audit. In the case of this study, the audit was the major method of confirming dependability of the research, since the research objective was idiographic in nature.

#### 3.3.3.4 Confirmability

According to Lincoln and Guba (1985), confirmability refers to the neutrality of the data and resultant findings. Subjective data is data which is obviously biased or otherwise contaminated, whereas objective data is that which is factual, reliable, and confirmable. By confirmable, they assert that if another person were to use the same method to collect data, that person would attain similar results. With respect to confirmability, it is not the characteristics of the particular researcher that are being questioned, but the characteristics of the data itself. The best method for determining the confirmability of data, outside of replicating the study, is through an external audit. Again, given the limits of this study, the audit was the major method of determining the confirmability of the data.

### 3.3.4 Interviewing

The meaning that the facilitator attaches to the various components of the group, including any nutrition education, is what will determine, in part, what constitutes the makeup of the group. Therefore, a data collection method was needed that could extract these perceptions and meanings. A comparison of various data collection methods revealed that personal, semi - structured interviews were the best way of collecting the data that was needed. These interviews were semi-structured, making use of an interview guide to help conduct the conversation, but still leaving room for the researcher to probe other issues that the participants brought up. These interviews were conducted in a one on one personal style, so as to highlight the individual facilitator's experiences.

#### 3.3.4.1 Interviewer Skills

There are certain personal characteristics that interviewers should possess in order to make the best use of the interview as a data collection method. According to Evans, Hearn, Uhlemann, and Ivey (1989), integral skills of an interviewer include such abilities as being able to inquire effectively, to communicate feeling and immediacy, to appropriately self disclose, and to give structure to the interview. Fontana and Frey (2000) outline how a researcher will traditionally maintain a friendly tone while conversing with the participant, beginning the conversation with some general questions to break the ice, and gradually moving on to more specific questions. These characteristics were refined in the researcher through a series of practice interviews and debriefings with the research supervisor before the interviews with the study participants.

According to Gorden (1980), it is not only the interviewer's skills that are important in an interview, but also who the interviewer is in terms of looks, personality, and education. For example, if the interviewer's traits in age, sex, class, ethnicity, dress, or disabilities are too far removed from those of the interviewee, the interviewee may feel alienated (Gorden, 1980). This issue did not arise in this research as most of the participants were female and well educated.

### 3.3.5 Researcher's Story

In qualitative research, the researcher is one of the research tools. While other research tools, such as surveys and laboratory methods, can have their limitations and biases objectively measured, the opinions and experiences of an individual are not so easily measured. However, the opinions and experiences of the researcher, which could influence the methods and findings of the research, must be accounted for. One way to do this is to have the researcher present his or her explanation of why he or she is interested in the research area, and how the researcher believes his or her opinions and experiences may bias the research findings. Here is the story of my research.

This research is the accumulation of many interests on my part. Academically, with a Bachelor of Science in Human Nutrition, I wanted to further my formal education to include a Master of Science, and I chose the field of Community Nutrition in which to specialize because it was the area of most interest to me.

After starting my graduate work, I became interested in the role of social support in health, with particular interest in the role that social support plays in individual nutritional status. One of my summer jobs was working with a charitable organization, and I became interested in the roles that charities could play in terms of the health of both individuals and populations and the health care system. I noticed that many charitable organizations were related to particular diseases and health conditions. Further inquiries indicated that many charities had some organized type of support for people with that particular disease. I was interested in learning more about how the programming of charities could play a part in servicing the needs of individuals within the health care system, which was becoming more focused on preventive and community based care.

My curiosities led me to design a research project investigating the nutritional impact of support programs offered by charities. In this research, the nutritional impact was nutrition education, and the support programs of charities were support groups for people with cancer offered by three organizations. With regards to my research, I have three concerns.

The first is that I may not connect with my research participants, as I have never been diagnosed with any serious disease, and I have never taken part in a support group.

The second is that I will do this research only to find out something that I already know. I have strong common sense ideas about how nutrition information is shared in support programs and about the role it plays in people's lives, but these ideas have not been supported by research. Thus, I am worried that doing the research will lend strength to my ideas but that my having the ideas will somehow influence the generation of the support for the ideas.

The third is my bias for nutrition education. As a result of my training in nutrition, I am a nutrition educator. I am actively searching for new avenues in which to offer nutrition education, and I want to be able to offer nutrition education to many types of groups and individuals. I want to show people how they can make use of nutrition to help them deal with some of the issues in their lives. My interest in nutrition education is the reason I designed this study. I wanted to examine how nutrition education could be used in support groups for people with cancer. This bias may also influence the results of this study, as I would like to be able to determine that there is a potential role for nutrition education in this particular situation.

To circumvent these concerns and biases, I have engaged in the criteria for building trustworthiness of my research as outlined by Lincoln and Guba (1985).

## 3.4 Data Collection Methods

### 3.4.1 Research Study Background

The original intent of this research was to assess the perceived nutrition related benefits that people with cancer obtained by participating in support groups run by cancer related organizations in the city of Saskatoon. After the collection of some contextual information, and difficulties with recruitment, the research focus changed. This section describes the reasons for these changes.

The original intended research participants were the members of support groups for people with cancer. It was thought by the researcher that having the group as a source of support may improve individuals' abilities to deal with the diet related effects of cancer. Background and contextual data regarding programming for two organizations that sponsor support groups for people with cancer in Saskatoon was collected through a review of organizational materials and meetings with key personnel (Appendix C). These meetings were conducted in May 1999. After examining this material, contacts were made with the specific program facilitators and more in depth personal interviews were conducted in order to fully understand the benefits participants receive from the groups (Appendix C). These contextual interviews were conducted from May to October of 1999. The first organization offered five different support programs, of which two were support groups, and the second organization offered four support groups. As a result of these interviews, the decision was made to approach the participants in the two groups in the first organization, and two groups in the second organization. Once this context was established, recruitment of people who had participated in support groups was undertaken.

Letters of recruitment (Appendix D) for the research study were prepared. In order to preserve confidentiality, the recruitment letters were presented to the offices of the organizations for distribution to persons on their mailing lists. The letters were distributed along with a letter of support from the organizations in at the beginning of February 2000. Recruitment letters were also given to the facilitators of the various support groups for distributions at their meetings.

By mid - April 2000, no one had responded to the recruitment letter. Calls to the facilitators of the groups yielded no recruitment. Upon the recommendation of key personnel in the organizations, and after meeting with the research supervisor, it was decided that the researcher would attend the next group meeting and personally invite group participants to participate in the study. By mid - May 2000, there was still no response, so the issue was addressed by the researcher and the advisory committee. Based on the contextual information gathered, there was an indication that the support group facilitators could be approached as key informants who would have information regarding the state of nutrition education in their groups. The focus of the research study was changed to reflect the views of the facilitators on nutrition education in the groups, rather than the views of the group members. The methods and procedures of the resultant study are outlined below.

### 3.4.2 Scope and Factors

The support groups for people with cancer that were accessed for this research are located in Saskatoon. Saskatoon is a large city located in western Canada with a population of just over 200,000 (Saskatoon Regional Economic Development Authority, 2002). Saskatoon is home to more than 40 community based organizations which offer services for the people of Saskatoon (Saskatoon Regional Economic Development Authority, 2002). A review of the support groups offered by various organizations in Saskatoon revealed that organizations related to cancer had the greatest number of groups. Facilitators of support groups from three organizations became participants in this research. The research was limited to Saskatoon and the surrounding area due to financial and logistical constraints of the researcher.

### 3.4.3 Subject Recruitment

The target population for this study was persons recognized as facilitators of support groups for people with cancer in the city of Saskatoon. The study participants previously identified as facilitators for support groups in the cancer related organizations were approached with a request to participate in this new study. Three facilitators from the first organization were unavailable to participate, but three did agree to participate. Of the three facilitators that were not available to participate, one interview had not been recorded due to technical difficulties, and so the information from it was not considered for this study. However, the group contextual information obtained from the interviews with the other two facilitators was included in this study. The three facilitators from the second organization agreed to participate. Finally, a third organization in the city of Saskatoon was approached with a request for their facilitators to participate in this research. A list of names to contact was forwarded to the researcher, and six facilitators agreed to participate. In all, fourteen support group facilitators participated in this research.

#### 3.4.3.1 Study Sample

There were fourteen participants in this study. Two were male, and twelve were female. Eight were cancer survivors, one was the spouse of a cancer patient, one was the parent of a cancer patient, and four had never been diagnosed with cancer. Four were professionally trained facilitators, and ten were volunteer facilitators.

### 3.4.4 Interview Design

#### 3.4.4.1 Interview Guide

Personal interviews with the group facilitators were conducted using an interview guide developed by the researcher, in conjunction with the research supervisor. Several practice interviews were conducted with the research supervisor and other students in order to assess the flow of the questions on the interview guide. Drafts of the interview guide were reworked.

According to Rubin and Rubin (1995), the best interviews are ones that incorporate three types of questions; main questions that guide the discussion, probing questions to allow for clarification and elaboration, and follow up questions in order to pursue the implications of the initial answers. The interview guide allowed for all of these questions. For example, one question on the interview guide was with regards to what the facilitators perceived as barriers to incorporating nutrition education in their groups. Most study participants would list some barriers and then they would be asked about each barrier in depth.

#### 3.4.4.2 Interview Location

The interviews were held in several locations. Some study participants allowed the researcher to come in to their homes. One study participant met with the researcher in the researcher's office. Some study participants met with the researcher in their offices. One study participant met with the researcher in a public place. One interview was conducted over the phone. Locations were chosen convenient to the study participants.

#### 3.4.4.3 Recording Procedures

Each interview was audio taped, with the participant's written permission, and then transcribed by the researcher. Only the researcher had access to the audio tapes, and only the study participants, the researcher, the research supervisor, and the auditor had access to the transcripts. In the transcripts, all identifying characteristics of the facilitators were deleted, so that their identity remained confidential to the researcher. The researcher took only minor notes, mostly of non verbal actions and pauses, so as not to unduly distract the participant.

#### 3.4.4.4 Transcript Review

The recording of each interview was transcribed verbatim by the researcher. Each transcript was then returned to the individual participant for the participant to review. The study participants were asked to review their transcript, and sign a release form authenticating that the transcript contained an accurate account of what was discussed during the interview. Study participants were also encouraged to clarify any points of thought or elaborate on points that they had made during the interview. Data contained within the transcripts was only analysed after the researcher received the signed transcript release form.

## 3.5 Data Analysis

### 3.5.1 Analysis Procedures

In qualitative research, as information is collected, data analysis occurs continuously as themes and patterns are recognized. These themes are then consolidated into the next step of the research as well as into the analysis. The transcripts of the study participants formed the data for this study. The transcripts were analysed in terms of what information the transcripts contained, otherwise known as content analysis (Miles & Huberman, 1994).

In content analysis, the most frequent issues in the data give rise to the first set of categories. In this study, multiple readings of all of the transcripts generated a list of themes.

Each theme was assigned a code letter or word to facilitate coding of the transcripts. Each of the transcripts was then coded by placing the codes next to the portion of the transcript that was relevant to the theme being coded.

According to the content analysis process, themes must be unitised by the researcher (Miles & Huberman, 1994). A piece of information is considered a unit if it is the smallest piece of information that can solely support the theme. The transcripts are then coded according to the defined units, and then the individual units are gathered in a "cut and paste" type arrangement, so that similar data units support the main themes. In this study, the themes were unitised by first creating data files of each of the themes generated in the first step. These files were created by taking the coded portions of the transcripts and placing all of the portions together. Each of these files was then read multiple times to assess for sub-themes within the themes. These subthemes were then given codes, and each sub-theme was coded for within the individual file. Where necessary, the sub – themes were then placed in files so that they could be considered as data units. Once each theme was developed, a written account of the data contained within that theme was generated that outlined the major point of the theme and examined all of the supporting factors for that theme.

Themes are subject to continuous scrutiny (Miles & Huberman, 1994). For example, initial themes may fall by the wayside as new ones emerge. There were a few incidences of this in this analysis, mostly when a study participant would make a particularly articulate statement that would attract the researcher's attention when coding, and it would be coded, only to find that it was just an individual participants' experience, not a continuing theme in the transcripts. Another example of how themes are under continuous scrutiny is how two slightly different themes may combine to form one broader theme. This occurred in the analysis of this data with regards to some themes that were coded individually at first, but were later found to be stronger when related than they were on their own. Finally, all data contained in the themes was related back to the research questions.

### 3.5.2 External Audit

At the end of the data analysis, an external audit was conducted as a means of strengthening the dependability and confirmability of the study. The auditor was a nutrition professional, external to the research study, who was familiar with qualitative research and who had conducted previous research audits. For the purposes of review, all documents, data, journals, and research drafts kept by the researcher were provided to the auditor. The auditor assessed the research in terms of its data categorization, confirmability, dependability, methodological shifts, implementation of design, and potential incidence of researcher bias. The purpose of the audit was to authenticate the research findings and increase trustworthiness in the study. Appendix E is a copy of the audit report confirming the trustworthiness of the study.

### 3.5.3 Reflexive Journal

Lincoln and Guba (1985) recommend that qualitative researchers make use of a data collection technique known as the reflexive journal during the entire research process. The purpose of the journal is to give the researcher a place to record thoughts regarding herself and the methods she is using. The components of the journal include a daily log of research events, such as meetings, a journal of personal thoughts to discuss biases and perspectives as they arise within the research, and a method log that chronicles the methods used, changes to methodology and other relevant issues.

The reflexive journal for this study occurred in two parts. During the development of the research project and the collection of the data, the reflexive journal was audio taped by the researcher in the privacy of her home. The tapes were stored in a secure place and retained for the duration of the study. Once the interviews were transcribed and analysis procedures had begun, the researcher found it easier to keep a written journal in a computer file with the analysis files. The journal encompassed all of the components as recommended by Lincoln and Guba (1985), but concentrated on the researcher's personal thoughts and the many changes to the research methodology.

### 3.6 Ethical Approval

An application for approval of the research was submitted to the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research. The application included an abstract, description of study participants, methods and procedures, and methods for ensuring the confidentiality of the research. Drafts of the interview guides and consent forms, including transcript release forms, were included for review. Ethical approval (Appendix F) for this research was received on November 14, 2000.

# Chapter 4 - Results and Discussion

## 4.1 Introduction

This chapter presents the results of the thematic content analysis of the data. The results are presented and discussed according to the themes which emerged from the transcripts of the interviews with the research participants. There are three major areas of discussion. The first major area of discussion is information regarding the study participants' experiences of cancer. The second major area of discussion is information about the support groups. Finally, the third area of discussion includes information about the state of nutrition education in the support groups. Following a description of the research participants, each of these major areas is discussed.

In the presentation of these results, the words "study participants" are used to indicate the personal experiences, thoughts, and ideas of the facilitators who participated in this research. The words "group members" are used to describe the perceptions that the facilitators had of other members of the support groups that they were facilitating.

## 4.2 Description of Research Participants

The participants for this research were the facilitators of various support groups in Saskatoon and the surrounding area. The facilitators were chosen as key informants who would have information regarding the current state of nutrition education in their groups, as well as thoughts on the future role of nutrition education in their groups. There were fourteen facilitators in total, each working for one of three organizations that offered support services for people with cancer. Of the fourteen facilitators, twelve were women and two were men. Eight facilitators were cancer survivors, one was a spouse of a cancer patient, one was a parent of a child with cancer, and four were not cancer survivors. The types of groups offered by the organizations and the number of facilitators participating in this study is outlined in Table 1.

Table 1. Description of study participants according to parent organization.

| Organization | Group Type | Study Participants |
|---|---|---|
| First (1) | One on One Visitation (2) | 2 |
| | Men with Prostate Cancer | 1 |
| | Parents of Children with Cancer | 1 |
| | General | 1 |
| Second (1) | Women with Cancer | 2 |
| | Men with Cancer | 1 |
| Third (1) | Open (3) | 5 |
| | Closed (3) | 1 |

1. For reasons of confidentiality, participating organizations are not named.
2. The one on one visitation program in the first organization is not an actual support group, but the leaders of that program had provided some contextual data about the experience of cancer and the role of social support.
3. The open group is the main group that is open to anyone with an issue related to having cancer. A closed group is a type of group that the governing body of the organization sometimes implements that is smaller than the open group, uses a registration system, and is limited to those people dealing with the issues for which the group is set up. For example, the closed group in this research had been set up for women with gynecological cancers.

The three organizations offered various types of groups. The first organization offered three types of groups. The first was a one on one visitation program where a group of women who had survived breast cancer for more than two years would visit newly diagnosed breast cancer patients to offer support. Second, there were general support groups, namely a group for any adult dealing with cancer, and a group specifically for men with prostate cancer. Finally, there was a group for parents of children who had cancer. This group met in the context of social activities for the children, and while the children were busy, the parents would meet. The support group in this case was made up of adults, but the discussions frequently centered around issues to do with their children.

The second organization offered two groups, both for adults with cancer. One was a group for women and the other was a group for men. The third organization offered two types of groups for adults with cancer. The first group was a large group that was open to anyone in the community who was facing issues as a result of having cancer. This group was the main support group in the organization. However, sometimes the governing body of the organization would implement what they called a closed group. The organization would implement a closed group when issues repeatedly arose in the open group that the governing body felt were beyond the scope of the open group. Some of these issues included people dealing with a metastasis of their cancer, or people dealing with a very specific cancer, or the needs of the spouses of people with cancer. Issues such as these were identified as being too specific to address in the larger group, and so people dealing with the specific issue would be asked to meet at a different time to address those specific issues with others who were in a similar situation. Closed groups were limited to smaller numbers, and required a registration. Closed groups would also be facilitated by a professional therapist or counselor, who could help those group members deal with the more specific issues.

