

Responding to the Needs of Rural Cancer Survivors:
Learning to *LiveWell with Chronic Conditions*

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Abstract

Background: Rural Saskatchewan cancer survivors have reported a lack of support once their cancer treatments have been completed. This problem is more acute the further away one lives from Saskatoon and Regina. A chronic disease self-management program titled *LiveWell with Chronic Conditions* (LWCC) is available to all people with any chronic condition in rural areas across Saskatchewan. This program addresses key areas of concern to survivors; however, participation is low for cancer survivors.

Purpose: To determine how LWCC can reach and respond to the needs of rural cancer survivors in Saskatchewan.

Objectives:

1. To gain an understanding of how the program responds to the needs of rural cancer survivors from the perspective of program leaders and cancer survivors.
2. To explore how the existing LWCC program could be enhanced in terms of content, format, delivery and marketing strategy.
3. Based on results, develop recommendations in coordination with agencies and institutions that provide services to cancer survivors.

Methods: A mixed-methods case study approach was adopted. Needs questionnaires were completed by cancer survivors who participated in the LWCC program offered in rural health regions across the province (n=4). Consenting survivors who attended the program and several program facilitators, some of whom were cancer survivors themselves, were interviewed in order to provide their opinion regarding content, format, and other relevant feedback that would improve the *fit* of the program with the needs of rural cancer survivors (n=10).

Results: Results indicate the material covered in the program is appropriate for cancer survivors who have finished acute treatment and are making the transition to life after cancer. Program benefits include improved self-efficacy and being able to manage emotional and physical issues from cancer including fatigue and pain. Rural survivors would like access to additional information to address issues specific to cancer survivorship including dealing with the fear of cancer recurrence, lymphedema and sexuality. A cancer specific rural health program would not be very feasible due to small populations. Cancer survivors felt comfortable in a group among people with other chronic conditions although support of another person with cancer participating in the LWCC group would be preferred.

Knowledge Translation: A think tank was held with key stakeholders who provide services to cancer survivors to review these findings and form recommendations for improving rural cancer survivor care. These recommendations are: 1) to promote LWCC to rural cancer survivors who have finished acute cancer treatment, 2) to broaden the awareness of the program among cancer care providers, and 3) to refer cancer survivors to an existing cancer survivorship single day workshop after participation in LWCC. This workshop is available in up to 10 communities outside of Regina and Saskatoon.

Conclusion: The *Live Well with Chronic Conditions* program is appropriate and beneficial for cancer survivors who have completed acute cancer treatments. As more cancer care providers make referrals to this program and an online version of the program becomes available, uptake will likely improve among rural cancer survivors in Saskatchewan.

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List of Abbreviations

CDSMP	Chronic disease self-management program
CCS	Canadian Cancer Society
CCSA	Cancer Council South Australia
CDM	Chronic Disease Management
CIHR	Canadian Institutes of Health Research
COPD	chronic obstructive pulmonary disorder
COPS	Community Oncology Program of Saskatchewan
CPAC	Canadian Partnerships against Cancer
LWCC	LiveWell with Chronic Conditions
SHR	Saskatoon Health Region
SCA	Saskatchewan Cancer Agency
SUNS	Survivor Unmet Needs Survey
YWCA	Young Women's Christian Association

CHAPTER 1: INTRODUCTION

1.1 Health Issue

The cancer survivor population is expanding, and determining appropriate intervention avenues is a high priority. Cancer survivors represent 2.5% of the Canadian population (1), and there are approximately 24.5 million cancer survivors worldwide (2). As cancer diagnosis and cancer treatment improve, and as the population ages, the number of cancer survivors will continue to rise. The last three decades have been witness to the transformation of cancer being an immediately fatal diagnosis to one of chronic illness in nature.

A survey facilitated by Canadian Partnerships Against Cancer (CPAC) was completed to elicit survivors' perspectives, in order to develop relevant programs that address survivorship issues. This survey identified that more information and better communication with health care providers would improve the cancer survivor's ability to cope (3). The need for more support from others with either personal or health care experience was expressed and support groups and follow up care were suggested (3). Some of the most frequent issues Canadian cancer survivors report are lack of follow-up support and having to travel to treatment (2). In Saskatchewan, cancer survivors have reported a lack of support and resources once their treatments have been completed, and this problem is more acute the further away a person lives from Saskatoon and Regina (4).

In 2008, survivorship and rehabilitation services were added to the mandate of the Saskatchewan Cancer Agency which included planning and implementation of a survivorship program based on the book *Picking up the Pieces: Moving forward after surviving cancer*. This program has been run at the two provincial cancer treatment centres in both Regina and Saskatoon (1). In 2010, the Saskatchewan Cancer Agency started planning and training health care providers to initiate a program titled *Cancer Transitions*. This program was developed by the Wellness Community and the Lance Armstrong Foundation in the United States and is an intervention program for cancer survivors who are making the transition from active treatment to long term care for optimal health and cancer recurrence prevention. It is currently being run throughout the United States and in several locations in Canada. In Saskatchewan, the *Cancer Transitions* program is being offered at the two urban cancer treatment centres in Regina and Saskatoon. These initiatives begin to address the needs of cancer survivors in Saskatchewan;

however as identified at a workshop in Regina with cancer survivors and health professionals in attendance, a key concern for cancer care in Saskatchewan is geographic inequality (5), and at this time there is not a cancer-survivor specific intervention available in rural communities.

In rural areas, health is defined in relation to the ability to function and work; pain appears to be less important in determining the rural person's notion of health (6). Self-reliance and self-help are significant strategies which rural people use to cope with illness, both their own and that of family members (7). Several studies have investigated the needs of rurally located cancer survivors and how their needs may be similar or differ from urban cancer survivors, and some recommendations have been made. Needs found to be most common between rural and urban survivors include: personal care, coping, support, and interpersonal interaction. Health problems of rural cancer survivors are intensified by factors such as geographic isolation, distance from health care and lack of transportation, poverty, lack of health care providers, health policy inequity and rural values, beliefs, and lifestyles (8).

Rural dwellers have expressed a need for self-help groups, and recommended that groups implemented for patients and caregivers should be community-based and community-run (9). Rural survivors request support to be *acceptable, available, and accurately address needs* of those attempting to maintain a quality lifestyle while living with cancer (8).