## 4.3 Study Participants Experiences of Cancer

In order to more accurately describe the context in which nutrition might be discussed in the support groups, information was needed about the issues that support group members were facing. To gather that information, at the end of the interviews, study participants were asked about their experiences with cancer. Study participants spoke both of their personal experiences with cancer and the experiences of other group members that they had observed at group meetings. There were several themes that arose from the data that provided information on the experiences of having cancer. These themes included being diagnosed with cancer, treatment issues, emotional aspects of dealing with cancer, family issues, and the impact of cancer on all aspects of a person's life.

### 4.3.1 Diagnosis

Study participants indicated that people who are diagnosed with cancer wonder why they got the disease. Many support group members question why they were diagnosed with cancer. Group members question their previous behaviors, such as their diet, or if they could have changed the outcome by behaving differently. Group members were shocked to be diagnosed with cancer because the group members never perceived themselves to be unhealthy.

> ....people are kind of questioning....why did I get cancer, they are looking for a reason or a cause....

Support group members not only have the ramifications of a devastating disease to deal with, but people with cancer also have the need to make sense of being diagnosed with cancer. In order to obtain an understanding of why they were diagnosed with cancer, some group members seek out as much information as they can find, so that they can construct their own personal beliefs about what is happening to them.

> People get, everybody has their, they build these theories in their minds cause everybody has to try and make sense of how they got to be here and why did I get this diagnosis....

These findings are consistent with those of other researchers. In a study of the functions of support groups for people with cancer, Cope (1995) found that group members frequently discussed various aspects of being diagnosed with cancer. In her study, group members would exchange information about the newest diagnostic tools, their own personal experiences of being diagnosed with cancer, as well as their personal feelings and reactions to having been diagnosed with cancer.

### 4.3.2 Treatment Issues

Study participants frequently mentioned that treatment for cancer impacts people with cancer. The main topic discussed was the side effects caused by treatment, with a particular focus on the physical side effects of chemotherapy.

Study participants indicated that some of the side effects are physical in nature. These include nausea, hair loss, skin changes, diarrhea, pain, fatigue, appetite changes, changes in taste sensations, hot flashes, and weight changes. The problems that support group members have with side effects from treatments are similar to those described by other researchers. Beisecker et al. (1997) conducted a survey of the side effects experienced by breast cancer patients. Hair loss, fatigue, nausea and infections were the most frequently described side effects. Berger and Farr (1999), studied the amount of cancer related fatigue suffered by women undergoing chemotherapy for breast cancer. Fatigue was greater in the midpoints of chemotherapy cycles, as well as in the later cycles. Demark - Wahnefried et al., (1997) found that weight gain experienced by breast cancer patients could be due in part to a reduction in resting metabolic rate and a decrease in physical activity levels.

Participants in this study also expressed that there are other side effects that are less physically draining, but no less devastating. Irritability, indecisiveness, learning disabilities, and depression, were either experienced by the study participants or observed from other group members.

Study participants revealed that there can be multiple medications required as part of treatment for cancer, and that these medications can interfere with the daily life of the person with cancer. These medications could have side effects of their own, such as weight loss or gain, and that dealing with these new side effects in addition to the disease can be especially distressful to the person with cancer.

Treatment issues were also a frequent topic for discussion in the support groups. Study participants recognized that the recent diagnosis and treatments are so overwhelming that it is all most people can do to manage their daily lives. Support group members want information on how to cope with the side effects of treatments. Sometimes, group members also want information on new treatment options. These findings are in agreement with those of other researchers. Cope (1995) found that participants in support groups often requested treatment information from other participants. Bauman et al. (1992) found that some cancer patients attended support groups in order to compare their own emotional and physical progress with that of others. Guidry et al. (1997) found that support groups were valuable in assisting cancer patients with continuing treatment.

Study participants described how some group members talk about their struggles within the medical system. Many of the pieces of advice described by participants in the discussions were related to what people did to cope with treatment and the side effects.

> I can think of one woman in particular in the small group who was having a great deal of difficulty in having anything stay in her system, she would either develop terrible diarrhea or she would be vomiting, and several of the other women has some suggestions for her to try things and she was actually able to eat some stuff and keep it down, other than just the ensure, and she was literally wasting away, she was so thin, but she actually go to the point where she could eat food and they talked about eating little bits and to heck with the meals, and you know, just do it when your body wants it.

Finally, treatment schedules was issue of concern for support group members. Study participants depicted how the families' schedule is centered around the treatments. At first, when people are on treatment, they see the same people all the time at the clinic. Other people on treatment at the clinic become a source of information and support. As treatment goes on, however, it gets more infrequent. As a result, people with cancer that used to see each other regularly now lose contact. Study participants stated that support group members often feel a sense of loss when treatment ends.

### 4.3.3 Emotional Aspects of Cancer

Study participants discussed how having cancer can impact on the emotions of the person with cancer, including feeling unsettled or upset as a result of being diagnosed with cancer. People with cancer also feel a great deal of fear. As well, study participants shared how some people with cancer will become depressed as a result of having to deal with so many emotional issues.

#### 4.3.3.1 Unsettled and Upset Feelings

Study participants recalled how group members would express feeling unsettled about what was happening in their lives. Other researchers have found that cancer is emotionally disruptive. Cope (1995) found that support group members would often report mood swings as their feelings about their diagnosis would vary.

Support group members in this study would often question the normalcy of what they were going through. They wanted to know if their feelings and reactions were normal. Group members want to know when they can expect their lives to return to normal. For example, women with breast cancer who have mastectomies often suffer from some nerve damage that affects the sensation in their arm, and they often want to know how long their arm is going to feel numb.

> I have met groups where the entire time has been looking at emotional issues, whether it be fear, how my family is reacting or not reacting, how my best friend is coping with this diagnosis or how she is stepping away from me....

Study participants also described how group members would be upset because the diagnosis of cancer meant that they had to redefine their perception of themselves, as well as contending with the changing perceptions of others. Many support group members would not have defined themselves as unhealthy before the cancer diagnosis, since many of them believed they had taken care of themselves. The destroying of self perceptions often made the diagnosis emotionally devastating. These findings are consistent with those of other researchers. Ferrell et al. (1996) found that the impact of having cancer on the self concept of cancer patients was a predominant psychological effect of cancer.

People with cancer also have to address feelings with regards to their preconceived ideas about the disease and its treatments. For example, study participants indicated that group members had been aware that individuals undergoing treatment for cancer are likely to be nauseated. However, support group members found that it was quite a different experience to be that person with cancer who was nauseated, vomiting, and unable to eat. Many group members felt a sense of disbelief in being diagnosed with cancer.

Support group members are also upset with the way a diagnosis of cancer changes the perceptions that others have of them. Not all the side effects of treatment for cancer are visible, and others in the person's life may not think that a person with cancer is very sick. Conversely, study participants also described how a person with cancer may not actually be very sick, but others in the person's life may hear the word cancer and think that the person is going to die. When the perceptions of one person change, the interactions in the relationship also change. Group members felt that even if they were sick, they didn't want other people thinking they were sick.

#### 4.3.3.2 Feelings of Fear and Depression

Study participants indicated that many group members have feelings of fear as a result of being diagnosed with cancer.

> ....we've never been there before, we don't know what's going to happen, and this is frightening, this is very scary stuff, cancer is very scary.

These fears include the fear of death, the fear of having to live with a serious illness, the fear of the treatments they will have to undergo, the fear of how their personal relationships might change as a result of the disease, and the fear of how they are going to be able to cope with all of these changes. These results are consistent with those of other studies. In conducting a study that evaluated various aspects of the quality of life of breast cancer patients, Ferrell et al. (1996) found that cancer patients feared the spread of cancer, the chance of a recurrence, and having to undergo future tests.

According to the participants of this study, people with cancer are never sure of what the future might hold. For example, every visit to the doctor causes anxiety in anticipation of a recurrence or an inability to attain remission. People with cancer can improve their emotional wellbeing somewhat by looking at their bout with the disease as a journey, and investigating anything that will help with healing. Study participants felt, that this way, people with cancer can realize that cancer is not the only important part of their lives.

Both voicing these fears and how to adequately deal with these fears were frequent topics of discussion at group meetings. Group members can also use these fears to effect change. Sometimes a drastic event, such as receiving a diagnosis of cancer, is necessary for people to reevaluate their lifestyle behaviors.

Sometimes, people with cancer end up being depressed as a result of not being able to deal with some of the overwhelming emotional issues. Treatments can take an emotional toll on patients as well as being a physical hardship. Having to deal with so much at one time sometimes results in people with cancer becoming depressed. The long journey in recovering from cancer can sometimes result in people with cancer becoming depressed. It is hard for a person with cancer to know that they will have to live with the possibility of recurrence for the rest of their life.

> Probably just the whole depression and worry and stress of it all, just the idea of, like you have the big c and it's, your still, even though there's treatments available, once your diagnosed with cancer it's like a great big bomb hanging over you so you have to kind of, get themselves into a frame of mind that they are going to beat it, once they have accepted it, probably be able to carry on with their life a little better.

These results are comparable to those of other researchers. Badger, Braden and Mishel (2001) studied the relationship between depression and side effects in women receiving treatment for breast cancer. Depression influenced the severity and number of side effects experienced by the women, especially fatigue, anxiety and difficulty with concentration.

### 4.3.4 Family Issues

Study participants identified some issues facing families in which a member has been diagnosed with cancer. Illness is a life event that can have lasting effects on the family, since there are usually physical changes in the person with cancer, upset feelings and feelings of fear in family members, and perhaps some unanticipated financial hardships. Each family member may be at different developmental stages, and have different responsive needs to the situation, which makes family issues a frequent topic of discussion at the support groups.

Study participants indicated that the physical changes that a cancer patient may endure may not be understood by all family members. For example, it may be hard for children to understand why a parent is always tired or why they are bald, and it may be uncomfortable for family members to learn how to deal with someone who is now physically different than they were before. Sometimes the person with cancer may want to make some lifestyle changes, and other family members may resist the changes that the person with cancer tries to implement in the home. Study participants described how other family members may not want to make lifestyle changes because they don't understand why they need to make the changes when they aren't the person with cancer.

Emotional issues on both the part of the person with cancer and the other family members may influence how the family deals with a member that has cancer. Study participants described how some group members became worried about family issues, such as who would care for the children if they, the parent, should die. The person with cancer may also feel that the family is burdened enough, and may not want to talk about what they are going through with the family members. These findings are consistent with those of Mesters et al. (1997), who found that family members often have contradictory feelings about cancer. He describes how the person with cancer is reluctant to discuss cancer related problems with other family members because he or she does not want to cause the rest of the family to worry.

Finally, family members may not be able to adjust to having to fill other emotional roles in the family. For example, if a mother is looked to as the person who provides comfort, and now is not able to do that because she is sick, the children have to learn to look for comfort in other places. Study participants offered that in some cases, the burden to keep things the same may still fall to the sick person, which can cause even more stress to the sick person.

> I remember one woman, who was experiencing a recurrence of her breast cancer, and she was really very sick, but the family, she had grown children, and the family was still expecting her to put on Christmas the way she always had, and often they will feel they can't just say no, I can't do this...

Sometimes, financial hardship is a result of the illness, and participants described how this can affect the whole family. Financial hardship may be due to the person with cancer having to come to the city for treatment, and the cost of maintaining two living places. Financial hardship may also be due to the person with cancer having to leave his or her job, either for an extended period of time or permanently, due to the illness. Study participants suggested that financial hardship might affect the family in that budgets would have to be reworked, perhaps causing changes for all members of the family.

> ...sometimes people have been forced to quit their jobs and have no income, except for a bit from disability...

### 4.3.5 Changes after Cancer

Study participants discussed how support group members would often change after being diagnosed with cancer. The two biggest types of changes identified by the study participants were behavior changes and changes in perspective.

#### 4.3.5.1 Behavior Change

Study participants described how being diagnosed with cancer led people to make changes to their lifestyle and behavior. Actual dietary changes made by support group members included lowering fat intake, reducing or eliminating red meat, reducing or eliminating caffeine, increasing fruits and vegetables, taking specific vitamins, such as Vitamin C or Vitamin E, or introducing new foods to the diet, such as soy, flax, and legumes. These findings parallel those of other researchers. Salminen et al. (2000) also found that cancer patients reduced their consumption of animal fats, sugars, and red meats, and increased their consumption of fruits, berries, and vegetables.

Conversely, group members often made no behavior changes as a result of their diagnosis. In some cases, the group members were maintaining a healthy lifestyle and there weren't many more changes they could make. In others, some group members didn't connect their diagnosis with their lifestyle and chose to maintain their current behaviors, including smoking, drinking and eating unhealthfully.

#### 4.3.5.2 Changes in Perspective

Study participants also mentioned instances of how some group members would change their perspective once they had received a diagnosis of cancer. Some group members, instead of maintaining their current lifestyle, would actively search out new ideas that might make a difference in the outcome of their diagnosis. For example, some group members would explore options that they had previously dismissed, such as adopting the vegetarian or macrobiotic diet to improve their health.

Study participants also outlined how, instead of immediately adopting the advice of another group member, group members would often research, and more carefully evaluate, how a change would fit into their lives. Some group members would become more open minded and less dismissive of new ideas, reading and evaluating information more carefully.

> I think when you have cancer, when you are diagnosed with cancer, and post cancer, you tend to look and read articles more carefully about foods and cancer related issues, and if there's something that comes out....you read the article and you assess on your own whether you can buy into it

Study participants also described how some group members would come to regard their cancer as somewhat of a blessing in disguise. That is, they viewed it as the wake up call they needed to force them to make some changes, not necessarily all physical, in their lives.

> I am not very good at explaining this. It gives them comfort, it gives them hope and they begin to see that they can fight this disease maybe and that they need to change their lifestyle perhaps, and that they do so after being to the group. They maybe change the way they eat, the way they rest, and relax, and they are told to not put themselves last, put themselves to the forefront and express their needs. I think the cancer personality maybe is a person that has got to fix people's lives for them quite

> often, they've got to be sort of a servant, and they have to learn that they have to think about themselves, and their health is immediate, they need to start right then and there for their health.

These findings parallel those of Kelly (1998), who evaluated the effectiveness of attending a support group on survival rates in women with breast cancer. All of the women surveyed responded that their outlook had changed as a result of being diagnosed with cancer. Kelly (1998) reports that initially, the women all saw their breast cancer diagnosis as a negative experience, but that participation in the support group allowed them to eventually view the experience as a positive one.

Study participants outlined several ways by which group members changed their perspective. Support group members may have been able to receive more information about a topic as a result of coming to the group. For example, one participant described how members of her group would share strategies to eat healthier, sleep better, reduce stress in their lives, and challenge their thinking about the issues that surface as a result of having cancer.

Support group members may have also observed role models during group meetings. Study participants outlined how having the support of people who have also been through the same type of problems helps the group members to change their perspective, because they can see how the change in perspective has affected others.

> ....they are not offered rich cookies or desserts at the meetings, they are offered something more healthy for them, so that they get the idea that they don't need coffee to exist.

### 4.3.6 Participants Experiences of Social Support

Study participants often provided first hand descriptions of their experiences of social support, as well as experiences of social support that they witnessed in other support group members. The benefits of social support, the mechanisms by which they received support in the support group, and the role of social support in health and wellbeing were all discussed by the study participants.

#### 4.3.6.1 Benefits of social support

Study participants identified and described several benefits of social support. Participating in a social support situation helped to reduce feelings of isolation, gave support group members an opportunity to discuss topics they might not normally discuss, and offered a sense of hope to the group members. Galinsky and Schopler (1994) found that benefits of participating in a support group for people with cancer included feelings of hope, acceptance, relief, and reassurance, as well as opportunities to gather information about cancer and hear different perspectives from other people with cancer.

Study participants felt that social support helped to reduce feelings of isolation. Other researchers have also found that participating in a support group helps in reducing feelings of isolation and alienation (Lavoie & Stewart, 1995; McLean, 1995). Support group members were able to share fears and concerns that they weren't able to share with anyone else. Group members didn't have to explain or justify their feelings to others in the group.

> It also provides a group where, a place where they can be heard and understood, they don't have to explain in great detail what they are wanting, people have been through a similar experience and they can understand, again, it's not the same, so it's not identical, so there's a lot of talking..., a place for people to come and make, ask questions, gee that is what happened to me, that's what happened to me, this is my experience, and women with all different types of cancers
>
> They know the fear, they know the frustration, they know all that, it's a time, to, often people will say thank goodness, I thought I was the only person who felt that way.

These findings echo those of Mesters et al. (1997), who found that cancer patients often have difficulties talking about their disease with their family members.

Study participants indicated that one of the benefits of support is that, in a supportive situation, people can talk about topics that they might not normally feel comfortable talking about. People in the support group can talk freely about certain topics. They can freely share their thoughts and experiences through the nature of the discussions that take place in a support group. Group members would often talk about treatment issues and some of the fears that they were experiencing as a result of being diagnosed with cancer. Group members could not discuss these concerns with people who were not diagnosed with cancer, simply because the level of understanding was not there. Group members could also talk about any type of concern that they had without the fear of being looked down upon by others.

> I think when you are, cancer, either in the treatment process or even past the treatment process, it's a safe group in which to talk about cancer, it's a safe group in which to talk about fears, to talk about things that can help you get through treatment, it's, women are terrifically supportive of each other, particularly in that context, and I can't quite understand that dynamics of it, that a group of women who don't know each other come together and are terrifically supportive of each other.......

Another benefit of social support mentioned by the participants is the sense of hope and encouragement that the participants received while participating in the support group. Support group members would reflect that it was easier to hear about the disease and its ramifications from someone who had had cancer rather than from a doctor or nurse. Group members felt the people who had already been through it were better able to understand the concerns of the new members because they afforded the new members a sense of hope. One of the reasons members stayed with the group was to provide that same sense of hope to the next person. Hearing from someone who had already lived through similar experiences provided hope, which is similar to what Lavoie and Stewart (1995) found when they reviewed the characteristics of social support groups in Canada.

> ...different people that I have visited have said, you know, it's so much easier for you to tell me about what I am going through, or have gone through, than somebody who has read it out of a book kind of thing...

#### 4.3.6.2 Mechanisms of social support

Study participants identified several mechanisms by which support group members derived social support. These mechanisms included finding relief from their concerns, being listened to, having their feelings validated, and feeling an emotional connection with others.

Social support allowed the support group members to feel relief from the concerns they felt. This relief occurred in various ways. Support group members can feel relief simply by being able to share their experiences with others in a relaxing situation. They are relieved to not have to keep up appearances. They are also relieved by being able to talk to someone who shares an understanding of the situation. They often found someone with whom they could bond. This finding echoes that of Everett et al. (1995) who found that one of the reasons support groups are so successful is because participants feel a sense of relief when they realize that they are not alone.

> ....For some people it's like, the first time they can talk and get support from other women, and they just, never ending, as far as their divulging of information....and people are able to talk about stuff now that they may not have been able to talk about before, so it opens that door...

Study participants identified the sense of satisfaction at being listened to as one of the ways in which group members obtained support. One of the roles of being a member of a support group is to be there to listen to others in the group. Many times, support group members felt that they had no one to listen to their concerns because they didn't want to burden their families further, and friends didn't completely understand. In the group, members didn't always have to have an answer for a person who was expressing a concern, often, it was simply enough that they were being listened to.

> .....we listen to them, I think listening is one of the things, they want to share but they don't want to share with their family because they are afraid they will make their family feel worse... they know that people there understand how they feel, why they feel that way, so I think that's a big part of the support, is talking to your peer....

Another mechanism by which group members obtain support is by having their concerns validated. Support group members feel validated by not having to justify their feelings or concerns. They also feel validated by being reassured by others who have been through a similar experience. Galinsky and Schopler (1994) also found that participants in support groups derive reassurance from other members of the group.

> ....So a lot of venting, it's amazing how good it feels to be with a group of other people that know without your saying, they know how you feel, and they know....They know the fear, they know the frustration, they know all that, it's a time, to, often people will say thank goodness, I thought I was the only person who felt that way.

Finally, support group members obtain support by feeling emotionally connected to others through their shared situations. Group members feel supported by not always having to explain how they are feeling or why they are feeling a certain way. Study participants indicated that once a group member feels that connection, they want to continue to feel that way, and so they will continue to come to the group.

> Yes, the support they feel it has helped them through it, they feel like they can talk about anything, they can talk, they aren't alone, they can relate, even if they can't really express what they feel the others kind of know what they are talking about, it helps the newer people to feel more comfortable.

#### 4.3.6.3 The role of social support in health and well being

Study participants identified a few ways that social support becomes important in health and wellbeing. Social support allows support group members to observe role models, and increase self awareness and understanding. Social support situations serve as a complement to the traditional medical system.

Participating in a social support situation provides an opportunity for group members to observe role models. A role model is someone in a particular situation who sets an example for others in that situation (Allen, 1990). Support group members become role models by talking about their experiences. Other group members learn that talking about the situation helps to resolve issues. Group members may also obtain valuable information by listening to the experiences of others. Group members are also role models by providing examples of how live with cancer.

> To be there for the patients to help them through a tough time and explain to them that it is not the end of the world...It's to be there to talk, or you can help them with their exercises, show them that "here I am, I have had it too"

Social support provides a method for increasing self awareness and understanding. Having others they could look to provided some group members insights into their own feelings. Support group members can increase their understanding of their experiences by gathering information from others who have had similar experiences. These findings parallel those of Cope (1995), who found that sharing the illness experience and providing strength were two functions of a support group for cancer patients.

### 4.3.7 Reasons Group Members Participate in the Support Groups

The study participants outlined several reasons that support group members gave for participating in the groups. These reasons included the group was a place for members to feel better, and for members to meet others in a similar situation.

The support group is a place for the members to feel better. Support group members sometimes feel the need to keep up appearances for the sake of their loved ones. When they are in the group, they can be open and honest because they know that other members understand how they are feeling. People with cancer can feel isolated and different from their loved ones as a result of their diagnosis. Coming to the group gives them a place where they are the normal people and everyone else is different. These findings agree with those of other researchers. McLean (1995) outlines how participating in a support group helps to reduce feelings of isolation and alienation. Galinsky and Schopler (1994) found that the normalization of the experience, and feelings of acceptance, hope, relief and reassurance were reasons why group members participated in the groups. In a study assessing the perceived benefits of attending support groups, Stevens and Duttlinger (1998) found that support group members identified coping skills, a sense of community, and obtaining medical information as the most helpful features of the group. Stevenson and Coles (1993) surveyed the reasons why women attend support groups and the benefits they perceive from attending. Women attending the support group wanted information and emotional support in coping with the psychological effects of cancer.

Group members expressed that knowing others are in the same situation was a great comfort. Observing someone who had come through a similar experience, and was enjoying life again, gave group members confidence to believe that they could survive cancer as well. This agrees with the findings of Lavoie and Stewart (1995), who maintain that cancer patients participate in support groups for the sense of hope and encouragement that they find there.

> They're seeking support, they just want to make that connection with other people, I mean a lot of people have good support from their family and friends, but it's that connection with another person with cancer and usually they come initially with a lot of questions and maybe about treatment or their diagnosis or whatever and then if they continue to come back to the group it's for the support that they find there.

## 4.3 Support Groups in Saskatoon

In order to more accurately describe the context in which nutrition education might be offered in the support groups, information was needed about the characteristics and factors that might influence the operations of the support groups. To gather that information, at the start of the interviews, study participants were asked to describe the operations of their groups. The research participants described the details of how their groups were formed, organized, and operated. Study participants also discussed the factors affecting the functioning of the groups, including, personal characteristics of the members, group dynamics, attendance issues, and the use of professional facilitators.

### 4.4.1 Group Formation

Study participants offered information regarding how their groups were formed. Each group was formed in different ways, and for different purposes. Most groups were formed as a result of individuals identifying a need for support services for people with cancer. Sometimes groups were formed when individuals at the organizations identified the need for a particular group. Sometimes the groups were formed as a result of an expanding network of support groups. Other times, groups were formed as a result of individuals in the community identifying their needs for support and collaborating with other individuals to form the groups. The formation of the support groups are discussed in generalities, because to provide more details would leave the groups vulnerable to identification.

### 4.4.2 Group Purpose

Study participants identified the main purpose for having support groups was as a way to help meet the needs identified by the people with cancer. These needs are both emotional and practical in nature. Emotional needs are met in the groups by the sharing of experiences with others who are in similar situations. Practical needs are met in the group by receiving advice, support, and information from others who have had similar experiences. These findings are consistent with those of other researchers. Crawford et al. (1997) outlines how support groups for prostate cancer patients have been established to help satisfy the informational and supportive needs of men with prostate cancer. Gregoire et al. (1997) indicate that the purposes of their support group for men with prostate cancer include helping men with prostate cancer better understand their illness, as well as helping them voice their emotional concerns about their disease within an emotionally supportive setting.

Support group members felt that the best person to offer advice was someone who had already been through a similar situation. Study participants also indicated that all of the needs of people with cancer are not immediately known, and the support group is available when a person with cancer needs the help. These findings agree with those of Cope (1995), who examined the functions of a support group for women with breast cancer. Sharing the illness experience was identified as a major function of the support group, in that the sharing included expressions of deep emotions and feelings and not just the exchange of superficial information.

Participants in the current study indicated that support group members sometimes felt that they couldn't address all of their concerns with their doctors. In some cases the groups were also set up to deal with concerns raised by specific diseases, such as breast cancer or prostate cancer.

### 4.4.3 Group Organization

Study participants described many aspects of the organization of their groups. The roles of the group members, the roles of the facilitators, the meeting logistics, and the topics discussed at meetings are all described below.

#### 4.4.3.1 Roles of Group Members

Study participants indicated that a person's role in a support group changes over time. The first role of a group member is to receive support. A group member does this by telling his or her story – diagnosis, treatment, reactions, etc. At this stage, people with cancer have many fears and feelings that they probably have never conceived of before. They also do not know how to cope with these new feelings. These feelings result in a feeling of crisis, and the first role of a support group member is to receive support to get through this crisis. These thoughts agree with those of Rootes and Aanes (1992) who indicate that one of the purposes of a support group is to "assist members emotionally and educationally until the crisis is past" (p. 379).

The second role of a support group member emerges as time passes. As treatment ends, and feelings of crisis subside, a group member then becomes someone who can give that support to someone else who needs it. This role is described by the study participants as a role model, someone who is energetic and positive, and who shows the new members that it is possible to live with cancer.

> I remember being very encouraged by how energetic and good humored and positive these other women were....it was like looking at the light at the end of the tunnel, you know thinking, I can get there, I can be like them, they've got hair and you know, they've got energy, and they are laughing, and I can back there too...just the sheer impact of a room full of people who all have cancer and don't appear to be dying right this minute....

#### 4.4.3.2 Facilitator Roles

Some facilitators described what they perceived as their role to be in the group. The facilitators direct discussion, provide information, and identify issues that might need more discussion. They also assess the needs of the group members and ensure that everyone has an opportunity to share. These roles are consistent with facilitator roles described by others. Cella and Yellen (1993) describe the various roles of facilitators in support groups for cancer patients. These roles include promoting cohesion by encouraging constructive discussions, developing a safe climate by helping group members accept each other's differences, and giving information without being thought of as the expert.

According to the study participants, it was the role of the facilitator to arrange for speakers and to guide the conversation so that everyone had an opportunity to discuss the issues that are most pressing to them. Topics are not deliberately planted in order to create discussion, but the facilitator is responsible for maintaining the discussion. Facilitators might guide the conversation by asking for the opinions and experiences of other members after one member has shared an experience.

> ....the facilitators task is one to make sure that we draw in as many of the people as we possibly can.

Facilitators indicated that they were responsible for reminding the group that what was shared in the group were people's experiences. Advice should be taken with caution. Facilitators also alerted organizers to prominent issues facing group members. They also suggested topics for the organization to deal with. As well, facilitators continually assessed the group and identified the needs of the group members as they arose.

> I think as a facilitator you're always aware of what the needs, you have to be aware of what the needs of the group are, and I think if nutrition comes up again and again and again, then you have to say if that's, if issues have come up over three sessions, it's darn well time we brought someone in here to talk about whatever the specific issues are....

#### 4.4.3.3 Meeting Logistics

The majority of study participants indicated that support group meetings are 90 minutes to two hours long. Meetings typically begin with a check in, followed by a discussion period, and a 20 minute meditation. During the check in, support group members typically introduce themselves and give a synopsis of their disease and treatment. Check in time was often where group members identified issues of utmost and personal concern for them.

After issues were identified, discussion would proceed in one of two ways. The first method of discussion was that group members would each take turns talking about their experiences with the issue, usually going around in a circle type of format. The second method of discussion was that group members would discuss issues in a back and forth dialogue. The dialogue would be between the person with the issue, and the person sharing his or her experience with the issue. Most support group meetings were informal and relatively unstructured, with everyone having an opportunity to share.

> It is just like a normal conversation, sometimes in the discussion we still go around in a circle so every person has an opportunity to speak.

Support group members would frequently bring up something they had recently read about, and then ask other members for opinions and input they might have on the subject. Group members are searching for the reasons they were diagnosed with cancer. Group members examine all aspects of their lives to see what they might be able to change in order to affect the outcome of their diagnosis and prevent a recurrence.

> Some of it is personal, about their own lives, some of it is what they have read, information about cancer. We talk even about the emotional, philosophical, spiritual aspects of it, of coping.

#### 4.4.3.3.1 Advice Sharing

The study participants identified advice sharing as one method by which the group members share their experiences. Group members would share advice around feelings of normalcy, similar experiences, and problem solving. Many new support group members want to know if what they are feeling is normal, what they can expect, and how to handle situations that arise. Group members also wanted to know about treatment, how to handle the emotional side of their illness, or even just new information about cancer.

> Most of the time I would say that the big area of concern is "How I'm reacting to the treatment and how has anyone else reacted?" like, "Am I normal?". That seems to be the issue we address many, many times; "Am I, when I feel this way or when I, I'm very tearful or can turn to tears at the drop of a hat, are those the kinds of experiences that other people have

Advice sharing was often in the format of older members answering questions and addressing concerns of newer members. The older members would recount their experiences, and share what they did to get cope with their disease. Support group members would share ideas that helped them solve various problems, such as dealing with treatments. Group members would also share feelings regarding what they have learned and how they have changed. The newer group members look to the experiences of the older group members to judge the normalcy of their feelings about what they are going through.

> ....they do a lot of problem solving, in terms of well gee when this happened to me, this is what I tried, have you tried, a lot of support for people who are going through a real difficult time, very practical suggestions for things, like this is what I did when my hair started growing back in and was driving me crazy and I found this worked really well, those kinds of real practical things as well.

This occurrence is explained by the findings of other researchers. Rootes and Aanes (1992) indicate how the shared experiences of group members are an important part of successful groups. They describe how members who have had similar experiences are in "a powerful position to understand and accept new and existing members" (p. 380). Cope (1995) found that when members of a support group for women with breast cancer would share their experiences, the detailed emotional discussions would provide a sense of normalcy for the feelings of the group members.

#### 4.4.3.3.2 Meditation

Meditation is a relaxation exercise that was practiced by several of the groups. Each meditation was about 20 minutes long, and each meditation was performed at the end of the regular group meeting. Study participants suggested that meditation is included in the group programming for two basic reasons. Firstly, meditation is used is to emphasize the need for relaxation and show how taking care of the whole body helps one feel better. Secondly, mediation is used to give participants a chance to experience meditation as a way of increasing the relaxation in their lives. Study participants indicated that meditation is well received by the participants of the groups that use it.

#### 4.4.3.4 Topics Discussed

Study participants identified many specific topics that are discussed in the groups, but there were three main frames of discussion, namely practical concerns, emotional concerns, and treatment related issues. These areas of discussion parallel those of Cella and Yellen (1993) who found that topics of discussion in support groups for people with cancer included psychological topics, interpersonal and social topics, and topics related to cancer. Psychological topics included feelings of anger, guilt, and fear, as well as incidences of denial. Interpersonal and social topics of discussion included marital problems, loneliness, isolation, and role changes at work and at home. Cancer related topics of discussion included coping with the side effects of treatments, alternative therapies, and the financial costs.

The topics of discussion at the support groups in this study are outlined in Table 2.

Table 2. Examples of Practical, Emotional, and Treatment Related Topics of Discussion at the Support Group Meetings.

| Practical Concerns | Emotional Concerns | Treatment Related Issues |
|---|---|---|
| Dealing with Side Effects | Personal Feelings | Medications |
| Financial Assistance | Feelings of Family | Comfort Levels |
| How to take Vitamins | Feelings of Friends | Side Effects |
| | Changing Relationships | |

Practical concerns were issues that group members simply needed more information about, such as dealing with lymphodema, taking vitamins, and obtaining financial assistance. One of the facilitators described how they have had speakers in to talk on adapting to lymphedema, a side effect which may cause physical limitations. Support group members frequently took the opportunity of being in the group to ask other members about the details of vitamin supplementation. Another facilitator explained that the organization tells its membership that they have resources to help with practical concerns, such as meals on wheels, and financial assistance for those who need it.

Emotional concerns included how group members were feeling about what was happening to them and how they were dealing with their feelings. Support group members wanted to know if what they were feeling was normal, and how others dealt with similar feelings, because the anger and the fear can be quite substantial.

> ...for emotional we probably discuss what, how to more effectively cope, some of their feelings around depression, some of their feelings around, dealing with having a cancer diagnosis and having it hang over your head, and the possibility of recurrence, dealing with fear would be one major emotion we deal with, coping with reactions of family members and support and various mixed feelings on that in their home situations, so it is not only their own coping but the coping of others, spouse or partner or you know family, friends....dealing with the hopelessness, hopefulness factor, that's pretty much the emotional aspect of it....

Treatment related issues, such as medication effects, increasing comfort levels during treatment, and using nutrition to help alleviate side effects, were also discussed. The facilitator from the group for parents of children with cancer described how the parents would talk of the effects of their children's steroid treatments. Study participants indicated that group members would discuss what they could do during treatment to make themselves more comfortable. Nutrition was often a topic discussed in relation to side effects. Group members discussed nutrition in terms of avoiding side effects, and how to manage nutrition in spite of the side effects. Group members also discussed nutrition in terms of what to eat or not eat in order to lessen the risk of recurrence of their cancer.

One of the groups now uses scheduled topics. The two facilitators from that group indicated that the group members identified that it was more convenient for them to know what was being planned in advance. The group cycled through ten topics every three months, including dealing with fear, the benefit of using a journal, sexuality, and nutrition.

Study participants also indicated that they often invited an expert to talk about major issues of concern. For example, one of the organizations has had speakers on various methods for alleviating fears associated with having cancer, such as the use of meditation and hypnosis.

### 4.4.4 Factors affecting the functioning of the groups

Study participants discussed a number of issues that affect the operation of the groups. Group dynamics, individual characteristics of group members, attendance issues, and the differences between peer facilitators and professional facilitators all affect how support groups work.

#### 4.4.4.1 Group Dynamics

Group dynamics are the processes by which people in groups interact and communicate (Forsyth, 1990). Group dynamics can be influenced by the individual personality traits of the people in the group, the purpose for which the group is meeting, and the context in which the group is meeting (Forsyth, 1990). Good group dynamics was seen as important in the support groups examined in this study.