To address this need for self-help groups, researchers have been working to determine a successful self-management program for cancer survivors. The Stanford University Chronic Disease Self-Management Program (CDSMP) has been piloted as such in the UK where it was titled the "Living with Cancer" course and in Australia where it was titled "Staying Healthy after Cancer". In Australia, 25 cancer survivors participated in "Staying Healthy after Cancer" and 10 survivors participated in the standard program model for heterogeneous chronic conditions. Benefits found that were common to both groups were a decreased sense of isolation, gain of motivation and skills to improve health, a sense of re-gaining control, and a sense of achievement (10). Recommendations for improvements made by cancer survivors attending these programs were similar in that they would like increased discussion time, a longer program, and more detail provided in relation to cancer specific issues (i.e. dietary advice, complementary therapies, mortality, depression) (10,11). As found on the Stanford University website, the CDSMP has been specifically marketed to cancer survivors in several locations worldwide

including: The Cancer Council South Australia, Macmillan Cancer Support United Kingdom, Cancer Care Resources Portland Oregon, Cancer and Chronic Disease Consortium El Paso Texas, Joe A Arrington Cancer Research and Treatment Centre Lubbock Texas, Mary Queen Hospital Cancer Centre Hong Kong, and the Canadian Cancer Society Ontario Division Canada. Although this program is offered to cancer survivors in these locations, a literature search indicated that only the above two studies have been conducted and published evaluating the Stanford University Chronic Disease Self-management Program for cancer survivors.

There is a need for more research exploring ways to support men and women experiencing cancer in rural areas and the evidence remains insufficient to determine how to best support self-management by these cancer survivors (12). Research is also needed to develop interventions that are theoretically grounded, optimally timed, delivered via appropriate channels and overcome barriers, the most prevalent barriers being geographic location and distance to travel (13).

Cancer survivorship research aims to understand the action of treatments and tailor therapies to maximize cure while minimizing adverse treatment-related effects. It is also important to develop and disseminate evidence-based interventions that reduce cancer morbidity and mortality (2). Many articles and literature reviews have identified gaps in cancer survivorship research and intervention research has been identified as one of these gaps. In particular, lifestyle interventions such as exercise and weight reduction to enhance quality of life and reduce adverse outcomes are timely and emerging research areas (14) (2) (15). Knowledge is particularly limited for diverse populations including cancer survivors in rural communities and requires further exploration (2).

This study addressed this research need by evaluating the Stanford University Chronic Disease Self-management Program (CDSMP) among rural cancer survivors in Saskatchewan. In Saskatchewan this program is titled *LiveWell with Chronic Conditions (LWCC)* and is offered in all 13 health regions of the province which include all rural areas. The focus of this study was how this program is perceived to meet the needs of rural cancer survivors and how this program could be enhanced and marketed to reach the rural cancer survivor population.

1.2 Purpose and Objectives

The overall purpose of this research was to determine how the program *LiveWell with Chronic Conditions* can reach and respond to the needs of rural cancer survivors in Saskatchewan. Three objectives were identified at the start of this research. They were as follows:

1. To understand how the existing *LiveWell with Chronic Conditions* program meets the needs of rural cancer survivors who seek support to make healthier lifestyle choices.
2. To explore from participants' perspectives how the program could be enhanced in terms of content, format, delivery and marketing strategy.
3. Based on results, develop recommendations in coordination with agencies and institutions that provide services to cancer survivors.

During the data collection process, it was determined that it would not be possible to collect enough data to meet the first objective and thus, research objectives shifted and became as follows:

1. To explore how the existing *LiveWell with Chronic Conditions* program could be enhanced in terms of content, format, delivery and marketing strategy.
2. To gain an understanding of how the program responds to the needs of rural cancer survivors from the perspective of program leaders and cancer survivors.
3. Based on results, develop recommendations in coordination with agencies and institutions that provide services to cancer survivors.

CHAPTER 2: LITERATURE REVIEW

2.1 Cancer Survivorship and Chronic Illness

For the purposes of this study, a cancer survivor is defined as “anyone who has been diagnosed with cancer from the time of diagnosis to the end of life” (14). Survivorship can be considered to have three phases. The first phase of survival is acute and lasts from the time of initial diagnosis to the completion of initial cancer treatment. The second phase is extended and is from completion of initial treatment for primary disease and or remission of disease onward. The third phase is permanent and is when recurrence risk is at the most minimal (14). Phase 2 has been described as one of the most traumatic periods in the cancer journey (1).

In the United States, the number of survivors dramatically increased between the years 1971-2004 from 3 million to 11 million survivors respectively (1). Across all cancers (except bladder cancer) the relative 5-year survival ratio has increased in cancers diagnosed from 2004-2006 as compared to those diagnosed from 1992-1994 (16). Breast cancer survivors make up the largest percentage of the survivor population at 22% followed by prostate cancer, 19%, and colorectal cancer at 11% (14). Cancer survivors represent 2.5% of the Canadian population and numbers continue to steadily climb (1). It is estimated that 60% of cancer survivors are older than 65 years of age and it is therefore considered a disease associated with aging (14). The North American population of people over 65 years of age will grow rapidly in the upcoming years. In 2011 the first of the baby boomers reached the age of 65 (2).

As well as being considered a disease associated with aging, more recently, cancer is now being seen as a chronic condition. Similarities between diseases commonly considered chronic conditions and cancer consist of the following: they all may be disabling, they may cause intense pain or embarrassment, can be stigmatizing, and have chronic points interspersed with acute episodes (17). In this research, the definition of chronic conditions or chronic illness was adopted from the Stanford CDSMP program and was described as a condition that begins slowly and proceeds slowly. They have multiple causes that vary over time including heredity, lifestyle factors, and exposure to environmental and physiological factors. Chronic conditions usually lead to more symptoms and loss of physical functioning (18).

For many people, a cancer diagnosis and its fatality potential provides justification for radically transforming their lives and although consideration of cancer as a chronic condition has become more common, some caution that cancer is a distinctive disease and categorizing it as a chronic condition may do a disservice to those it affects (17). Several national health surveys were used to compare the impact of seven chronic conditions. In this analysis, cancer was determined to be one of seven most common chronic conditions in the United States and has separated this group of seven into fatal and non-fatal categories. Although the prevalence of cancer was found to be significantly lower than other conditions (likely due to its higher case-fatality rate) it was still very prominent as a limiting condition, and was placed in the fatal category. Of the seven chronic conditions assessed, those with cancer were likely to require more medical visits and hospital care (19).

As cancer treatments improve, those diagnosed with cancer are living for longer periods of time following their cancer diagnosis. Secondary cancers now account for a large number of new cancer diagnoses. The chronic condition of obesity is associated with these cancer recurrences and a decreased quality of life. This provides evidence to support weight control efforts in the cancer survivor population for decreased recurrence risk and improved quality of life. This recommendation is considered such a high priority that the American Cancer Society's primary goal for cancer prevention is to achieve a healthy weight (20). Other commonly considered chronic conditions such as cardiovascular disease and osteoporosis manifest within the cancer survivor population. Cardiovascular disease is a major health issue among cancer survivors and accounts for half of the non-cancer related deaths among survivors (20). Osteoporosis is a prevalent cancer survivor health problem particularly for premenopausal breast cancer patients and prostate cancer patients. Both groups are at increased risk of osteopenia following treatment induced ovarian failure or androgen ablation (20).