Study participants described how group members are not forced into talking about a topic. Group members are allowed to talk as much or as little about an issue in discussion as they want. Study participants emphasized that the groups are run with good rules of conversation in mind. That is, members must be quiet when another is talking, moderate voice is used, and everyone must be open, honest, and respectful of the experiences of others.

> I would if it was a fruitful discussion, if there were many different positions offered, and people are speaking openly and respectfully to one another and as long as it is not excluding certain people, if it is not just a back and forth debate between two people which tends to dominate the discussion. Some rules just improve dynamics.

Study participants described how important good dynamics were to the functioning ability of the group. Study participants spoke of the sense of safety the group provides, and how upsetting comments and conversation can destroy that sense of safety. Study participants emphasized that good group dynamics leaves the group members with a sense of hope, safety and comfort.

One study participant talked about an incident when one member's offhand statement about cancer being a blessing in disguise greatly upset the other members of the group. Another study participant recalled an incident where one person took up an entire series of meetings talking about her feelings and fears, but then that same person was then able to offer empathy and support to others as a result of having obtained the support when she needed it. Study participants recalled how some group members never missed meetings because seeing how others had survived having cancer was very encouraging.

> Once again, it depends on who's in the group, depends on how safe they feel with that, how many groups they have gone to in the past, if they are comfortable in the groups, sometimes people come just to check it out and it's unfamiliar, they have never done a group before, wanted to give it a try, see how it felt, it really depends. For some people it's like, the first time they can talk and get support from other women, and they just, neverending, as far as their divulging of information.

There are specific issues that can threaten the dynamics of the group. If there are many new members, the storytelling aspect may get boring for the older members. Study participants identified that women seem to have an easier time of talking about things than do men. Deans et al. (1988) found that women outnumbered men by a ratio of 3:1 in attending support groups. They theorized that more women attended groups because of differences in the socialization of the sexes. Socially, men were expected to contain their emotions more than women, which may lead the men to be "less willing to participate in a group where feelings are shared openly" (p. 673).

Study participants also indicated that having guest speakers was only detrimental if the group felt the person was not an expert on the issue. One study participant spoke of how having group members with similar diseases seemed to improve dynamics, as opposed to having group members with all different cancers.

#### 4.4.4.2 Individual characteristics of group members

Various characteristics of group members may affect the functioning of the group. Withdrawn group members and if a group member was actively receiving treatment might impact on the functioning of the group.

Study participants indicated that what group members choose to share can influence how the group works. If people are quiet and withdrawn, or if someone monopolizes all the time, the group may not function properly. One study participant commented that group members tended to focus on the negative aspects of their lives, and that she would make it a point of asking the members of her group about the positive aspects. Study participants indicated that it is usually the role of the facilitator to assess the needs of the group and to include everyone in a conversation.

> .....who needs more time in this group on this particular occasion? How do you, again as a lay person, determine how to facilitate that person having the best opportunity to get off their chest what they need to get off their chest? How do you stop the gabby person who always wants to talk at every meeting....how does one accommodate the various personalities in a group?

Whether or not a person was actively receiving treatment sometimes dictated when the person would start attending the support group. One facilitator described how some people with cancer would often come to the group after their treatments were completed, which is consistent with the findings of Montazeri (1996) who found that most people attending a support group would do so after finishing treatment for cancer. However, other facilitators from other groups described how some group members would be attending the groups in the midst of their treatments.

#### 4.4.4.3 Attendance issues

Most of the support groups for people with cancer are of a drop-in nature. People facing issues to do with cancer can choose whether or not to attend any given meeting, and in most groups registration is not required. Only the closed groups in the third organization require group members to register. The drop-in nature of the groups sometimes results in irregular attendance.

The number of people attending a group is usually not consistent. Study participants described how membership in the support group follows a pattern. People attend meetings for a period of time, but eventually they stop attending, and other people start to attend the group meetings. The study participants theorized that this pattern of attendance exists because eventually people with cancer want to move on to other aspects of their lives. After group members have survived the experience of having cancer, they just want to put their cancer experience in the past. Part of putting the experience in the past is no longer attending the support group.

> The people that come aren't always the same people. They come for a time and then they want to go ahead with something else in their life, they don't always want to be thinking about cancer, and so they don't always come....

One result of the group members' irregular pattern of attendance at group meetings is a high turnover rate in the group's membership roster. A high rate of member turnover can also influence the functioning ability of the group. Study participants described how the level of conversation can remain relatively superficial if turnover is high because group members haven't had a chance to get to know other members enough to trust them when discussing personal issues. It is also hard to decide when to offer programming, such as guest speakers, to the group, because the group members in attendance have diverse needs and interests. Group facilitators want to offer programming when it will be of the most use and most interest to the most group members. Choosing issues to focus on and when to offer programming about a specific issue are all dependent on the needs and interests of the group members in attendance. For example, if not everyone in attendance is undergoing chemotherapy, providing programming about chemotherapy may leave the needs of some group members unsatisfied. One of the tasks of the facilitators is to assess the needs of the group, and participants commented that this is made harder by frequent turnover, since people may not stay in the group long enough to have their needs adequately assessed and met.

As well, maintaining the operation of the organization requires commitment from some of the members. Frequent participant turnover can limit the ability of the organization to function efficiently. If most group members attend only a few meetings, the likelihood of those group members fulfilling a long term commitment is reduced.

> ....what seems to be happening now, is a small group will come and they will be kind of stable, they'll be the same three, four, five, six, and they'll come for six months or so, and then they'll maybe get through the most acute, critical time, and then not come as frequently, or even stop altogether, and then a different group will come, whereas it used to be much more random, you might have two, three new ones, you might have all old ones, you know....

Study participants suggested that sometimes, irregular attendance by group members is simply due to other commitments, weather concerns, or treatment issues.

These findings parallel those of Galinsky and Schopler (1994) who investigated the nature of problems in support groups for people with cancer. Irregular attendance, premature termination of membership, and varied length of membership were identified as attendance related problems in the support groups. As a result, they suggest that it is "important to understand the uniqueness of support groups and to be prepared to deal with the special issues and problems they present" (p. 91).

#### 4.4.4.4 Peer and Professional Facilitators

Study participants made occasional references to the abilities and qualities of professional facilitators and peer facilitators.

Professional facilitators were defined by the researcher as professionally trained facilitators, such as social workers or therapists, who were brought in to do specific facilitating of some of the groups. Some of the professional facilitators indicated that their role in the group was to primarily direct the conversation in order to maximize effectiveness. These facilitators were not cancer survivors, so their role was an external one, drawing people into the conversation and providing unbiased information.

> As facilitator, like it's part of my job...my role there is just to provide structure to it, to be a contact person, and to promote the group, to provide facilitation in the running of the group, provide guidelines for the members and facilitate the discussion and keep it going.

Conversely, peer facilitators were defined by the researcher as people who had cancer, and who had attended a number of group meetings, and who were asked to lead group meetings.

> Facilitators, maybe peer facilitators, that means the people who are currently or have had cancer and that is what happens on the twice monthly support group, but focused groups we tend to hire professional, professionally trained therapists, they may be social workers, they may be mediation therapists, counselors, that type of thing.

According to the participants, most groups fell into one of two distinct categories. Groups were either peer facilitated, calling in professional facilitators only as needed, or they were professionally facilitated and informal peer education, such as advice sharing, took place under the supervision of the professional facilitator. These findings are consistent with those of other researchers. Rootes and Aanes (1992) suggest that support groups can be effectively led by health professionals. Cope (1995) studied the functions of a support group for breast cancer patients and found that role of the professional leader of the group was to present information.

Overall, both types of facilitators were seen to have a role in support groups. The professional facilitators felt that they were needed in their groups, and the peer facilitators did not think that the occasional guest session by a professional facilitator was a problem. Most of the times that the groups needed a professional facilitator, the topic was too specific for them to deal with on their own. Some study participants thought that the professional facilitators were better able to focus the discussions, draw people into the conversations, and present unbiased information. Some study participants who identified themselves as peer facilitators wondered about using professional facilitators in order to improve effectiveness. These facilitators described how professional facilitators have been trained in the art of drawing people into a conversation. The peer facilitators also indicated that the professional facilitators would have much more opportunity to develop and refine their group skills just by being professionals, whereas the peer facilitators might not have as much opportunity. Finally, the peer facilitators described how sometimes people in the group might have complex needs that the facilitators are not able to handle like a professional facilitator might be able to address. The peer facilitators felt that they had a place in offering their help because they had been through a similar experience, but they felt overwhelmed when a group member presented with more complex needs.

> One of the reasons why some people feel that the professional led support group would be the better route to go is that the professional has many more ways of drawing the other people in, whereas the peer support, the peer led, that is something that we're not as well trained in, although we do have training sessions its not the same, for some of

> us its automatic, we can do it very well, but for some of us that may not be so automatic to draw others in.

Predominantly among the professional facilitators, advice sharing as a label to what they were doing was given a negative connotation. For example, the sharing of experiences wasn't to be labeled as giving advice. The professional facilitators were emphatic in encouraging individual group members to carefully examine suggestions made during the meetings and to take offers of advice with caution.

> Well we try to steer away from advice sharing, even within the participants in the group, certainly you will always get somebody who wants to give another person advice and stuff like that. I think we usually manage to facilitate that fairly well and provide information and not in such a direct way as giving advice, but general information about whatever they are looking for, and encourage them to talk to the appropriate person too, like their doctor if it's a medical issue.

## 4.5 Nutrition Education in the Support Groups

In order to more accurately describe the context in which future nutrition education might be offered in the support groups, descriptive information was needed about any nutrition education currently occurring in the groups. After information regarding the details of the operations of the groups had been gathered, discussion turned to the state of nutrition education in the groups. Study participants were questioned about what nutrition education currently takes place in the groups, what they perceived as the barriers to more nutrition education, and what types and kinds of nutrition education would improve the effectiveness of nutrition education if it was to be offered in the groups.

Several themes arose from the discussions regarding the current state and future role of nutrition education in support groups. These themes included the study participants' definition of nutrition education, descriptions of current nutrition education in the support groups, both formal and informal, the barriers to implementing nutrition education in the support groups, and the study participants' suggestions for how to more effectively implement nutrition education in the groups. These findings are outlined in Table 3.

Table 3. Nutrition education in the support groups

| **Nutrition Education Component** | **Descriptors of Each Component** | |
|---|---|---|
| Definition | Topics<br>Methods | |
| Current Nutrition Education | Formal | Presentations |
| | Informal | Advice Sharing |
| Barriers to Nutrition Education | Drop In Nature of the Groups<br>Competing Priorities<br>Timing of Nutrition Education<br>Resource Availability<br>Characteristics of Group Members<br>Characteristics of Facilitators | |
| Enhancers of Nutrition Education | Format<br>Direction<br>Resources<br>Satisfaction | |
| Potential Nutrition Education | Topics<br>Format<br>Nature of Nutrition Education<br>Suggestions<br>Nature of Group | |

### 4.5.1 Definition of nutrition education

Study participants were asked to define nutrition education. Many study participants felt that nutrition education focussed on various parts of the diet, including learning how to generally eat healthfully, and learning how to incorporate specific foods into the diet. Study participants noted that nutrition education is about balancing one's lifestyle.

> Nutrition education.....to me, it's learning as much as you can about what foods are good for you, the amounts that are good for you, the balance of what is good for you and the things you like to eat that aren't good for you....

Some study participants also defined nutrition education by how one learns about nutrition. They mentioned self study, referrals to dietitian or nutritionists, and participation in organized nutrition education programs.

> I would look at it as more of a self learning process where information is available whether it is from a speaker, from a binder of some kind, from a video, and where there is an opportunity for participants to learn. That is what I would, how I would define nutrition education.

The study participants' definitions of nutrition education seem to agree with certain elements of those of nutrition professionals. Study participants described nutrition education as learning about the value of foods and how to balance one's lifestyle. Nutrition professionals describe nutrition education as a form of planned change that aims to improve nutritional well being by providing information or other types of behavioral interventions (Contento, 1995). This planned change to improve nutritional well being could include some information on the value of foods and balancing one's lifestyle.

### 4.5.2 Current Nutrition Education

Study participants were asked about the current state of nutrition education in their groups. Current nutrition education was described in terms of the format of nutrition education, the frequency of nutrition education, the resources accessed for nutrition education, and the topics included in nutrition education in the groups.

#### 4.5.2.1 Format of Nutrition Education

Study participants identified two basic formats for nutrition education in their groups. The first format was having an organized type of nutrition education, such as having a dietitian or nutritionist in to speak to the group. This was defined by the researcher as formal nutrition education. The second format was the sharing of advice and experiences with regard to nutrition related issues in the absence of a nutrition professional, defined by the researcher as informal nutrition education.

#### 4.5.2.1.1 Formal Nutrition Education

Formal nutrition education occurred most often in the form of a guest talk by a dietitian or nutritionist. A guest was invited to speak at the request of the group members. The topic of discussion was something of interest to the group members, with topics ranging from healthy eating to handling side effects of chemotherapy. Many sessions were interactive and practical in format. The guest speaker would usually leave time for questions. Study participants elaborated on a number of reasons why they chose to have a presentation by a dietitian or nutritionist. They described how the dietitian or nutritionist would have more knowledge about nutrition, and could better focus the discussion to the specific concerns of the audience.

> ... we have had speakers from time to time, who come specifically, we have known ahead of time that they were coming to talk about nutrition and so maybe that's more got information rather than come with questions. I remember there was a speaker when I was in the middle of my treatment and she talked specifically about keeping up your, ways to get protein and calories and fats and you know, even in the midst of your treatment, when you're not feeling like eating, and talking about those kinds of things...

#### 4.5.2.1.2 Informal Nutrition Education

The second format for nutrition education was where group members would share what had worked for them in trying to solve a nutrition related problem. Most nutrition related discussions occurred in a format of one group member bringing up an issue and asking other group members for their experiences with that issue. These discussions would include such topics as using food as a healing mechanism, or how they overcame nutritional challenges during chemotherapy, such as fighting nausea and fatigue.

> ...people have, well sometimes, people will talk about I don't feel like eating, that sort of thing, they are being affected by their chemo, and then people might make suggestions, have you tried this, you know, this worked for me, or I tried that....more, more like, you know, I have concerns, how might, I know I need to be eating, I know I need to get the calories in and I don't feel like eating, or I have mouth sores and that bothers me, that sort of thing, fairly general..: With suggestions or things that had worked for them.....Yeah, various things, and they'll say you know, has anybody taken that and how did you feel, and what did you think about that

#### 4.5.2.2 Frequency of nutrition education

According to the study participants, the frequency of nutrition education varies. In the case of formal nutrition education, several groups have had presentations, usually by a dietitian or nutritionist. Two groups have had one presentation in the last year, one group has had two presentations in the last three years, and one group has had one presentation in the last three years. As well, two of the study participants share the facilitating duties for a group that cycles through about ten structured topics every three months. Nutrition is one of the topics the group addresses. This was considered formal nutrition education because it is a time when nutrition is the focus of the meeting.

With regards to informal nutrition education, some study participants indicated that nutrition was a frequent topic of discussion while others couldn't recall their groups ever talking about nutrition. Facilitators from some groups recalled that a nutrition related question or concern was raised at least once an evening. Interestingly, the facilitators from the groups for men with prostate cancer were the facilitators who couldn't recall that their group had ever discussed nutrition. Carlsson et al. (1999) conducted a qualitative analysis of the questions raised at support groups for cancer patients. A total of 48 out of 329 questions were with regards to nutrition. This suggests that nutrition was not the most frequent topic of discussion, but that it was discussed at times.

#### 4.5.2.3 Nutrition education resources accessed by groups

Study participants identified a number of nutrition education resources that were accessed by their groups. The most frequently mentioned resource was printed matter, such as books and pamphlets. *Eating Right*, a book available from the Cancer Centre, was mentioned often. Other study participants described how group members would obtain nutrition information from other people. Some group members would exchange recipes, thus obtaining some nutrition information. Other group members had had a personal session with a dietitian or nutritionist, and would share information from the session with other group members.

> We have the resources and we know where to get the other resources if we don't have them, we've got all kinds of pamphlets on nutrition for cancer patients.

#### 4.5.2.4 Nutrition Related Topics of Discussion

Many topics arose during nutrition related discussions in the groups. Topics ranged from healthy diets to alleviating side effects to food trends such as the use of soy and flax. When study participants discussed healthy diets, some mentioned that they had had a presentation by a dietitian that reviewed the changes to Canada's Food Guide to Healthy Eating. Other times group members would discuss foods in general.

Group members would often discuss changes they had made in their diet. Changes included reducing the intake of fat, sweets and red meats, and increasing the intake of fruits and vegetables, as well as changing to more complementary types of diets, such as macrobiotic. The changes made were not always positive. Some group members would start to overeat and use food as a crutch to cope with the emotional aspects of having cancer.

Nutrition discussions sometimes centered around side effects of treatments, such as how to deal with nausea and loss of appetite during chemotherapy. One study participant described how sometimes group members would investigate alternative treatments. At times, group members discussed how they coped with food aversions induced by chemotherapy. This finding is consistent with that of other researchers. For example, Boakes, Tarrier, Barnes, and Tattersall (1993) found that cancer patients often changed their diet after starting chemotherapy because of aversions to meat and coffee, changes in taste sensations, and loss of appetite.

Group members would look to nutrition as a way of healing from cancer, in that nutrition could help to alleviate side effects of treatments, or help to reduce the risk of a recurrence of the cancer.