A population that was not included in this research but is important to note is adult survivors of childhood cancers, as this group also copes with disease related long term chronic conditions. Today, approximately 80% of children with a diagnosis of cancer become long term survivors(6). In a retrospective cohort including over 13,000 participants, researchers were able to determine incidence and severity of chronic health conditions in adult survivors of childhood cancer. Cancer survivors were found to be eight times as likely as their siblings to have severe

or life-threatening chronic conditions, and 62% of survivors reported having at least one chronic condition (6). Current follow-up recommendations for adult survivors of childhood cancers include continued surveillance for cancer recurrence as well as secondary and tertiary prevention of cancer including physical activity, tobacco cessation, weight management and management of chronic disease.

2.2 Survivorship Needs

Whether cancer survivors attend a lifestyle intervention program or not, they are a highly motivated group to attempt lifestyle changes in diet and physical activity as long as two years post diagnosis (21). Questionnaires completed by 356 breast, prostate and colorectal cancer survivors indicate 66% of survivors reported making lifestyle changes, the most common of those being eating more fruits and vegetables, aerobic exercise, and taking a multivitamin and/or vitamin E supplement (21). Cancer survivors have many reasons behind this motivation for lifestyle change including improved well-being, preventing cancer recurrence, and taking control of their health (22). Although a highly motivated group, this data is not applicable to all cancer survivor populations. 44% of head and neck cancer survivors report that they are less physically active after diagnosis and this trend is similar with colorectal cancer survivors (n=59) (23). Both groups show that this decline in physical activity is associated with a decreased quality of life (23).

A 65-item survey examined the stage of readiness to change among 1667 breast and prostate cancer survivors, with breast cancer survivors demonstrating a more advanced stage of readiness. Eighty percent of respondents indicated an interest in health promotion programs, and the majority of these respondents indicate a preference for intervention within six to twelve months of their cancer diagnosis (24). The end of acute cancer treatment has been considered the ideal teachable moment for promoting healthy lifestyle behavior change. Because the incidence of chronic conditions in adult survivors of childhood cancer population continues to increase over time and does not appear to have a plateau (6), this group may continue to see benefits from lifestyle intervention well beyond 6-12 months of their cancer diagnosis.

Health promotion efforts that target multiple behaviours are needed and multiple risk factor interventions that target diet and exercise may be of benefit given evidence of clustering

among these behaviours (24). Once cancer treatment has ended, a cancer survivor may have impaired physical functioning, reduced fertility, neuro-cognitive deficits, pain/fatigue, cardiovascular disease, osteoporosis, and fear (25). Increasing physical activity, eating a healthy low-fat high-fibre diet, maintaining an ideal body weight, and maintaining social connections may decrease risk of illness and are found to influence overall survival and quality of life in breast cancer patients (26). Supportive care needs have also been assessed through an online questionnaire in the young adult cancer survivor population and are similar to those from the CPAC survey. This group of 879 young adult cancer survivors indicated a need for information about their illness, treatment, and long-term effects of disease as well as guidance about exercise and nutrition (27).

Cancer survivors have psychosocial needs as well as needs regarding nutrition, exercise, and medical information. Psychological distress has a high prevalence among cancer survivors ranging from 29.6% for gynecological cancers to 43.4% for lung cancer (28). Individuals with mild-moderate distress may experience a significant decrease in functioning and require psychological intervention. Those who do not manage this distress may compromise cancer treatment with delays or changes in treatment course, and unmanaged depressive symptoms have been associated with a small increase in mortality among cancer survivors (28). It is therefore recommended that survivors with or at risk of psychosocial concerns or distress be offered psychosocial interventions provided by trained professionals (29).

A survey titled the “Survivor Unmet Needs Survey” (SUNS) has been developed by a research group out of the University of Waterloo in Canada. This group gathered data and information from a comprehensive literature review, qualitative analysis, and pilot test among 100 cancer survivors to develop their instrument. A stratified random sample of 550 cancer survivors in Canada completed the survey to establish reliability and validity (30). From this sample, the researchers outlined the top 10 unmet needs of these survivors. An unmet need is defined as: a requirement for some desirable, necessary or useful action to be taken or some resource to be provided, in order to attain optimal well-being (30). This top 10 list is: 1) fears about cancer spreading, 2) being told I had cancer, 3) not feeling sure that the cancer has gone, 4) feeling tired, 5) finding financial assistance, 6) feeling stressed, 7) finding information about

complementary and alternative medicine 8) coping with bad memory, lack of focus, 9) dealing with feeling worried (anxious), 10) worrying whether treatment has worked (30).

A review of the literature indicates appetite loss, pain and fatigue are important independent predictors of survival time in many different cancer populations (31). When developing intervention and support programs for cancer survivors it is important to address these topics to achieve the end goal of a longer and higher quality survival. Survivors are increasingly looking to their oncology care provider for counsel and guidance in these areas (20).

The Wellness Community, a nonprofit organization providing survivorship support services explains “Through participation in professionally-led support groups, education workshops, nutrition and exercise programs, and mind and body classes, people affected by cancer learn vital skills that enable them to regain control, reduce isolation, and restore hope” (25).

2.3 Intervention Research

The types and nature of support interventions available for cancer survivors has changed dramatically over the last few decades. Psychological interventions for cancer patients began in the 1970s (32). The psycho-oncology community emphasized the critical importance of achieving better quality of life through psychosocial support and in the 1990s a meta-analysis of randomized trials indicated that psychosocial interventions have positive effects on emotional adjustment, functional adjustment and treatment and disease-related symptoms in adult cancer patients (33). A meta-analysis of psychosocial oncology interventions from 1989-2003 indicate interventions during this time period were professionally-led in the form of individual or group interventions (34). Since then data has been accumulating to suggest that healthy lifestyle practices may prevent progressive or recurrent disease (13) and interventions over the past decade have reflected this evidence by combining the focus of psychological support with promoting healthy lifestyle behaviours including nutrition and exercise. Interventions leadership and mode of delivery have also shifted from primarily professionally led to peer-led or mixed leadership interventions as well as including options of participating over the internet. Interventions vary with respect to program content, route of administration, length of program, timing of intervention, etc. Multidimensional, multidisciplinary cancer rehabilitation programs which address psychosocial and healthy lifestyle factors appear to be the most commonly

evaluated in the current literature and the research regarding these interventions has been discussed.

In a prospective randomized design, a rehabilitation program for cancer patients titled “Starting Again” was evaluated by comparing 98 participants with cancer to 101 participants with a control condition. The program design was a 7 week, 11 information session program facilitated by an oncology nurse specialist and experts from various fields (35). The main findings from this intervention were that physical strength, appraisal of having received sufficient information and frequency of sleep problems prior to program attendance improved significantly compared to controls. Researchers found substantial short term positive effect of this structured rehabilitation program in the areas of physical training and strength, information, and coping skills (35). In another study, a 15 week program including both physical and psychosocial interventions has been developed and evaluated. Using group-wise randomization of 63 cancer survivors, this study showed significant improvements in health related quality of life following program participation (36). Given that 15 weeks is a long time commitment, participants were also asked their preference of program content and length. These participants indicated that they would choose to attend this entire program if offered a choice. These cancer patients may have a preference for a multidisciplinary program because their complaints are physical, psychological and social (36). McGill University in Canada has a now well-established program titled the McGill Cancer Nutrition and Rehabilitation (CNR) program. Their program objective is to use an interdisciplinary approach to empower individuals who are experiencing loss of function, fatigue, malnutrition, psychological distress, and other symptoms as a result of their cancer and cancer treatment to improve quality of life (37). This is an 8 week program led by multidisciplinary health professionals. Outcomes of this program participation include empowerment to take control by improving nutrition, body weight, exercise, communication with others, and lowering anxiety (37). As outcomes of this program have been positive, a recommendation that most cancer treatment programs include a CNR program has been made (37).

A lifestyle intervention development study involving 182 older adults with cancer explored whether a 6 month home-based diet and exercise program of telephone counseling and mailed materials would improve lifestyle behaviours among elderly cancer survivors and

whether these enhanced physical functioning (38). Using the physical functioning short-form 36 subscale, physical activity, and diet quality were assessed at baseline, 6 months, and 12 months. Their data suggests that this program can be safely delivered and improves lifestyle and behaviours however the differences seen between intervention and control groups dwindled over time. Further research is indicated to determine the length of time these program participants need follow-up or if they require further programming (38). The intervention method used in this research could also be applicable for a geographically isolated population as they would not need to leave their home to receive the intervention.

Research on cancer survivorship interventions among rural populations is particularly limited. A randomized control trial involving one hundred breast cancer survivors in rural California had a goal of developing and evaluating a workbook-journal for improving psychosocial functioning of rural women with breast cancer, as this group's rural setting had been prohibiting them from participating in support groups (39). Results of this study show no main effects of the workbook-journal on mood, or coping. However; women who were ending cancer treatment experienced fewer post-traumatic stress disorder symptoms if they received the workbook-journal (39). When comparing rural and urban cancer survivors, it was found that in rural areas, although one individual may be diagnosed with cancer, this disease has the potential to affect an entire rural community. The stigma attached to the disease can alter relations between many within a small community (12) and it is suggested that rural people believe to be better off with no program at all compared to a program being implemented with poor sustainability (40), both important points for consideration when implementing a rural health intervention.

A review of 28 randomized trials of cancer survivor interventions indicated that less than one third of these interventions were theoretically based (13). The reviewers state that interventions that integrate survivor specific needs into a theory-driven framework are likely to yield success (13). The self-efficacy theory is one that many chronic condition lifestyle intervention programs have been based on and will be discussed further in its use among cancer survivors living with chronic conditions.

2.4 Self-management of disease-related chronic conditions

Bandura's theory of self-efficacy was developed within the framework of the social-cognitive theory and postulates that all processes of psychological change operate through a person's alteration of expectancies of mastery. Bandura suggests efficacy expectations can be formed through information derived from actual performance accomplishments, vicarious experience, verbal persuasion and physiological states (41). The literature which applied self-efficacy theory to oncology was examined and indicates that programs involving training of goal setting and stress reduction strategies achieve more positive results and a higher level of self-efficacy improves an individual's ability to adjust to cancer (41). Focus groups held with the oncology patient population indicate that those who have had a recent diagnosis of cancer want to be more involved in the decision-making process of their care. Self-management is a term that is often used and can be described as having a focus on disease management, guided at some point by a clinician and involves an individual in making therapeutic adjustments to their treatment regimen (10). Self-management strategies were adopted by members of this group for self-empowerment and for guiding them in finding practical ways to improve their health, thus enhancing overall medical treatment. It has been recommended to those working with cancer patients to establish and support self-management activity (42).

A research group in the United States has taken these recommendations and has developed and pilot tested a program titled "Taking CHARGE", a self-management program developed for women following breast cancer treatment. The goal of this program was to facilitate a successful transition to long-term survivorship following completion of cancer treatments. Key areas this program addressed were managing symptoms and side-effects, exercise and nutrition, lowering stress levels, and developing communication skills with health care professionals (43). This intervention involved a two-pronged approach to equip women with self-management skills and to provide information about common survivorship topics, and it involved four intervention contacts including small group meetings and individual telephone sessions. Following data collection with 25 women who participated in the program, the development of this program was deemed successful. The participants found it to be timely, relevant, and the self-management skills were useful in dealing with future concerns, although one concern with this program was that it was difficult for rurally located women to attend (43).

This pilot program can be considered a starting point to this research area. A systematic literature review reveals there is very little evidence detailing self-management strategies people use when living with problems associated with cancer (44). One published journal article was found by this researcher that has formally evaluated CDSMP as a program for cancer survivors. The researchers used semi-structured telephone interviews to collect qualitative data. No known quantitative data has been collected in this research area, and there is no known qualitative or quantitative research data on the CDSMP as a cancer survivorship program for rural cancer survivors.

2.5 Description of the Intervention

The most common and researched self-management program known worldwide is the Stanford CDSMP. This program is a community-based peer-led self-management education course. Assumptions that underlie this program are: patients with different chronic diseases have similar self-management problems and disease related tasks, patients can learn to take responsibility for the day-to-day management of their disease, and knowledgeable patients practicing self-management will experience improved health status and will use fewer health care resources (45). Topics covered in this six-week-long program include: exercise, cognitive symptom management techniques, nutrition, fatigue, use of community resources, medication management, dealing with fear, anger, depression, communication with health care professionals, problem-solving and goal-setting (45). In Saskatchewan, the CDSMP is titled *LiveWell with Chronic Conditions* and is run in all 13 health regions of the province. It is typically offered as a 2.5 hour session once weekly for 6 weeks with ideally no more than 15 participants per group. This course is based on Bandura's self-efficacy theory and is taught by lay leaders often who are coping with a chronic condition themselves. In some areas of Saskatchewan this course is co-facilitated by a trained health care provider and a trained volunteer. Participants in this program receive a free reference book titled *Living a Healthy Life with Chronic Conditions* that they are able to refer to during and following completion of the program. The book includes topics covered in the course as well as more specific information about several specific chronic diseases. Participants are able to bring a caregiver or support person with them to the sessions if so desired. It is free of charge for all who attend.