> ....and some of them were, when they are having chemotherapy, they are nauseous, and some of them were talking about some things they could eat, and some said just get through the chemotherapy, eat what you can, don't worry about what's healthy for you and what isn't, so long as it's something that you can eat...

> Participants discuss....They talk about the role of food as a healing mechanism or as a therapeutic approach.

Study participants indicated that some of the nutrition discussions were about supplements. Group members would often talk about nutritional supplements, particularly vitamins, minerals, and nutraceuticals such as soy and flax. Group members often wonder if such supplements are right for them, and if taking supplements actually makes a difference, as well as how and why to use a particular supplement. Supplements discussed in the groups included Vitamin C, Vitamin E, Iron, Green Tea, Barley Green, Co - Enzyme Q10, shark's cartilage, soy isoflavones, and flaxseed. These findings parallel those of other researchers. Monnin and Schiller (1993) studied the need for nutrition counseling among breast cancer patients. They found that a significant percentage of women breast cancer wanted information about vitamin (26.2%) and mineral (23.3%) supplementation, and to a lesser extent, information about macrobiotic diets (10.7%).

Several reasons were given on why nutrition is a popular discussion topic at the group meetings. Dietary change was one lifestyle change that members of the support groups were making. Group members also wonder if their eating habits were a possible cause of their cancer. They are looking for as much information as possible in order to avoid a recurrence. Finally, they feel that they still have some control over their nutrition.

Nutrition related discussions are often framed within the context of making lifestyle changes as a result of the cancer diagnosis. Some of the nutritional changes were simple, such as reducing red meat intake, increasing fruit and vegetable intake, eliminating caffeine, or using nutritional supplements. Other changes were more complex, such as becoming a vegetarian, or adopting a macrobiotic diet.

Some support group members often wonder why they were diagnosed with cancer. Many group members think their prior nutritional habits were a factor in the development of their cancer. This finding is consistent with that of other researchers. Dwyer (1986) suggests that many cancer patients incorrectly fault diet alone as the cause of their cancer due to the presentation format of cancer risk reducing dietary guidelines.

> People get, everybody has their, they build these theories in their minds cause everybody has to try and make sense of how they got to be here and why did I get this diagnosis....

Study participants also described how some group members are looking for nutrition information in order to make changes so they can prevent a recurrence. One study participant explained how the members of his group talk about the change process with regards to changing their health behaviors.

Finally, another study participant suggested that a diagnosis of cancer may make a person feel powerless. Nutrition is one aspect of life in which a person can exert control. Nutrition may be a frequent topic of discussion because it can help people in the groups feel more in control.

### 4.5.3 Barriers to Nutrition Education

Study participants identified several barriers to implementing nutrition education in their groups. The drop-in nature of the groups, the competing priorities of the group members, and the timing of nutrition education in the groups were barriers. The availability of resources in order to offer nutrition education was also a barrier. As well, some of the personal characteristics of both the group members and the group facilitators may be barriers to offering nutrition education in the groups. The barriers to nutrition education are outlined in Table 4.

Table 4. Barriers to Nutrition Education Identified by Study Participants

| **Individual Barriers to Nutrition Education** | **Descriptors of the Barriers** |
|---|---|
| Drop In Nature of Groups | Hard to Decide When to offer Nutrition Education |
| Competing Priorities of Group Members | Other Commitments<br>Treatment Issues |
| Timing of Nutrition Education | |
| Resource Availability | Resource Person<br>Organizational Resources |
| Characteristics of Group Members | Impact on Group Dynamics<br>Strong Opinions<br>Differences in Knowledge Levels |
| Characteristics of Facilitators | Hesitant to Determine Discussion Topics |

#### 4.5.3.1 The Drop-in Nature of the Groups

Most of the support groups for people with cancer are of a drop-in nature. Group members choose whether or not to attend any given meeting. The drop-in nature of the groups sometimes results in different numbers of people attending any given meeting. This attendance pattern may impede the implementation of formal nutrition education in the groups. The facilitators indicated that they decide to offer programming to the group based on the needs that they identify from the people in attendance. If many people are in attendance, there may be many different needs. It might be difficult for facilitators and organizers to find common needs among group members in attendance. If the facilitators can not find common ground among the needs of the group members, it is difficult to decide which needs to address, and when to most appropriately address it.

#### 4.5.3.2 Competing Priorities of Group Members

Another barrier to the implementation of nutrition education in the support groups is the other commitments of the group members. Study participants acknowledged that the people in their group were adults with full lives, and that sometimes people were simply unable to attend the group meetings because of other commitments. Some of those mentioned by study participants include family commitments, such as children's sports, and work commitments. Study participants also identified bad weather and lack of transportation to the program as reasons for not attending.

Treatment issues of the group members may limit their participation in nutrition education. Firstly, study participants indicated that people actively going through treatment are less likely to attend. This finding is comparable to that of Montazeri (1996), who found that most participants of support groups were post treatment.

Secondly, treatment issues are also one of the main topics of discussion for support group members. Study participants questioned the efficacy of taking time away from treatment issues to discuss a topic that may not be as pressing, such as nutrition. Study participants indicated that treatments and nutrition were interrelated, but expressed that being able to freely talk about the impact of treatment on the individual group member was more important than forcing the group to talk about one issue that relates to treatment.

Finally, people with cancer who are undergoing treatment may experience fatigue or be required to stay relatively isolated, which would affect their ability to attend and concentrate on nutrition education.

> The other factor is a person, people that we are trying to address may very well be going through a side effect of their chemotherapy that leaves them particularly, very, very tired, their energy level is limited, or they have to stay, make sure that they stay in an environment that is relatively germ free, you know, they are coming out into the public, even here someone may have a cold or whatever, and they pick that up and then their blood count falls rapidly and that will affect their next chemotherapy.... It's not unusual for people to say you know my chemo brain today is just not allowing me to attend, and so that's a bit of a problem. There's only so much information they can absorb....

#### 4.5.3.3 Timing of Nutrition Education

The timing of nutrition education in the support group may be a barrier to implementing formal nutrition education. Study participants indicated that people with cancer are confronted with multiple issues at once, and that people who attend the groups discuss the issues that are most pressing to them. Study participants questioned the ability to identify the most appropriate time to address one specific issue. Some study participants also identified the ever changing member roster as a barrier to formal nutrition education. If the different people attending the group constantly had different needs, the facilitators have a difficult task in assessing the needs of the group in order to present nutrition education at the time that it would benefit the most group members.

> The drop-in nature of our regular support group, because I think this kind of thing would work best if participants follow the process through so that they wouldn't miss a key section. I think that it could have a logical flow. We would then be predetermining what the discussion would be. Women may come having some burning issues on other fronts and there wouldn't be the opportunity within the group.

#### 4.5.3.4 Availability of Resources

Study participants described how nutrition education in the support groups would need a specific type of trained resource person. Finding such a person may be a barrier to formal nutrition education. This person would have to be familiar with many of the concepts required to implement effective nutrition education, such as how to interact with ill people, nutrition knowledge relevant to cancer, and skills in dealing with the emotional aspects of a life threatening disease. The resource person would also have to be personable and enjoyable, because a negative experience with one person may damper the groups' enthusiasm to explore that topic area again.

> I think one would need a pretty skilled resource person...somebody who understood about the cancer itself and how illness affects emotions and so forth, be prepared to deal with a lot of myths, be prepared to deal with the emotional part, the resource person would have to be skilled in a life threatening illness phenomenon, skilled in group dynamics, very well grounded in the whole nutrition spectrum of what might be important in health and healing. It would also be kind of a dicey path to carve in terms of allowing people the right to pursue what might be considered fads, and know how to support that, again back to the control issue, and know when to maybe raise a flag if there might be some danger inherent in this habit

Lack of organizational resources could also be a barrier to implementing formal nutrition education. Organizational resources include someone to organize the offering of the nutrition education, such as finding a presenter, and surveying group members to determine a topic. Study participants described how once the organizational resources are in place, implementing timely and relevant programming, including nutrition education, might become easier.

#### 4.5.3.5 Characteristics of Group Members

The dynamics of any group are influenced by the personality traits of the individual group members. Study participants described how the personalities of some group members affected the comfort levels of participants within the groups. Study participants described how individuals within the groups can affect the comfort level of others, such as when one member monopolizes all the talk time, or when one member expresses very strong opinions that may not be shared by all members of the group. Study participants identified nutrition as a topic that most group participants would be comfortable discussing, but they indicated that some group members might not feel confident in their nutrition knowledge. The feeling of vulnerability may lead group members to not participate in the discussion, which might impact on the dynamics of the group.

Several study participants revealed that some group members had strong inclinations to follow certain diet and health related practices, such as becoming vegetarian or following the macrobiotic diet. Nutrition education that didn't incorporate information about those practices might not be as successful. Study participants also described how some people with cancer are not very interested in nutrition, and that might affect the success of nutrition education.

> I would like to see vegetarianism because I have heard of people, you know, that have had their cancer reversed because of vegetarianism and I would like to see that stressed and the meat left out.

A few study participants revealed that the knowledge level of the group members could be a barrier to implementing nutrition education. In some cases, support group members already know a good deal of nutrition information. Some people with cancer address their diagnosis by starting to read everything they can, in order to improve their knowledge of what is happening to them. People with cancer will read research and news articles, review them more carefully, and share the information at meetings. Study participants speculated that these group members might not be interested in nutrition education because they would already know a great deal.

In other cases, study participants suggested that support group members don't know that much about nutrition. Some support group members have expressed a lack of confidence in addressing nutrition issues, particularly with the practical implementation of some nutrition recommendations. The resulting mix of knowledge levels could be a barrier to implementing nutrition education in the support groups, as it may present problems when designing effective nutrition education.

> ....but the other thing is that most of us feel quite ill informed and we don't feel very sure about any particular role or value of a certain individual food or family of foods, or a particular supplement, so I think it I would say it is the lack of confidence in the information, there is a lack of confidence in the role of any particular food.

#### 4.5.3.6 Characteristics of Facilitators

Study participants recognized that nutrition education was important for the group members, but maintained that, as facilitators, they had to follow what the group wanted to talk about. In most cases, the group members did not perceive there to be a need for nutrition education. One study participant described how his group wanted to focus on the emotional connecting that went on within the group. His members did not want specific programming. Several facilitators of another group indicated that most people in the group take nutrition and eating for granted. Group members don't always focus on the effects of good nutrition. Nutrition is not seen as something important to focus on in the group. It was an important group rule that topics of discussion were not to be determined by the facilitators or organizers. Group discussion were to be free and derived from the needs of the members present.

> A nutrition program? Perceived need, do they think it is a need, and if the patients don't think it's a need, I wouldn't plan it, because that's not the purpose of the group.....I am focusing on the emotional aspects of cancer.

### 4.5.4 Nutrition Education Enhancers

Several factors were mentioned that could enhance the implementation of both formal and informal nutrition education within support groups. These included the format of nutrition education, the importance and timeliness with which nutrition education is offered, available nutrition education resources, and satisfaction with previous nutrition education.

#### 4.5.4.1 Format of Nutrition Education

Study participants identified several ways that the format of nutrition education could enhance the continued implementation of both formal and informal nutrition education in the groups.

Some study participants thought that nutrition education should be provided by a dietitian or nutritionist. This is one type of formal nutrition education, as defined for the purposes of this research. However, study participants indicated that this formal nutrition education could be improved by having time for questions and being interactive. Having a question and answer session as part of nutrition education would be valuable, as support group members might have questions on topics other than the topics being covered. One study participant suggested that if there was more than one topic being covered in a single session, that there be time for questions and answers after each topic, to make sure that those in attendance are able to ask questions when they think of them. Formal nutrition education should also be short term, limited to a small number of people, and cover topics that are of interest to the group members.

> I would suggest short term, maybe one or two sessions....Say one might happen in the spring and one in the fall....hands on I would say would be valuable, short, a brief number of topics but making it as practical as possible, that would be valuable

Study participants suggested that one of the best ways of providing nutrition education to their group members would be through presentations by dietitian or nutritionists, because professionals can better focus the discussion and enhance people's experiences. Topics such as nutrition were seen as needing someone knowledgeable in the area. Topics included dealing with side effects of chemotherapy, and way of increasing fruits, vegetables and protein in the diet. Study participants also commented on the hands on, practical approach used by dietitians and nutritionists. Finally, study participants felt that a professional is better able to focus the discussion so that people are able to best use the information.

> It seems to me that it would, it's again, having a speaker, having a focus, having somebody ask specific questions....I think having a speaker is probably the best idea, because it gives, I mean, who am I to tell somebody else that they should be adding so many grams of bread to their diet, you know that kind of thing, so when you are talking nutrition with people in a group of lay people, you, it's pretty general, it's not very specific because none of us is qualified to give specific answers.

With regards to informal nutrition education, study participants identified how having peer education within their groups has proved valuable. One study participant described how a group member had brought some information forward to the group about a regimen some group members were following that was actually contraindicated for their conditions. Study participants described peer education as a way for group members to compare notes as to what works and doesn't work for people in similar situations.

> I would say yes, probably because they see value in getting information from a peer, either from the point of view of "Yes, this is working for me" or "No, that particular item didn't work."
>
> I think it is because it's a good learning time and what one guy talks about will influence the other men a lot of times, you know, what they've learned and what they've had.

#### 4.5.4.2 Importance and Timeliness of Nutrition Education

The importance and timeliness with which nutrition education is offered to the group could be a way to enhance the implementation of nutrition education in the support groups. Study participants shared how the group members will appreciate nutrition education if they think nutrition is important in their lives at that time. Many people with cancer place importance on obtaining information on any subject that they think will help them cope with their treatment and possibly prevent a recurrence.

> I suppose the biggest one would be if there's a, someone is facing chemotherapy, or facing their cancer diagnosis just by the mere fact of having that diagnosis should be sort of, pull you in and want you to participate. I want to get more information, therefore I will go to the session, or I know that I am going to be, they're talking about chemotherapy as one of my options and maybe I need to find out if diet has an impact on my, on lessening my side effects that type of thing.

As well, study participants indicated that nutrition education might be better received by the support group members if it was something that might impact on their diagnosis and treatment. Group members were interested in nutrition because they were interested in finding out what might possibly make a difference in their diagnosis, treatment and outcome.

> I would say it's largely due to the fact that they have been diagnosed with cancer, and so they are looking at anything and everything that they can address to try and make a difference in their diagnosis.

Nutrition education might be better received by the support group members if it originated from the group and not from the leaders. Some group members want to learn everything they can about their disease, and will suggest topics for the group to explore. The most popular topics are ones that originate from within the group.

> I think there should be a bit of a ground swell from the membership that this is something that wants to be pursued in more depth than just the current support group, in terms of their opinions and experiences.

Finally, study participants indicated that nutrition education might be better received by the support group members if it was provided as one part of how to holistically care for themselves. Nutrition may have an impact on being diagnosed with cancer, undergoing treatment, and helping to reduce the risk of a recurrence. A support group that examines the whole experience of cancer would include some information on nutrition. Study participants described how making nutrition a part of a holistically based cancer support group would make nutrition education more effective.

> Yeah, because it, the support group just doesn't gear to one topic, one area, its a holistic look at the person in their cancer journey and that covers a lot of things. It covers treatment, nutrition, sexuality, all that kind of stuff so it would, I think it would be very beneficial to incorporate that, and we do.

#### 4.5.4.3 Resources

Study participants identified how having appropriate resources would enhance nutrition education by providing group members with information they could refer to outside of group meetings. Some support group members liked to engage in study about topics relevant to their cancer at their own pace. Study participants indicated that nutrition education could be made a part of this self study, as long as the proper resources were available.

### 4.5.5 Potential for Nutrition Education

Study participants offered many suggestions as to how future nutrition education could be incorporated into their groups. The main ideas focused around topics and format of the nutrition education. Some study participants had suggestions for future nutrition education that could be implemented. The nature of the group would also lend itself well to implementing future nutrition education.

#### 4.5.5.1 Topics for Discussion

Study participants suggested some topics that would be suitable to include in nutrition education for people with cancer. Topics included healthy eating, fat, label reading, dealing with chemotherapy, special diets, and vitamins. The information should be presented in as practical a format as possible. For example, people with cancer may need information on healthy eating, but they may also need information regarding how to substitute foods when suffering from aversions to certain foods. Support group members also want information about vegetarianism and the macrobiotic diet, and how to plan a menu around the tastes and budgets of their families.

> They want to know what makes a nutritious, balanced, healthy, nutritional plan. They want more than the food groups...and if I am sick, what do I need more of and if so, what is it and how do I balance that, and how do I balance that into what I am doing with my family, and if I've got allergies to something or have developed a real sensitivity to this and my family likes it and I cook it, what can I eat instead, those real kinds of practical things....

#### 4.5.5.2 Format of Nutrition Education

Study participants suggested numerous formats by which nutrition education could be offered to the group members. One format was a resource based, self study type of nutrition education, which would be accomplished mainly through reading and talking with others. It would be good to have a number of resources on hand for those group members interested in learning some more about nutrition, including pamphlets, videos, and display boards. One of the organizations has a newsletter for its members and one participant suggested putting nutrition information in the newsletter. Other study participants suggested having professionals in to speak on nutrition as a way of conducting nutrition education for their groups. Having the dietitian or nutritionists speak would provide the group members with the best nutrition information.

#### 4.5.5.3 Nature of Nutrition Education

Study participants also commented on the nature of the nutrition education itself. Nutrition education would possibly be more effective if it was done with a sense of awareness about the vulnerabilities of the audience. One study participant pointed out how people with cancer will put faith in products that promise to cure cancer. Ultimately, many product promises do not meet the expectations of people with cancer. A presenter who can provide information in helpful ways that allow for people to try these products without sacrificing their health would improve the effectiveness of nutrition education. Nutrition education might also be more effective if it was based on the needs of the audience, and addressed their specific concerns.