A six-month randomized controlled trial comparing treatment subjects with wait-list control subjects (n=952) evaluated the effectiveness of a self-management program for chronic disease. At six months results indicate the CDSMP to be feasible, beneficial beyond usual care in terms of improved self-reported health, communication with physicians, health distress, and fatigue. Participants in the treatment group also showed an increased frequency of cognitive symptom management. This program demonstrated that it can decrease hospitalizations with a potential for substantial savings in health care costs (45). When the CDSMP was assessed in a further 1 and 2 year follow-up study results maintained significant improvements in health distress and reductions in ambulatory health care use each year during a 2 year period. Participants of the CDSMP perceived their self-efficacy to continue to improve over this 2 year time period as well (46). A great deal of success has been seen with CDSMP and the program is now being facilitated globally.

Australian researchers have taken evaluation of the CDSMP a step further in a study reporting implementation processes and patient outcomes following the introduction of CDSMP in a rural setting. Semi-structured interviews were conducted with 12 leaders and 8 participants of the CDSMP and participant outcomes were evaluated using a pre-test post-test design with 14 program participants. Results of this study strengthen previous results as they also demonstrate improved self-management for these participants (47). This program was successfully implemented rurally and participants were recruited using newspapers, community presentations, information stands, shopping centres, and local health care staff. An increase of barriers was noted by researchers when the CDSMP was implemented in 3 rural and remote locations in Tasmania, Australia, including limited participant education, increased physical frailty of a rural population, and poverty. These barriers made implementation of the program more difficult, however similar benefits were again noted with a decrease in overall participant distress, improvement of symptoms including depression and overall general health improved (40). An important point that gives strength to the CDSMP is the program is inclusive of all chronic conditions, facilitated by lay leaders, and no fees are charged to the participants. These three factors give the CDSMP the capability to be a highly sustainable program by a variety of rural communities.

As previously described with past research, the CDSMP has been piloted in cancer survivor populations in the United Kingdom and in Australia. Some suggested research areas of focus could be the measurement of attitudes and behaviors before and after CDSMP program participation with an extended cancer survivor participant follow-up period (11). It is also recommended that more rigorous research is needed to strengthen the evidence base for using the CDSMP program as a healthy lifestyle intervention program among cancer survivors (10).

2.6 Knowledge Use in the Health Sector

High quality evidence is not consistently being applied in health care practices (48). Recognition of this knowledge-to-practice gap has recently led to attempts of effecting change within health care policy and clinical practice by targeting knowledge formation and exchange with all involved in decision making (48). Knowledge exchange involves active collaboration between researchers and knowledge users throughout the research process and this active involvement is most appropriate for “real-life” health system issues (49). When completing research regarding community health programming, it is important to involve administrative decision makers including program managers, program coordinators, and regional administrators. These individuals may use health services research to make decisions about program design and quality improvement strategies (50). Created knowledge around a concrete issue within the time frame of the decision process is of most use to this decision-making group and may be in the form of networking, seminars, or workshops (50). Active engagement between researchers and those who can use the knowledge has been shown to be a strong predictor that research findings will be used and that the research endeavor will achieve a greater impact (49).

Knowledge translation has been defined as a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products to strengthen the health care system (51). The methods or process of knowledge translation has been outlined by the Canadian Institutes of Health Research as milestones essential in bridging the knowledge-to-action gap. These steps or stages have been presented in the series of a cycle in Figure 1 (52).

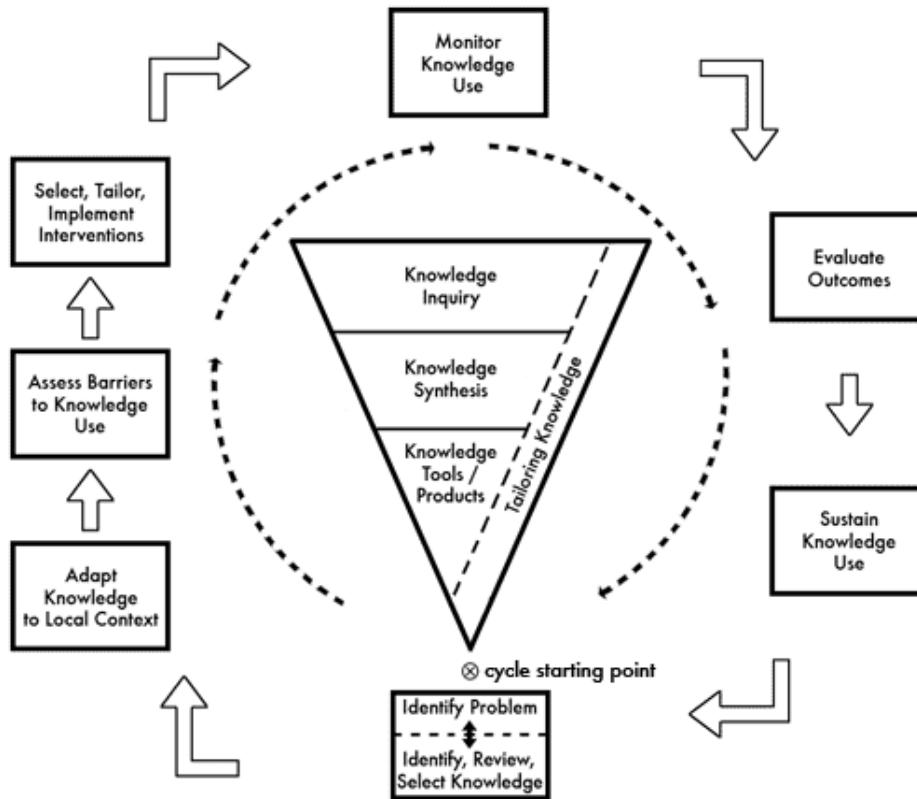


Figure 1: The Knowledge-To-Action Cycle: CIHR (51,52)