> In helpful ways, balanced ways, realistic ways, you know, realistic things to what's available here, for number one...Or it may not be part of their culture, either, and so it's got to be sort of cultural based too....

#### 4.5.5.4 Suggestions for Nutrition Education

Some study participants suggested how nutrition education could be implemented. Suggestions ranged from addressing nutrition at every group meeting to designing nutrition education for delivery to interested group members.

One study participant suggested looking at one small topic at every group meeting. Support group members could receive information about nutrition while still being able to address the other issues in their lives. Several study participants suggested that continuing to offer nutrition education at various times to the whole group. The regular programming of the group would not interrupted, and the nutrition education needs of the group would still be met.

Two study participants each described nutrition education that they would like to offer to their groups. One suggested nutrition education that would incorporate discussions of people's personal habits, the origins of their food habits, mechanisms and barriers to making changes, and current research, as well as support for group led changes. The other suggested a four week nutrition education program that would be held external to the regular support group. The nutrition education program could explore what nutrition means to the group participants. Information related to dealing with cancer could also be presented, such as balancing your diet, weight control in the face of cancer treatment, and improving the skills needed to integrate good nutrition into the lives of the participants and their families.

#### 4.5.5.5 Nature of Group

Some study participants commented on how the nature of the group could facilitate the implementation of nutrition education. The group is a place for group members to deal with cancer related issues. Nutrition can be one of those issues, which facilitates the discussion of nutrition in the group. Study participants indicated that a diagnosis of cancer increases patients' feelings of vulnerability and that an increase of knowledge and self confidence about any aspect of dealing with cancer can alleviate these feelings of vulnerability. Support group members become role models for each other, and role models can increase the effectiveness of any education, nutrition related or not. Group members often place importance on healthy lifestyles, which could facilitate the implementation of nutrition education. Some group members are learners, often wanting information about all aspects of their disease. This quest for knowledge could facilitate the implementation of a nutrition education program.

> I think what encourages them to talk about it is, if it's, if one of the other members thinks that this is an important topic and talks about it, gets them going on it, so it has to be, not just one person in the group, something relevant to them, something they have found useful and learned. I think what motivates them is that they don't want to get cancer, again, or they want to keep in under control, and so I think that would be a great motivator cause what's going to help with, you know, dealing with the cancer, what are some aspects of the overall picture of dealing with health, how can I be as healthy as I can, and nutrition would enter into that.

### 4.6 Nutrition Education and Social Support

As the above discussion indicates, social support and nutrition education can be related to each other through the importance of diet to people with cancer. People with cancer are interested in their diet for two basic reasons. People with cancer use diet to prevent a recurrence of the cancer (Carter et al., 1993; Chlebowski et al., 1993; Hebert et al., 2001;

Rohan et al., 1993; Salminen et al., 2000). People with cancer also use diet to increase their overall feelings of wellness, especially in relation to dealing with side effects of treatments (Goodwin et al., 1998; McTiernan et al., 1998; Salminen et al., 2000). Research examining the relationship between social support and diet choices has shown that social support can be an enabling factor for dietary change and therefore can be an important target for nutrition intervention programs, such as nutrition education (Baranowski et al., 1999; Kristal et al., 2000; Sorensen et al., 1998)

The relationship between nutrition education and social support may be demonstrated through the use of a setting in which they both occur, such as a support group for people with cancer. People with cancer attend support groups in order to obtain social support so that they may better deal with the issues in their lives related to their cancer (Cella & Yellen, 1993; Cope, 1995; Ferrell et al., 1996; McLean, 1995; Mesters et al., 1997). This study has demonstrated that some of these issues are related to nutrition. For example, the facilitators of the support groups for people with cancer indicated that group members were making dietary changes as a result of their diagnosis, and that they shared these dietary changes with others at the support group meetings. This finding suggests that support groups may be a place to offer nutrition education. Nutrition education can impact diet by providing timely and relevant information and skills training which enables people to make any necessary dietary changes (Contento et al., 1995).

Nutrition education can be assimilated into the support groups in several ways. To start, nutrition education and support groups share one common purpose, namely the sharing of information. Providing information is an important part of nutrition education (Contento et al., 1995; Kristal et al., 1990: Wardle et al., 2000). Information sharing is also an important part of support groups (Cope, 1995; Galinsky & Schopler, 1994; Norris &

Kaniasty, 1996; Stevens & Duttlinger, 1998; Stevenson & Coles, 1993). Nutrition has been shown to be a frequent topic of discussion at support groups for people with cancer (Carlsson et al., 1999).

The other purpose of support groups is the provision of emotional support. Emotional support has been shown to be a vital part of behavior change, some of which could be nutrition related (Sorensen et al., 1998). According to the participants of this study, some of the roles of social support in health and well being include the opportunity to observe role models and the opportunity to increase self awareness. These could be used by programs whose aim is behavior change, including nutrition education. For example, increasing self awareness as a result of attending a support group can help when making diet changes that require self awareness. A nutrition educator planning a nutrition education program could tailor the program to incorporate activities that make use of the group members increased sense of self awareness.

Finally, offering nutrition education in support groups may be appropriate from the viewpoint of theoretical models of behavior change. One of the determinants of health is the social environment of individuals and populations, of which social support is a component (Evans & Stoddart, 1990; Frank, 1995). Descriptions of various health behavior change theories and models include discussions on the effects of social support. Behavior change theories, such as the social learning theory and the health belief model, have social support as important components, or at least as moderating factors (Strecher & Rosenstock, 1997; Wallston, 1992).

Participants in this study have indicated that nutrition education could be valuable to people with cancer for several reasons. Firstly, nutrition education helps to explain possible causes of their disease. Secondly, nutrition education provides group members with information and skills that they can use in order to lessen their chances of a recurrence. Finally, nutrition education provides group members with information and skills that they can use in order to help alleviate some of the side effects of cancer treatment.

## 4.7 Summary

The results of this research were obtained through interviews with facilitators of support groups for people with cancer in Saskatoon. Study participants described the impact that cancer had on their lives. The biggest impacts were in the physical changes and the emotional upheaval that being diagnosed with cancer had caused. Study participants outlined their experiences of social support in the groups, including the benefits, mechanisms, and roles of social support in health and well being. Most of the groups had an open format for discussion. Topics of discussion in the groups included emotional concerns, practical concerns, and treatment issues. The functioning of the group was affected by group dynamics, issues that affected the attendance of the group members, and the characteristics of the facilitators.

Most groups have had some sort of formal nutrition education, usually in the form of a presentation by a dietitian or nutritionist on a topic of interest to the groups. Informal nutrition education was also occurring in the support groups. Study participants indicated that nutrition is frequently a topic for discussion in the regular operating of the support group, especially as it relates to the side effects of treatments.

There were several barriers to incorporating more nutrition education into the groups. Barriers to implementing more formal nutrition education included the dorp in nature of the group, the competing priorities of the group members, the timing of nutrition education, and the availability of resources. Barriers to both formal and informal nutrition education included the characteristics of the group members and the characteristics of the group facilitators. The opinions of the group members, the varied knowledge level of the group members, and the hesitancy of the group facilitators to force group members to discuss a particular topic may all impede the offering of nutrition education to the groups.

Study participants described some ways in which the incorporation of nutrition education could be enhanced within their groups. These enhancers included the format, importance, and timeliness of nutrition education. Some study participants made suggestions for future nutrition education in the groups. Nutrition education that takes account of the nature of the support group has a potential role in the support groups.

# Chapter 5 - Conclusions, Implications, and Recommendations

## 5.1 Introduction

In this chapter, the research findings are summarized according to the research questions. Based on these findings, recommendations for nutrition education for members of support groups for people with cancer are given. The significance of relevant nutrition education, and implications for nutrition educators and health professionals are addressed. Finally, the limitations of this study and the potential areas for further research are discussed.

## 5.2 Summary of Research Findings by Research Question

There were four questions that guided this research study. The research questions examined some of the issues surrounding the relationship between cancer and nutrition, with particular focus on the state of nutrition education in various support groups for cancer patients. Using information provided by the data themes, each of these questions will be answered individually below.

### 5.2.1 Research Question 1

What factors, if any, do facilitators of cancer support groups observe that affect the nutritional status of people with cancer?

The participants in this study observed several ways in which cancer affected eating behavior in their group members, and thus probably nutritional status. Treatment side effects often led to fatigue, nausea, vomiting, appetite changes, and changes in taste sensations. These factors affected eating behavior by decreasing appetite or altering the taste of foods. Group members often had aversions to foods, especially meat. Study participants also described how a patient suffering from fatigue might not make the healthiest food choices. Finally, study participants shared how some treatments, such as surgery and radiation, can directly impact a patient's nutrition because of physical impairments.

Often, emotional reactions to cancer, such as fear, guilt, and depression, were observed by the study participants as affecting eating behavior. Some group members would use food as a coping mechanism, and food choices would often be high sugar and high fat snack type foods, not healthier high fibre, low fat type foods. Some group members would become depressed following the diagnosis and treatment for their cancer.

Study participants also indicated that sometimes group members would totally change their diets, either out of fear of recurrence or out of guilt that they may have somehow caused their diagnosis.

This question was asked in order to generate a context for the discussion of nutrition education in the groups. The assumption of the researcher was that the nutrition education provided to the groups would be topics of interest to the group members, and that the topics of interest expressed by the group members would be determined from their experiences. By knowing how the nutrition of some of the group members has been affected by cancer, the discussions of the nutrition education in the groups could be more accurately framed.

### 5.2.2 Research Question 2

What, if any, nutrition education, either formal or informal, currently takes place in cancer support groups in Saskatoon?

Nutrition education does take place in support groups in Saskatoon. With regards to formal nutrition education, most of the groups had had presentations by nutrition professionals. Three groups have had a presentation in the last year, one group has had two presentations in the last three years, and one group has had one presentation in the last three years. One group cycles through about ten topics every three months, and nutrition is one topic that is covered. Topics of discussion in formal nutrition education situations ranged from general, such as healthy eating, to specific, such as how to increase protein intake while on chemotherapy. The presenter at most nutrition presentations would allow time for group members to ask questions about any nutrition related concerns.

Group members would often casually discuss nutrition related concerns in the general discussion time of the groups, which was defined as informal nutrition education. Group members would bring up nutrition related concerns related to effects from treatments. For example, one common topic of discussion in informal nutrition education situations was how to maintain energy and eating behavior when nauseated and vomiting as a result of chemotherapy. Advice was often shared regarding the implementation of new personal dietary regimens.

### 5.2.3 Research Question 3

What factors do facilitators see as enhancing or detracting from nutrition education, either formal or informal, in cancer support groups in Saskatoon?

Study participants identified several barriers and enhancers to nutrition education in their groups.

Barriers to incorporating formal nutrition education in the groups included the drop-in nature of the groups, group dynamics issues, the facilitator's hesitancy to determine the topic of discussion, and the knowledge levels of group members.

Most of the groups are drop-in groups where group members choose whether or not to attend each meeting. As a result, attendance at the groups is not consistent. Study participants thought that the inconsistent attendance pattern would be a barrier to having more formal nutrition education. Due to the inconsistent attendance, the needs of group members might not be adequately assessed. The facilitators felt that it would be difficult to implement nutrition education if the needs of the group were not adequately assessed, given that the nutrition education would be implemented to try and meet the needs of the group.

Study participants identified factors that unfavorably affect group dynamics as a barrier to implementing nutrition education. For example, individuals within the groups can affect the comfort level of others, such as when one member expresses very strong opinions that may not be shared by all members of the group.

The hesitancy of the facilitators to determine what the groups' topic of discussion should be was also identified as a barrier to implementing more formal nutrition education. The facilitators described how the groups are run based on what the group members need and want. The study participants were very emphatic that the discussion of the groups was to be determined from the needs of the group members, not by the facilitators. Although the study participants indicated that they believed the group members needed nutrition information, the facilitators were hesitant to suggest nutrition education, because it would then be the facilitators determining the topic of discussion.

The knowledge levels of the group varies. Study participants indicated that designing nutrition education that accounted for the variety of knowledge might be very difficult.

The facilitators also recognized the importance of nutrition education for their group members and were supportive of the group incorporating more nutrition education. Study participants made some suggestions with regards to what might enhance the groups' ability to offer more nutrition education. The two basic enhancers of nutrition education that were identified by study participants were the format of nutrition education and the importance and timeliness of nutrition education.

In order to make nutrition education more appealing to the group members, the format should be short term, and very interactive. Nutrition education should focus on topics that are relevant to cancer patients, but also leave some time in the program for questions on other topics. A format using the principles of peer education, where the format is not like an expert lecturing, might also enhance the groups' ability to offer nutrition education.

The offering of nutrition education in the groups would be enhanced if the nutrition education focused on the importance of nutrition after being diagnosed with cancer and while undergoing treatment for cancer. Nutrition education would also be better received by group members if it was offered in a timely fashion. For example, nutrition education might be better received if it had been suggested by group members, and if it looked at nutrition as part of holistically dealing with cancer. Finally, study participants suggested that the best way to enhance further nutrition education in the groups was to be satisfied with previous and ongoing nutrition education. If previous nutrition education had been successful and enjoyable, group members would be more likely to want to have more nutrition education.

### 5.2.4 Research Question 4

What role may the facilitators of the support programs for cancer patients identify for nutrition education, either formal or informal, within their cancer support groups?

Study participants described what topics should be discussed and what resources should be used as part of nutrition education for the groups. Study participants also commented on the nature of the nutrition education, and suggested a few possible formats for nutrition education.

Topics that would be suitable for nutrition education for group members of cancer support groups include healthy eating, fat, label reading, dealing with chemotherapy, special diets, menu planning, and vitamin and mineral supplementation. Topics should not just be discussed, but addressed in practical formats.

Several resources could be used in nutrition education for group members of cancer support groups. Study participants indicated that resources, such as pamphlets and videos, should be available for group members interested in learning more about nutrition. Having nutrition professionals speak to the group was also a good way to provide nutrition education because the nutrition professionals could provide good information.

Study participants also commented on the nature of the nutrition education itself. Nutrition education could be done with a sense of awareness about the vulnerabilities of the audience. Nutrition education should address specific issues related to the nutrition concerns of group members. Nutrition education should provide information in helpful ways that allow for group members to try new regimens without adversely affecting their health.

Some study participants suggested how nutrition education could be implemented. One suggestion was to have one nutrition topic at every group meeting. Another suggestion was to design separate nutrition education for the group members who are interested in nutrition. Two study participants described the type of nutrition education that they would like to offer to their group members.

### 5.3 Summary of Major Research Findings

There were several major findings of this research. The major findings included information on the impact of cancer on group members, insight into the characteristics and mechanisms of social support, and details of how the groups are organized. Nutrition education is occurring in the support groups. There is a potential role for nutrition education in the support groups, but barriers exist that may impede the implementation of nutrition education in the support groups. Finally, study participants had some suggestions to help enhance the implementation of nutrition education in the support groups.

**People with cancer are physically and emotionally impacted by having cancer.** People with cancer are physically affected by the disease, and even more so by the treatments and side effects of the treatments. Physical issues included weight changes, appetite changes, hair loss, nausea, vomiting, and fatigue. People with cancer also have to deal with feelings of fear, guilt, and anger. People with cancer have to deal with changing relationships with their spouses and loved ones, as the spouses and loved ones also deal with their own feelings of fear and anger. Physical and emotional factors impact attendance and participation in the support groups, as well as dietary habits.

**Study participants in this research shared their first hand experiences of social support.** Participation in a cancer support group helps to reduce feelings of isolation felt by people with cancer. Support groups also provide an opportunity to talk about issues that might not normally be talked about. Study participants described how social support helps people in the group by providing people with an opportunity to feel relief, as well as an opportunity to have their concerns validated. Social support also enables people to forge emotional connections with others in a similar situation. Social support contributes to health and well being by providing relief and an opportunity to increase self awareness.

**Each group in each organization operates differently.** Each group in each organization was formed differently, and operates under different circumstances. In the first organization, each group operates independently. Each facilitator is responsible for the operation of the group, including the offering of any programming to group members. In the second organization, the group facilitators are employees of the organization. Each facilitator can manage the group as he or she sees fit, as long as the mandate of the organization is followed in the programming of the group. In the third organization, the facilitators often report the events of the groups to the governing body of the organization, who then makes decisions regarding the programming of the groups.

**Group facilitators do not want to determine what the group discusses.** The facilitators of some of the support groups shared how they had repeatedly asked the group members if they wanted to be given specific information on issues related to cancer. The group members always refused, preferring to have open discussions. For example, the facilitators shared that they thought the group members needed nutrition information, but they also shared that, as facilitators, they were hesitant to determine discussions of any particular topic.

**The meetings of the groups share some similarities.** Groups meet on a regular basis, usually bi-weekly or monthly. Most of the people who attend the groups have been personally diagnosed with cancer, but several of the groups have had the spouses and loved ones of the person with cancer attend as well. Most groups have a check in where the people attending can introduce themselves and identify any issues of concern for them. Discussions usually proceed in the format of conversations, with someone raising a concern, and then others with experience replying. Several groups close each meeting with a meditation.

**Nutrition education occurs in the support groups**. Nutrition education occurs both formally and informally. Formal nutrition education usually occurs in the form of a presentation on nutrition by a dietitian or nutritionist. Informal nutrition education usually occurs in the form of a group member raising a nutrition related concern, and other group members providing advice on how they dealt with that issue.

**There is potential for nutrition education in support groups for people with cancer**. The support group is a place for people with cancer to deal with issues that arise as a result of having cancer. Nutrition can be one of those issues. Study participants supported nutrition education in the support groups. People with cancer often feel vulnerable. Offering nutrition education may help to decrease some of the group members' feelings of vulnerability by increasing their knowledge and abilities to deal with nutrition related concerns. Also, people with cancer often make physical and emotional lifestyle changes, which could include dietary changes. Nutrition education might help them be able to make effective dietary changes.

**There are barriers to implementing nutrition education**. The drop-in nature of the group, competing priorities of the group members, timing of nutrition education, and availability of resources are barriers to formal nutrition education. The characteristics of the group members and the characteristics of the group facilitators are barriers to both formal and informal nutrition education.

**Study participants believe nutrition education can be enhanced in the current cancer support groups**. Focusing on the format, the importance, and the timeliness of any suggested nutrition education may enhance its implementation. Formal nutrition education should be short term, interactive, and practical in nature. Informal nutrition education should use principles of peer education.

Nutrition education should account for the mixed knowledge level of the group members. The group members should identify the need for nutrition education. Nutrition education that proposes good nutrition as one part of dealing with having cancer might enhance nutrition education in the support group. If the group was satisfied with nutrition education in the past, inviting the presenter of that nutrition education to do more nutrition education might enhance the implementation of nutrition education in the support group.

## 5.4 Implications for Stakeholders

The results of this research have implications for a number of stakeholders, including organizations that offer support groups for people with cancer, support group facilitators, support group members, and nutrition educators.

The organizations that offer support groups for people with cancer can use the information gleaned from this research as a basis for further investigation into the role of nutrition education in their groups. Several findings of this research may impact these investigations. Individual groups in each of the organizations are managed and operated differently. This results in unique challenges for each group in terms of evaluating the feasibility of offering programming in the groups. Individual groups in each of the organizations will have to assess the methods by which they identify the needs of the group. For example, the needs of the general group in the third organization are reported by the facilitators to the governing body of the organization, which then determines what programming will be offered to the group. Individual groups will also have to examine the specific issues that affect their particular group in terms of offering programming such as nutrition education. For example, the drop-in nature of the groups may make it difficult for facilitators to decide when to offer programming. The groups that are of a drop-in nature may have to explore ways to address the drop-in nature so that they are better able to offer programming.

The facilitators of the support groups can use the information obtained from this research to provide effective programs for group members. By becoming aware of the state of nutrition education in their group, group facilitators can adjust their programming accordingly. Group facilitators may also benefit from the results of this research by seeing what other similar groups are doing with regards to nutrition education. The group members that attend the groups will likely benefit from this research as the facilitators alter the programming of the group to best meet the needs of the members.

Using the information obtained in this research, nutrition educators can learn about how support groups for people with cancer operate. They can better understand the enhancers and barriers to nutrition education in support groups. They can plan nutrition education more knowledgably. Nutrition educators could become advocates for the usefulness of nutrition education in the support groups, as well as resource persons for groups who want to explore alternative means of providing nutrition education.

This research also shows the importance of understanding the nature of support groups and their needs and interests. Nutrition educators need to know the information needs of the group, the level of knowledge that group members have, and the stages of the disease that group members are in, because the group members have diverse needs and interests. If the information obtained in this research is incorporated into future nutrition education, the group members may benefit by having access to nutrition education that has been tailored to meet their needs.

## 5.5 Recommendations

Information regarding the operation and functioning of the support groups for people with cancer was obtained in this study. Information was also obtained about current nutrition education in the groups, as well as the facilitator's thoughts on future nutrition education for the groups. Based on this information, recommendations regarding future nutrition education in the groups can be made on several levels. These levels include recommendations for the organizations in general, recommendations for the organizations about nutrition education, and recommendations for nutrition professionals.

### 5.5.1 Recommendations for Organizations

The organizations that offer the support groups for people with cancer all operate and manage their groups individually. As a result, each group and organization determines the needs of the group members by different methods. Each group and organization must also determine how to address the unique issues that arise with regards to programming in each group.

1. **Individual groups in each organization should evaluate the methods by which the group identifies the needs of the group members.**

This research has found that members in support groups for people with cancer have diverse needs. One reason people with cancer attend support groups is to address the needs that they have as a result of having cancer. To meet these needs, the facilitators and organizers of the support groups must be able to identify the needs of the group members.

Currently, the needs of the group members do not appear to be assessed by the facilitators of the groups by any standardized method. The needs of the group members are identified as a result of the perceptions of the facilitators. Conducting an appropriate needs assessment is the first step in planning effective programming. Identifying the needs of the group and understanding the factors that affect those needs are vital parts of designing programs that are effective in meeting the needs of the group.

2. **Individual groups in each organization should examine the potential for addressing issues that arise with regards to providing programming in the support groups.**

Study participants described several barriers to nutrition education that might be more appropriately addressed as issues that arise with regards to any type of programming that the groups attempt to offer. Examples of such issues include the drop-in nature of the groups and the timing of the programming.

Study participants outlined that many of the groups are of a drop-in nature. Registration to attend the group is not required and group members are free to choose whether or not to attend a given group meeting. Study participants recognized this was an issue with regards to planning programming for group members. It was difficult for facilitators to plan programming when they did not know how many people would be at any given meeting. Groups and organizations with a drop-in nature may want to evaluate the feasibility of changing the nature of the group. If the organizations could offer a group that was more demanding with regards to the attendance of group members at meetings, programming decisions might become less difficult for facilitators.

The third organization currently operates several groups that are set up for people with certain, very specific, needs, such as a certain type of cancer. These groups are not of a drop-in nature, in that registration is required, and the programming of the group is planned by the facilitator to address the issues that arise from the specific needs. This organization also operates a general group for anyone with an issue having to do with cancer, which is of a drop-in nature. This organization could compare the effectiveness of the two groups to evaluate the impact of the drop-in nature of the general group on the planning of programming for the group.

The groups should also examine how to best address the issue of the timing of any specific programming that is offered to the group. In discussing nutrition education as programming that could be offered, the group facilitators indicated that people with cancer are often confronted with multiple issues at once. Group members attend the meetings in order to address the issues that are most pressing to them. This makes it difficult for the facilitators to decide when to offer programming. The facilitators are hesitant to detract from the importance of any other issue by focussing on just one issue. The organizations should evaluate the factors surrounding the feasibility of offering more programming in each group. For example, if the drop-in nature of the group is affecting the timing of programming, the groups should evaluate how they might change the drop-in nature of the group to a more structured pattern of attendance.

### 5.5.2 Nutrition Education Recommendations for Organizations

This research identified and described the current role of nutrition education in support groups for people with cancer. Research participants also shared their thoughts about factors that would impede or enhance the implementation of future nutrition education in the groups. As a result of these findings, several recommendations about nutrition education in the groups can be made.

**1. Nutrition education should continue to be a part of the groups.**

Study participants indicated that currently, both formal and informal nutrition education occur in the groups. People with cancer attend the group meetings to address issues in their lives having to do with cancer, and nutrition is one of those issues. Formal nutrition education should be continued in order to address the specific nutrition topics that nutrition professionals can best address. Informal nutrition education will continue as long as group members have food and nutrition related issues that they discuss in the groups. As well, nutrition education should continue to be offered to the group members as the membership roster continues to change. Current members will begin to leave the group once they are no longer in need of the support, and new people diagnosed with cancer will choose to attend the meetings.

**2. Organizers and group facilitators at each organization should explore the various options for nutrition education within their individual groups.**

Each organization should explore the feasibility and suitability of each of the nutrition education options that are available. Current nutrition education options include presentations, informal discussions, and self study using printed matter and videos. Each option has advantages and disadvantages. Each organization should evaluate the feasibility of each option for their individual groups, since different options may be best suited for different groups.

**3. The organizations should evaluate the feasibility of offering study participants' suggestions for nutrition education within their groups.**

Some study participants suggested potential nutrition education formats, such as offering information on one topic at every meeting, or developing and conducting in-depth nutrition education external to the regular programming of the support group. Study participants suggested that nutrition education that originates from within the ranks of the group might be received better than nutrition education that is suggested by the governing bodies of the organizations. Each suggestion should be evaluated by each group to determine the suitability of its adoption by each group, since each group operates under different mandates.

**4. Groups should evaluate the feasibility of offering formal nutrition education external to the regular meetings of the support group.**

Study participants indicated that most formal nutrition education lasted the duration of one group meeting. The time that formal nutrition education would consume was identified as a barrier to more formal nutrition education, because time would not be available to discuss other issues that group members might have. Each group should evaluate the feasibility of offering nutrition education external to regular support group meetings, by exploring the benefits and limitations to doing so. Each individual group would have unique factors affecting their choice to offer nutrition education external to regular group meetings. Conducting nutrition education external to regular support group meetings would provide an opportunity for interested group members to obtain information about nutrition while still having regular meeting times to address other issues.

5. **Future formal nutrition education should include the factors that study participants identified as enhancing nutrition education.**

These factors included having formal nutrition education that is short term, interactive, and delivered to a small number of people. If nutrition education is short term, more group members might be able to participate in it. The competing priorities of the group members were also identified as a barrier to implementing more formal nutrition education. If formal nutrition education is practical and interactive, it might be perceived as more enjoyable and satisfactory by those who participated in it. The research participants identified group satisfaction as a nutrition education enhancer.

### 5.5.3 Recommendations for Nutrition Professionals

Some of the nutrition professionals in the area are the people who are making the formal nutrition presentations to the support groups. As such, these nutrition professionals may benefit from the results of this research. Several recommendations can be made for nutrition professionals as a result of this research.

**1. Circulate a report on the results of the research study to all clinical and community based nutrition professionals in the area.**

The report could make nutrition professionals aware of the programming challenges faced by the groups, as well as the challenges that the nutrition professionals might face in working with the groups. For example, it is important that nutrition professionals are aware that groups are not all operated in similar fashion. Nutrition professionals could then use the information to plan nutrition education which accommodates these challenges. Nutrition professionals could also use this information to develop means of collaboration with the groups that accounts for the operational challenges of working with the groups.

The report could also outline the nutrition education needs of the support groups that were identified by the research participants, such as suggested topics of discussion and presentation formats. The nutrition education professionals could then use the report as a resource for planning more effective nutrition education because they would have information that would allow them to tailor their programs to meet the needs of their audience.

**2. Nutrition professionals should explore the development of less traditional methods of nutrition education.**

In the groups, formal nutrition education most often occurs in the form of presentations by nutrition professionals. However, study participants have identified several barriers to this format. As a result, nutrition education professionals in the area are encouraged to explore the possibility of developing less traditional methods of nutrition education, such as self study workbooks. If another method of nutrition education existed, the organizations might be able to make use of the method without encountering as many barriers, while still addressing nutrition education needs.

3. **Nutrition professionals should explore their roles as advocates for nutrition education in the setting of support groups for people with cancer.**

To date, nutrition professionals have been invited to provide nutrition education to the groups, most often in the form of presentations. Nutrition professionals are, by the nature of their training, advocates for nutrition education and healthy eating messages. Nutrition professionals are continuously searching for new vehicles and settings in which to present nutrition education.

The information obtained in this research indicates that support groups for people with cancer may be an appropriate vehicle for nutrition education, since study participants identified that nutrition is an issue for people with cancer. Therefore, nutrition professionals are recommended to explore the potential for advocating nutrition education to support groups. By becoming aware of the challenges groups face in terms of offering programming, nutrition professionals can better target their advocacy of nutrition education to the groups.

### 5.5.4 Recommendations for Collaboration

Opportunities exist for collaboration between organizations that offer support groups for people with cancer and nutrition professionals. The organizations have a need for nutrition education, and the nutrition professionals have the ability to provide nutrition education. As a result of the findings of this research, several recommendations can be made with regards to collaboration between the groups and organizations and nutrition professionals.

### 1. Resource development for topics of interest.

Study participants identified a number of nutrition related topics for which group members had requested information. Although study participants did not specifically identify a need for resource development in general, some study participants identified areas where more nutrition information is needed. These areas included food substitutions, meal preparation and planning, ways to deal with the effects of lower body radiation, and the specifics of supplementation regimens.

The organizations are encouraged to examine the potential for resource development on the issues identified by study participants. Development of resources could be completed through collaboration between the organizations and area nutrition professionals. Resources developed could include tip sheets and information booklets.

### 2. Organizations should explore the feasibility of nutrition training for facilitators.

Study participants outlined how most of the nutrition education that takes place in the support groups is informal. One group member expresses a nutrition related concern, and other members share their experiences and advice for dealing with the concern. Study participants have expressed concerns that this type of information sharing may lead to the transmission of misinformation.

Nutrition related educational training for the facilitators of the support groups might be suggested to the organizations as a possible method of minimizing the transmission of nutrition misinformation. This nutrition education training could provide an overview of some of the nutrition related issues that arise in group meetings, and provide accurate topical and practical information, so that where informal nutrition education occurs, facilitators can identify any misinformation. The individual organizations are encouraged to evaluate the feasibility of offering such training to the facilitators of their support groups. Such educational training might present the opportunity for collaboration between the organizations that offer the support groups and organizations that offer nutrition education.

## 5.6 Limitations

This study used a convenience sample. Study participants were facilitators of support groups for cancer patients in Saskatoon and the surrounding area. The organizations that participated were identified from the 1999 Saskatoon Community Directory. The researcher approached the organizations that were available at that time, and the facilitators were those who agreed to participate in the research. As a result, this study may not cover all support groups for people with cancer in Saskatoon.

The study participants in this research were the facilitators of support groups for people with cancer. Some of the facilitators were cancer survivors, while others were not, and the facilitators that were cancer survivors spoke both of their own experiences and those of other group members. All of the facilitators were asked to frame their discussions around what had happened in the groups, therefore the data is based on the perceptions and views of the facilitators. This could contribute to response bias in the data, since the data was drawn from the facilitators perceptions of their groups and not an actual record of the proceedings of the group.

The research tool used in this study was an in depth personal interview with people who were identified as facilitators of support groups for cancer patients. The interviews were conducted in a series over the course of six months. Because the researcher was unable to go back to previous study participants and discuss issues brought up by later study participants, some issues may not have been examined to the depth that they could have been.

There is the potential for researcher bias because the researcher conducted all of the interviews and analyzed all of the data. The researcher attempted to minimize the effects of researcher bias through an external audit and numerous debriefings with the research supervisor.

## 5.6 Further Research

Informal nutrition education occurs in the groups. There is not enough known about the factors and issues surrounding the informal nutrition education that is occurring in the groups. These issues could be explored in further research. There is not enough known about the source or the authenticity of the information that might be shared in this situation. For example, are group members sharing information they received from health professionals, or information they obtained off of the internet, or at a health food store? Is the information they are sharing anecdotal, or grounded in scientific research? If information that is being shared is not being obtained from reputable sources, are group members disclosing details about their sources when they share the information? Each of these queries could be the subject of further research regarding the informal nutrition education that takes place.

Study participants indicated that most of the support groups had had at least one formal nutrition education session. The purpose of this study was to identify and describe the role of current nutrition education, but not to evaluate it. Also, this study did not examine the value of having nutrition education, either formal or informal, in the support groups. Further research might include evaluations of both the current formal and informal nutrition education in the support groups.

Both formal nutrition education, in the form of presentations by nutrition professionals, and informal nutrition education, in the form of advice sharing, are ongoing in the support groups. One area for further research might examine the feasibility of developing different types of formal nutrition education other than presentations by nutrition professionals, such as workbooks or journals. Another area for further research might be a comparison of the effectiveness of each nutrition education method. For example, further research might examine whether or not the use of a nutrition professional is necessary. Further research might also explore the effectiveness of providing the facilitators with some nutrition related training.

Study participants also indicated that many cancer patients make changes to their dietary habits after receiving a diagnosis and undergoing treatments for cancer. While the participants in this study speculated on nutrition related areas of people's lives that may have been impacted by their having cancer, actual nutrient intakes were not assessed. Nutrient intakes of cancer patients and changes in nutrient intakes as a result of behavior changes may also be areas for further research.

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# Appendix A

## Consent Form for Study Participants

# NUTRITION AND SOCIAL SUPPORT: AN EXAMINATION OF THE CURRENT AND POTENTIAL ROLE OF NUTRITION EDUCATION IN SUPPORT GROUPS FOR CANCER PATIENTS

## Consent Form

## PURPOSE

The purpose of the research is to identify and describe the factors influencing the current and potential nutrition education in support programs for cancer patients in the city of Saskatoon. The researcher will be interviewing you to find out more about your views regarding the role of nutrition education in support groups.

## NATURE OF STUDY & RISKS / BENEFITS TO PARTICIPATION

Your participation in this study is completely voluntary and will involve a 1 hour taped interview with the researcher. The 1 hour interview will take place in a location convenient to you. Please be assured that you can withdraw from the interview at any time if you so wish. All data collected up to that time will be destroyed upon your withdrawal.

There are no risks to your involvement in the study. The potential benefits of this study are to program planners and participants in that feedback is crucial to the development of more effective and efficient programs. The researcher cannot guarantee that the information collected will be used to improve current programs.

## PROCESS

This one on one interview is a part of a series that will involve individuals who organize and lead support groups for cancer patients in the city of Saskatoon. With your permission, the interview will be audio taped in order to ensure that your views are collected accurately and completely. The tapes will not identify you by name, address, or phone number, and will be used by the researcher only. Tapes and printed transcripts will be safely stored in a locked desk drawer when not in use. The tapes will be held in a locked drawer of the research supervisor, Dr. S. Berenbaum, for a period of five years, as per university requirements, and then destroyed.

If for whatever reason, you are uncomfortable with being taped, you will not be taped. The interviewer, with your permission, will take brief notes of the key issues discussed. After the interview has been transcribed, you will receive a copy of the transcript to review, along with a transcript release form. The data contained within the transcript will not be part of the study until the researcher has received a signed copy of the release form. After the analysis of the data, a summary report of the findings will be available, if you would like to receive one. Unfortunately, we are not able to provide you with individual advice and suggestions based on your own data.