At the cycle starting point, a problem is identified, and knowledge is created by the research process of inquiry, data collection and analysis. The results of a study are the “knowledge products” that are selected to start the cycle of knowledge translation. Selecting knowledge should be based on a needs assessment (53). The second phase of this cycle indicates knowledge should be adapted to local context to ensure that it is relevant and feasible (53). This phase is important to avoid duplication of efforts and to optimize use of existing resources (50). The third step of the knowledge translation cycle focuses on assessing barriers to knowledge use. There has been consensus within the implementation research community that most efforts in knowledge translation and exchange at the clinical level have had little success likely due to such potential barriers (50). In the fourth step, selecting and tailoring a knowledge translation intervention should be based on the previously identified barriers (53). More than one method of knowledge translation may be selected and once these have been tailored to the barriers within

the local context they are then implemented. The method of knowledge translation may include formation of a knowledge network within a community of practice (a group of people with a common concern). This network might not otherwise have the opportunity to interact and formation of this group enables dialogue and can stimulate learning throughout the knowledge translation intervention or dissemination of knowledge (49). The CIHR identifies three types of knowledge use to be conceptual, instrumental or persuasive and recommend the use of knowledge to be monitored (53). Approaches to knowledge implementation should be evaluated as described in the sixth step of this cycle. This step can be lengthy and can require significant resources. Both quantitative and qualitative methods should be considered (53) and this step would be considered a research process within itself. The monitoring and evaluation of knowledge use may identify problems that require further research and it is with the results of this research that the cycle would start all over again. The final step of the knowledge-to-action cycle is sustaining knowledge use which refers to the constant application of evidence over time (53).

CHAPTER 3: METHODS

3.1 Design

A mixed-method case study approach was adopted for conducting this project. Mixed-methods research is an approach to inquiry that combines qualitative and quantitative forms of research. It is more than collecting and analyzing both kinds of data; it also involves the use of both approaches in tandem so that the overall strength of a study is greater than qualitative or quantitative alone (54). The adoption of a mixed methods strategy became obvious because a variety of data collection and perspectives could answer the research questions at hand (55).

In this particular study, the type of mixed-method design was called *embedded design*. The embedded design is a mixed methods approach where the researcher combines the collection and analysis of either quantitative data or qualitative data within a traditional quantitative or qualitative research design (55). This approach allows for a primary method to guide the project and a secondary method to provide a supporting role in the procedures (54). The primary research method used was qualitative; it is based on the belief that the reality we perceive is constructed by our social, historical, and individual contexts, and so there can be no absolute shared truth (56). By embedding quantitative research as the secondary data set in a primarily qualitative focused study, it allowed for a more complete understanding of the process and outcomes of interest (55).

Case study research can be defined as an approach in which the investigator explores a bounded system (or case) over time through detailed, in-depth data collection involving multiple sources of information (57). It is an intensive study of a particular contextual, and bounded, phenomena that is undertaken in real life situations (58). A program, event, activity, process, or one or more individuals are commonly identified as the case or bounded system (54). The *LiveWell with Chronic Conditions* program offered in rural communities was the case which was selected and explored in depth among the rural cancer survivor and *LiveWell with Chronic Conditions* rural program leader populations in Saskatchewan. Data sources used to explore a case may include interviews, observations, audiovisual material, documents, questionnaires and reports (57)(58). It has been argued that because any set of methods that will help you develop an understanding of the case can be used, case study methodology is a bridge that spans the quantitative and qualitative research paradigms and can be considered qualitative, quantitative,

or both depending on the research purpose, questions, and design (58). Data collected through the case study are first intended to describe the case and its context. Categorical aggregation is then used to establish themes or patterns (57).

As found in the literature, there are several *types* of case study designs. In instrumental and collective case study designs, the researcher selects one issue or concern and then selects one or more cases to illustrate the issue (57). The *type* of case study design used in this study was an *intrinsic* case study in which the focus is on the case itself because the case presents an unusual or unique situation (57). The focus of this study is on the case of rural *LiveWell with Chronic Conditions* programs to present the unique situation of how this program is perceived and used among rural cancer survivors in Saskatchewan.

In mixed methods research the collection and analysis of the secondary data set may occur before, during, and/or after the implementation of the data collection and analysis procedures traditionally associated with the larger design (55). The collection of quantitative data through questionnaires provided this secondary data set. Although the quantitative data was considered secondary in this study, the majority of it was collected before and/or during qualitative data collection. Questionnaires were distributed to the study sample during winter and early spring of 2011. Upon completion of the questionnaires, all respondents were invited to participate in semi-structured interviews. Semi-structured interviews were carried out at the same time that questionnaires were completed by the sample group.

In this study, data from the quantitative questionnaires were collected and analyzed separately from the data collection and analysis of the qualitative semi-structured interviews. This method allowed the data to reside side by side as two different pictures that provide an overall assessment of the problem. This method is often used to gain a broader perspective of the research problem (54).

3.2 Qualitative Procedures

3.2a Participant Recruitment

At the start of the study period promotion specifically directed to cancer survivors was added to previous LWCC promotional strategies. This included adding the word cancer to posters, brochures and other LWCC promotional material. These brochures are now included in

new patient information packages distributed by the SCA and are available in the clinic waiting areas of both the Allan Blair (Regina) and Saskatoon Cancer Centres. The LWCC program has connected with the Canadian Cancer Society (CCS) Saskatchewan Division and is advertising the program through this organization's offices. LWCC has posted program information on both the SCA and CCS websites. As well, they have been providing program orientation to supportive care staff at the SCA to enable this group to make referrals to the program.

Purposeful sampling was used for the qualitative portion of this study. During the fall/winter 2010/2011 rural LWCC programs in Saskatchewan, participants attending who indicated they were cancer survivors to their group facilitator during the program were provided information on this research study as well as a questionnaire described in the quantitative procedures section. A separate page was attached to this questionnaire which indicated the reasons for conducting one-on-one interviews. If participants were interested in completing one of these interviews they provided their contact information including their name, address, phone number and e-mail. These forms were collected from various program leaders throughout rural Saskatchewan. These individuals were then contacted to discuss the study and interview process further. A complete formal consent form was obtained from interview participants prior to conducting interviews.

Program leaders were also invited to participate solely in the qualitative interview part of this study. Group leaders of rural LWCC programs that have had cancer survivors as participants in the fall/winter 2010/2011 were contacted to participate in this study and were considered to be within this key stakeholder group. The number of rural cancer survivors who participated in both the LWCC program and this study during the data collection period was far below the initial number estimated. A third group of key stakeholders was identified at this point. This group was LWCC program leaders who were cancer survivors themselves. It was felt that this group would offer a unique perspective to the study questions and thus were included in the qualitative participant sample. A formal consent form was obtained from the program leaders prior to conducting these interviews. Please see appendix 2 for consent forms used.

Two key informants were also contacted, one of whom is a representative from the Saskatchewan branch of the CCS who had been involved with facilitating a cancer survivorship

program in the past. This individual provided a deeper perspective of a program that had previously been developed and run in Saskatchewan for cancer survivors in the urban settings of Regina and Saskatoon and rural locations of Yorkton and Swift Current. As discussed in the introduction, this survivorship program is based on the book *Picking up the Pieces: Moving forward after surviving cancer* and is titled “The Transition from Treatment to Living Well Workshop” (1). The discussion provided information about program content, history of program provision, and appropriateness of this program’s use among rural Saskatchewan cancer survivors. During the literature review it was identified that the Ontario branch of the CCS had been using the CDSMP as a cancer survivorship program. A representative from this branch was contacted as the second key informant to discuss their thoughts and experiences of this program within the cancer survivor population.

3.2b Qualitative Data Collection

Qualitative data was collected through semi-structured interviews. This interview process is appropriate to use when the researcher knows enough about the domain of inquiry to develop questions in advance of interviewing, but not enough to be able to anticipate answers (59). Pre-planned open-ended questions allowed for better organization and more comfort during this type of interview (59). Data collection through interviews began when contact information forms were received from participants in the rural LWCC groups. This was initiated in January 2011 and completed by May 2011. Some of this data collection phase occurred following quantitative data collection, and some was simultaneous, as quantitative data collection also took place during winter 2011. Semi-structured interviews collecting qualitative data were conducted over the phone with consenting participants. The main intent of these interviews was to elicit views and opinions from the participants, to solicit participants’ and group leaders’ perspectives of program suitability, and cancer survivor satisfaction. The appropriate interview guide developed for either a cancer survivor participant of LWCC or a group leader of a LWCC program was followed during these interviews. See appendix 3 for these interview guides.

The interview protocol included space to record information during the interview process. Interview notes were taken by the researcher during all interviews and the interviews were also

recorded in full with an audio recorder. Transcripts were prepared following each interview to organize and prepare data for analysis.

3.2c Qualitative Data Analysis

The qualitative data analysis procedures followed the process outlined in the data analysis spiral as described by Creswell (57). The first loop of the spiral is data management where the data from semi-structured interviews is organized by typing up the interview transcripts into a computer document (57).

The data was reviewed to gain a general sense of the information obtained. Transcripts were read in their entirety several times. During the second read-through, general thoughts were recorded about the data by writing memos in the margins of the documents. These memos were short phrases, ideas, or key concepts discovered (57). The next loop of the data analysis spiral as described by Creswell is the describing, coding, and interpreting loop (57). Coding has been described as the process of organizing the material into chunks or segments of text before bringing meaning to information (54). It is also used to expand and tease out data, in order to formulate new questions and levels of interpretation (60). A short list of tentative codes or *priori* codes was developed and used to guide the coding process. These pre-figured codes represented information that the researcher expected to find before the study. Some of these codes reflected part of the guide followed in the semi-structured interviews themselves (60). The pre-figured codes could have potentially limited the analysis therefore additional codes were created as they emerged during the analysis process (57). These codes emerged through the discovery of particular events, key words not previously identified, processes, or characters that captured the essence of the piece (60). The codes created were considered tools to think with and were expanded, changed, or scrapped altogether as ideas developed through repeated interactions with the data (60).

To move from coding to interpreting, the data was recontextualized by placing all of the data sections that relate to a particular code physically together in the same place in a computer document (60).

To further interpret the data six general themes were identified. This interpretive analysis process made meaning of the data where meaning was personal interpretation as well as the meaning derived from comparison of the findings with previous literature (54).

The final phase of the data analysis spiral is the presentation of the data. In case-study research an in-depth picture of the case has been presented using narrative and tables (57) .

To strengthen the qualitative scientific merit of this study, three strategies were employed. The bias I brought to the study was clarified in the ‘Researcher’s Journey’. This section explains how the interpretation of the findings is shaped by my background (54). Peer debriefing was used to enhance the accuracy of the semi-structured interviews (54). Peer debriefing involved locating a peer who reviewed and asked questions about the qualitative study so that the account would resonate with people other than me (54). The peer selected for this debriefing was a member of the research advisory committee. Thirdly, the different data sources were triangulated and themes were established based on several sources of data and participant views and responses (54).

3.3 Quantitative Procedures

3.3a Sampling:

Purposeful sampling was used so that individuals who have experienced the same central phenomenon were selected. Cancer survivors who had participated in a rural LWCC program in fall/winter 2010/2011 were invited to participate in the quantitative portion of this study. It was determined that this group of participants would best help to gain an understanding of the research problem as they have experienced living with cancer as a chronic illness and have been involved in the program.

In the past, *some* cancer survivors had registered to participate in LWCC although through consultation with LWCC staff and group leaders, it was felt that the cancer survivor participation in this program had been low. In efforts to better promote this program to cancer survivors across Saskatchewan some steps had been taken by organizations during the study period. The program was promoted to cancer survivors through various avenues including the Canadian Cancer Society, Saskatchewan Cancer Agency, rural cancer support groups, rural allied health professionals, and the word *cancer* had been included as a chronic illness on LWCC

promotional material. Through these promotional efforts it was thought there would likely be larger numbers of rural cancer survivors attending this program and therefore a larger sample of people to be invited to complete the questionnaire.

In September 2010, new evaluation forms of LWCC were introduced. These forms included a section for program participants to identify their “illness diagnosis”. Rural participants who indicated cancer as their “illness diagnosis” and presumably the reason for their program participation would be invited to participate by completing a questionnaire in this study. However, during the study period, no program participants in rural areas indicated cancer as their “illness diagnosis”.

The rural program leaders had received information about this research study prior to the quantitative data collection period and these individuals were able to identify participants in their LWCC group who were cancer survivors. These program leaders provided information about the study to these rural cancer survivors and invited them to participate. The program leaders distributed the quantitative questionnaires to those interested in participating in the study.

3.3b Questionnaire

The quantitative data was collected through completion of questionnaires. Information about the study was provided at the top of the questionnaires. Each questionnaire was numbered to maintain participant anonymity. The action of reading the study information and then completing the questionnaire was considered participant consent. Participants were not asked to include identifiers such as name, address, or phone number on the questionnaire. The questionnaire developed for this study used some previously validated scales. See Appendix 1 to review the questionnaire.

The questionnaire was developed to ascertain information regarding the experience of the cancer survivors with LWCC and if they found the program useful and/or helpful in areas of their life relating to cancer survivorship. The questionnaire was developed specifically for this study and includes both validated and non-validated scales. The design of this evaluation questionnaire was a one group post-test design which involved providing the intervention and then collecting data only from those who received the intervention (61). This design was selected because it is a useful method for individual-level evaluations. It is also often selected

for programs and research with a limited budget, and for researchers with minimal experience in program evaluation which was the case in this research study (61).

The study tool asked for demographic data. The demographic questions asked were adopted from those asked in the SUNS. As discussed in the literature review, the SUNS is a recently developed psychometrically robust instrument that enables accurate assessment of issues and problems with which all cancer survivors want help. It was developed to enable more effective targeting of programs and services and to examine the effectiveness of interventions (30). Not all demographic questions asked in the SUNS were included in this questionnaire. The questions included were those that were deemed most relevant to this study by the researcher.