## CONFIDENTIALITY

Complete confidentiality is assured. Your participation in this study will not be revealed to anyone. This interview will be audio taped, if you so consent, and the audio tapes will be kept in a locked desk drawer to which only the researcher has access. The tapes will be transcribed by the researcher. The research supervisor and study auditor will have access to the transcripts, but no participants will be identified within them. After completion of the research and the defense of the thesis, the tapes will be destroyed. You are free to withdraw from the study and/or interview at any time. Results from this research, when analysed and summarized, will be written in the form of a research thesis, which will then be available at the University of Saskatchewan library. As well, results may be published in scientific journals, various community resources, and presented at conferences. All published data will be cumulative, and will not identify individual study participants in any way.

FOR MORE INFORMATION

If you have further questions about your rights as a subject participating in a study like this, or if you would like to discuss your participation in the study, contact Julia Taylor, Director of Research Services, University of Saskatchewan at (306) 966-8576. If you have questions and/or comments, please do not hesitate to contact the researcher and/or research supervisor at any time. Thank you for your participation in this study.

Carolyn Burton
Graduate Student
University of Saskatchewan
966-6346 (office)

Dr. Shawna Berenbaum
Associate Professor and Research Supervisor
University of Saskatchewan
966-5836 (office)

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I have been informed as to the structure of this study and the conditions of consent. I understand the implications of this consent and will maintain a copy for my own records. I agree to participate in this research study.

Participant ____________________ Date ____________________

Researcher ____________________ Date ____________________

NUTRITION AND SOCIAL SUPPORT : AN EXAMINATION OF THE CURRENT AND POTENTIAL ROLE OF NUTRITION EDUCATION IN SUPPORT GROUPS FOR CANCER PATIENTS

## Transcript Release Form

I, ------------------------------------------, have reviewed the complete transcript of my personal interview in this study and acknowledge that the transcript accurately reflects what I said in my personal interview with the researcher. I hereby authorize the release of this transcript to the researcher to be used in the manner as described in the consent form. I have received a copy of this transcript release form for my own records.

| | |
|---|---|
| Participant | Date |
| Researcher | Date |

# Appendix B

## Interview Guide for Study Participants

## *Interview guide questions based on research questions*

Thank you for agreeing to be interviewed today. I am interested in the health benefits that people gain through their social support systems, especially nutrition related benefits. Support groups for people with cancer is the system that I have chosen to look at for my research project. I am interviewing support group leaders, like yourself, so that I can develop a better understanding of the role of nutrition in the support groups for cancer patients.

I would like to ask you to read over this consent form and sign it in order for me to conduct this interview. The consent form explains that anything you say here will be kept confidential, and that any identifying remarks will be omitted. If you so agree, this interview will be tape recorded and the tape will be transcribed by me. The tapes are locked in a drawer in my desk, and no one else will have access to either the tapes or the transcripts. Once the interview is transcribed, you will have a chance to review your interview and make any changes. No one but me knows that you have agreed to be interviewed.

To begin with, I would like to ask some questions about the group itself. My first question is.....

In what year did this group form?

What led to the formation of this group?

How long have you been the leader of this group?

How did you become a leader?

What is your role as group leader?

What is the purpose of this group?
    Does the group have specific goals? If so, how were they determined?

Please describe a typical session for me.
    What is the structure of the sessions?
    What topics are usually covered at the sessions?
    What types of information are usually shared amongst participants in the sessions?

What are the reasons the participants usually give for belonging to this group?

What, if anything, have members told you about how they feel about this group?

How many people usually participate in each session?
    Since the group began, approximately how many people have participated?

What problems, if any, has your group encountered since it formed?
    How were those problems handled?
    The readings I have done in the area suggest that things like irregular attendance, disruptive members, and having people at different stages can all have a negative influence on the group.

<u>On current nutrition education in the programs.....</u>

Is nutrition ever discussed in your sessions?

Is nutrition information casually or informally shared among group members?

How, if at all, do leaders facilitate the sharing of nutrition information during group meetings?

What is your definition of nutrition education?

## Formal Nutrition Discussions

How and when does NE occur in your program? What format is used?

Who decides the topic? Are guest speakers used? If so, who arranges the speaker?

What topics have been discussed? What ones will be discussed?

Do you think that NE is useful to the participants? In what way?

Do you find participants willing to discuss nutrition?

If so, what encourages them to talk about nutrition?

If not, what might discourage them?

Do you think the participants would want to learn more more about nutrition?

## Informal Nutrition Discussions

Can you describe how and when it is discussed?

Who initiates the discussion on nutrition?

What issues have been, or are typically, discussed?

Do you think that these discussions are useful to the participants? In what way?

Do you find participants willing to discuss nutrition?

If so, what encourages them to talk about nutrition?

If not, what might discourage them?

Do you think the participants would want to learn more more about nutrition?

If there is no specific nutrition education component in the programs.....

Do you feel that there should be? Why or why not?

What do the leaders think are some of the barriers to implementing a NE program?

What do the leaders think are some of the enhancers to implementing a NE program?

What value do leaders see in nutrition information being given in support programs?

What topics do you think should be covered?

Who do you think should present the information?

How do you think the information should be presented?

On nutrition and cancer......

What are some of the ways that you (the leaders) see the nutritional status of the patients being affected by cancer?

What aspects of living with cancer do you think have an affect on patients' nutrition?

# Appendix C

## Consent Forms and Interview Guides for Contextual Interviews in First Study

# NUTRITION AND SOCIAL SUPPORT: AN EXAMINATION OF THE CURRENT AND POTENTIAL ROLE OF NUTRITION EDUCATION IN SUPPORT GROUPS FOR CANCER PATIENTS

## Consent Form for Organization Personnel and Group Leaders

## PURPOSE

The purpose of the research is to identify and describe the factors influencing the current and potential nutrition education in support programs for cancer patients in the city of Saskatoon. The researcher will be interviewing you to find out more about your views regarding the role of nutrition education in support groups.

## NATURE OF STUDY & RISKS / BENEFITS TO PARTICIPATION

Your participation in this study is completely voluntary and will involve a 1 hour taped interview with the researcher. The 1 hour interview will take place in a location convenient to you. Please be assured that you can withdraw from the interview at any time if you so wish. All data collected up to that time will be destroyed upon your withdrawal.

There are no risks to your involvement in the study. The potential benefits of this study are to program planners and participants in that feedback is crucial to the development of more effective and efficient programs. The researcher cannot guarantee that the information collected will be used to improve current programs.

## PROCESS

This one on one interview is a part of a series that will involve individuals who organize and lead support groups for cancer patients in the city of Saskatoon. With your permission, the interview will be audio taped in order to ensure that your views are collected accurately and completely. The tapes will not identify you by name, address, or phone number, and will be used by the researcher only. Tapes and printed transcripts will be safely stored in a locked desk drawer when not in use. The tapes will be held in a locked drawer of the research supervisor, Dr. S. Berenbaum, for a period of five years, as per university requirements, and then destroyed.

If for whatever reason, you are uncomfortable with being taped, you will not be taped. The interviewer, with your permission, will take brief notes of the key issues discussed. After the interview has been transcribed, you will receive a copy of the transcript to review, along with a transcript release form. The data contained within the transcript will not be part of the study until the researcher has received a signed copy of the release form. After the analysis of the data, a summary report of the findings will be available, if you would like to receive one. Unfortunately, we are not able to provide you with individual advice and suggestions based on your own data.

## CONFIDENTIALITY

Complete confidentiality is assured. Your participation in this study will not be revealed to anyone. This interview will be audio taped, if you so consent, and the audio tapes will be kept in a locked desk drawer to which only the researcher has access. The tapes will be transcribed by the researcher. The research supervisor and study auditor will have access to the transcripts, but no participants will be identified within them. After completion of the research and the defense of the thesis, the tapes will be destroyed. You are free to withdraw from the study and/or interview at any time. Results from this research, when analysed and summarized, will be written in the form of a research thesis, which will then be available at the University of Saskatchewan library. As well, results may be published in scientific journals, various community resources, and presented at conferences. All published data will be cumulative, and will not identify individual study participants in any way.

FOR MORE INFORMATION

If you have further questions about your rights as a subject participating in a study like this, or if you would like to discuss your participation in the study, contact Julia Taylor, Director of Research Services, University of Saskatchewan at (306) 966-8576. If you have questions and/or comments, please do not hesitate to contact the researcher and/or research supervisor at any time. Thank you for your participation in this study.

| | |
|---|---|
| Carolyn Burton | Dr. Shawna Berenbaum |
| Graduate Student | Associate Professor and Research Supervisor |
| University of Saskatchewan | University of Saskatchewan |
| 966-6346 (office) | 966-5836 (office) |

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I have been informed as to the structure of this study and the conditions of consent. I understand the implications of this consent and will maintain a copy for my own records. I agree to participate in this research study.

| | |
|---|---|
| Participant | Date |
| Researcher | Date |

# NUTRITION AND SOCIAL SUPPORT : AN EXAMINATION OF THE CURRENT AND POTENTIAL ROLE OF NUTRITION EDUCATION IN SUPPORT GROUPS FOR CANCER PATIENTS

## Transcript Release Form for Organization Personnel and Group Leaders

I, ------------------------------------------, have reviewed the complete transcript of my personal interview in this study and acknowledge that the transcript accurately reflects what I said in my personal interview with the researcher. I hereby authorize the release of this transcript to the researcher to be used in the manner as described in the consent form. I have received a copy of this transcript release form for my own records.

| | |
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| Participant | Date |
| Researcher | Date |

Why did CCS develop support programs? What was the rationale?

What is the purpose of each group? What are the goals of each group? How are these determined?

Are the groups structured or unstructured? What are the structures of the programs?

Who leads groups? How is the agenda developed? How are topics decided?

What topics are covered?

Are there guest speakers? On what topics?

Where are programs offered? Hospital? Community? Private Home?

What time of day are the programs offered?

Is there a minimum or maximum number of participants for group effectiveness?

Are any kind of records kept?

Are evaluations done? Formal or informal?

How are negative group experiences handled?

How are the following accomplished -
- establishing group as psychological entity
- Structuring group
- Monitoring and promoting group development
- Managing group processes

Are any of the following principles of self help groups part of CCS groups -
- shared experiences
- education
- self governance
- self responsibility
- single purpose
- voluntary membership
- committment to personal change
- anonymous & confidential

Do you think that CCS programs fill a void left in the health care system?

## *Interview Guide for Cancer Support Program Leaders*

Thank you for agreeing to be interviewed today. I am interested in the health benefits that people gain through their social support systems, and support groups for people with cancer is the system that I have chosen to look at for my research project. I am interviewing support group leaders, like yourself, so that I can develop a better understanding of the types of groups my study participants are involved in.

I would like to ask you to read over this consent form and sign it in order for me to conduct this interview. The consent form explains that anything you say here will be kept confidential, and that any identifying remarks will be omitted. If you so agree, this interview will be tape recorded and the tape will be transcribed by me. The tapes are locked in a drawer in my desk, and no one else will have access to either the tapes or the transcripts. Once the interview is transcribed, you will have a chance to review your interview and make any changes. No one but me knows that you have agreed to be interviewed.

To begin, my first question is.....

In what year did this group form?

What led to the formation of this group?

How long have you been the leader of this group?

How did you become a leader?

What is your role as group leader?

What is the purpose of this group?
    Does the group have specific goals? If so, how were they determined?

Please describe a typical session for me.
    What is the structure of the sessions?
    What topics are usually covered at the sessions?
    What types of information are usually shared amongst participants in the sessions?

What are the reasons the participants usually give for belonging to this group?

What, if anything, have members told you about how they feel about this group?

How many people usually participate in each session?
    Since the group began, approximately how many people have participated?

What problems, if any, has your group encountered since it formed?
    How were those problems handled?

The readings I have done in the area suggest that things like irregular attendance, disruptive members, and having people at different stages can all have a negative influence on the group.

Finally, in order to complete my study, I need to talk to people in support programs to find out their views on social support and health. Would you be able to distribute my recruitment letter in your group?

# Appendix D

## Recruitment Letter in First Study

Dear Support GroupMember,

My name is Carolyn Burton and I am a graduate student at the University of Saskatchewan. I am currently studying for my Master of Science in Nutrition. I am interested in nutrition education, and how people apply nutrition to their lives. I am also interested in alternative types of health care programs, such as the support groups. For my master's thesis project, I would like to conduct a study that combines all of these interests. My research aim is to identify and describe the current and potential role of nutrition education, if any, in support groups for cancer patients. I have asked your group facilitator to pass this invitation on to you so that confidentiality is not compromised. .

I would like to invite you to share your experiences of the support group you attend. Specifically, I would like to talk with you about any nutrition education you may have obtained. I will not be asking questions about your disease and personal medical history, except that which is related to nutrition, nor will I be asking about other aspects of the support group. Questions that will be asked will be on your participation in the group, nutrition topics covered in the group, and how being part of the program has affected nutrition related aspects of your life, such as eating, shopping, and food preparation habits .

I believe the best way to gather information of this type is through one-on-one conversations with the people who are in the situation. I would like to conduct in-person interviews with people who have facilitated various support groups. The interview would be about an hour long. These interviews will be held in a neutral, private location that is convenient to you, and the date and time of the interview will be determined at your convenience. No one else will be present at the interview, and no one other than myself will know your identity and that you are participating in my research.

The interviews will be audio taped, if you so consent, and then transcribed by myself. The transcripts will be non identifiable. All tapes and transcripts will be safely stored in a locked drawer in my office until the completion of the study. They will then safely stored in a locked drawer of the desk of my supervisor, Dr. S. Berenbaum, for five years after the completion of the study, as per university requirements.

Before I can use the transcripts in my study, I will give you an opportunity to review the transcript and make any changes to clarify or correct what was said. I will then be requesting that you sign a Transcript Release form, which will authorize me to use the transcript to generate data for my study.

If you would like to participate in the study, please contact me directly. The best time to reach me is at home in the evening between 7 and 10 pm. My home phone number is (306) 242-9413 and if I do not happen to be there, you are welcome to leave a message. I can also be reached by email (csb854@mail.usask.ca). I would be happy to provide you with more information about myself and my research at your convenience. You need not give a name or phone number if you would like more information. You may also contact my research supervisor, Dr. Shawna Berenbaum, at 966-5836, for more information about this research project.

I appreciate you taking the time to read this letter and look forward to hearing from you.

Sincerely,

Carolyn Burton

cc : Dr Shawna Berenbaum

# Appendix E

## Report of the External Auditor

## Audit Report for Carolyn Medernach

I was asked to complete this audit by Carolyn Medernach (researcher). I began by reviewing the thesis materials to be audited (transcripts of interviews, coded cue cards, reflexive journal of major themes, data files from transcripts, typed supporting quotes from transcripts, the thesis, etc.). As auditor, my primary goal was to establish the dependability and confirmability of "The Current and Potential Roles for Nutrition Education in Cancer Support Groups in Saskatoon".

The thesis was reviewed for content and two themes were self-selected for the audit. The following themes were chosen for review:

- **4.5.2 Current Nutrition Education**
  - 4.5.2.1 Format of Nutrition Education
    - 4.5.2.1.1. Formal Nutrition Education
    - 4.5.2.1.2 Informal Nutrition Education
  - 4.5.2.2 Frequency of Nutrition Education
  - 4.5.2.3 Nutrition Education Resources Assessed by Groups
  - 4.5.2.4 Nutrition Related Topics of Discussion

- **4.5.3 Barriers and Enhancers of Further Nutrition in Groups**
  - 4.5.3.1 The Drop in Nature of the Groups
  - 4.5.3.2 Competing Priorities of Group Members
  - 4.5.3.3 Timing of Nutrition Education
  - 4.5.3.4 Availability of Resources
  - 4.5.3.5 Characteristics of Group Members
  - 4.5.3.6 Characteristics of Facilitators

The package of research materials was found to be complete with clearly labeled materials. Items were well-organized and neatly coded which provided a traceable path from the thesis to the original interview data.

The themes selected were found to be based in the raw interview data. The explanation codes provided were relatively simple to follow and made the audit trail clear. Quotations from participants were accurate and confirmable in the primary data. Participants' language was presented without bias in single-line format for each of the themes analyzed. Interview comments were presented in the participants own words and researcher inferences regarding the selected themes appear unbiased.

The data was found to be dependable and appropriate for the researchers themes. Findings within the thesis were well-supported with references and numerous examples from the raw interview data. In my opinion, the researchers' summations and results were found to be trustworthy and based in the original interview data collected.

Sheila L. Brown B.Sc. Nutr. P.Dt.
August 17, 2002

# Appendix F

## Confirmation of Ethical Approval

# UNIVERSITY ADVISORY COMMITTEE ON ETHICS IN BEHAVIOURAL SCIENCE RESEARCH

**NAME:** S. Berenbuam (C Burton) **BSC #:** 1999-55
Division of Nutrition and Dietetics
College of Pharmacy

**DATE:** November 14, 2000

The University Advisory Committee on Ethics in Behavioural Science Research has reviewed the modification(s) to your study "Perceived Nutrition Related Benefits of Participating in Support Group Programs offered by the Saskatoon Unit of the Canadian Cancer Society (CSS)" (99-55).

1. The modification(s) to your study has been APPROVED.
2. Any significant changes to your study should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval remains three years from the original approval date.

Sincerely,

Valerie Thompson, Chair
University Advisory Committee
on Ethics in Behavioural Science Research

VT/bk

**Office of Research Services, University of Saskatchewan**
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