Participants were also asked several general questions that more specifically evaluated the LWCC program. These included questions such as: where the participant found out about the program, how much of the information in LWCC did they feel was applicable to them as a cancer survivor, what information that was not provided at LWCC would be of interest to them and applicable to cancer survivorship, and if they would recommend LWCC to other rural cancer survivors. These LWCC evaluation questions were not validated.

The survey tool asked participants if they felt they had an improved ability to cope with or address the top 10 unmet cancer survivor needs as defined through the development of the SUNS after attending the LWCC program. This question was included to assist in determining if the LWCC program met the needs of rural cancer survivors in this study. The wording of the description of the top ten needs had been maintained from the SUNS to this questionnaire; however the exact question format of 'level of unmet need' was not maintained. It was felt that the original SUNS questions were not specific enough within the context of this study. Responses to these questions were indicated on a 4-point Likert scale. Although these questions had not been validated, the wording had been maintained and the questions are based on the validated SUNS. Three other questions on this study's questionnaire were derived from SUNS questions. Although these three were not among the top ten needs as identified by SUNS researchers, they were important topics to ask participants within the context of this study because they addressed the 'transitioning' process of cancer survivorship, a topic that has been included in many recently developed cancer survivorship programs.

This research study also aimed to evaluate the impact of this particular program among rural cancer survivors. As determined in the literature review, it was found that important areas cancer survivorship programming should address were exercise, nutrition, fatigue, and psychosocial concerns including stress and fear. By using previously developed and validated subscales by Stanford University Research Centre, the researcher measured outcomes that would be desired in a cancer survivorship program. Stanford University acknowledged they had not found or developed a scale to measure nutrition information that was brief (62). In this questionnaire general questions were asked of the participants regarding their perceptions of the impact LWCC had on their nutrition, physical activity level, and body weight.

The Stanford Patient Education Research Centre developed research scales to be used for research subjects with chronic diseases for the purpose of outcome evaluation for the CDSMP, or LWCC in the case of this study (62). These scales were free to use within this research without permission from Stanford University (62). The intention for using these scales was to give insight to program outcomes for this particular chronic condition of cancer survivorship. Members from the Stanford Patient Education Research Centre have written a report guiding the use of the scales they have developed including information as to what the scales measure and their usefulness in outcome evaluation.

The three validated scales developed by Stanford Research Centre that were included in this questionnaire were the health distress scale, the cognitive symptom management scale and the self-efficacy scale. The health distress scale is a 4-item scale that has been tested on 1,130 subjects with chronic disease and gives a good idea of distress caused by illness over the past month (62). Responses to this question indicate the level of distress caused by illness during the month the participant was enrolled in LWCC. The cognitive symptom management scale is a behaviour change measure to find out if people are practicing any cognitive stress and/or pain reduction techniques (62). This is a 6-item scale that has been tested on 1129 people with chronic disease (62).

A 6-item validated self-administered scale assessing self-efficacy for managing chronic disease was also included in the questionnaire developed for this study. It was included to help understand rural cancer survivors' self-efficacy in disease management following program participation. Specifically, how confident the participants were in completing certain activities

following attendance of the LWCC program. This scale has been tested on 605 subjects and covers several domains which are common among many chronic diseases including symptom control, role function, emotional functioning, and communicating with physicians (62).

The final page of the questionnaire indicated my interest in conducting interviews and invited participants to volunteer for an interview. There was room for participants to include their contact information on this page. When contact information was provided, this page was separated from the questionnaire and provided to the researcher. By separating this page from the questionnaire it maintained anonymity of the participant, as their contact information was not connected to their responses in the questionnaire.

3.3c Quantitative Data Analysis

Information was reported about the number of participants who received the questionnaire including the number who completed it and the number who did not complete it. Respondents were considered those that chose to answer a portion or the entire questionnaire and submitted their questionnaires to their LWCC leader or the research team. Non-respondents were considered those who received a questionnaire and chose not to complete it or submit it to the research team.

To score and analyze validated scales used from the Stanford University Research Centre, the following statistics and scoring guides as provided by the centre were used. This information for the scales has been described in detail below.

Table 1: Health Distress Scale

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
4	0-5	2.04	1.16	0.87	0.87

This scale was scored as follows: Each item was scored as the number circled. If two consecutive numbers were circled, the higher (more distress) number was considered the score. If the numbers were not consecutive, they were not scored. The scale score was the mean of the four items. If more than 1 item was missing, the value of the scale was set to missing. Scores range from 0-5 and the higher score indicates more distress about health (62).

Table 2: Self-Efficacy Scale

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	0.91	NA

This scale was scored as follows: The score for each item was the number circled. If two consecutive numbers were circled, the lower number (less self-efficacy) was coded. If the numbers were not consecutive, the item was not scored. The score for the scale was the mean of the six items. If more than two items were missing, the scale was not scored. The higher number scored indicated higher self-efficacy (62).

Table 3: Cognitive Symptom Management Scale

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	0-5	0.33	0.91	0.75	0.83

This scale was scored as follows: The score for each item was the number circled. If more than one consecutive number was circled, the lower number (less management) was taken as the score. If the numbers were not consecutive, the item was not scored. The scale score was the mean of the six items. If more than two items were missing answers, the value of the score for this scale was set to missing. Scores range from 0 to 5, with a higher score indicating more practice of these techniques (62).

All information used in the quantitative analysis was derived from the questionnaire. Results have been presented in tables and further interpretation was completed.

3.4 Mixed Methods Case Study Data Analysis

The mixed method data analysis approach for this concurrent embedded study was to examine multiple levels of results and consisted of making a detailed description of the case, its setting and any other contextual consideration designed to better understand and capture the participants' views (57). The *mixing* of the quantitative and qualitative data is the process by

which the researcher implements the independent or interactive relationship of a mixed methods study (55). The two sets of results were *mixed* during the interpretation step of this research process and the supportive (quantitative) dataset was used to reinforce the results of the primary (qualitative) dataset (63). Conclusions were then drawn which reflect what was learned from the combination of the results (55).

When using this mixed methods study design, the two methods are unequal in their priority and result in unequal evidence within a study. This situation can constitute a disadvantage to researchers when interpreting the final results and it was in fact the situation in this research study (54). This research does not represent a true mixed-methods case study because quantitative data was so limited. What has been presented in this thesis is a primarily qualitative case study. The data explores how the LWCC program responds to needs of cancer survivors in the eyes of LWCC program leaders, some who have had cancer and some who have not. It qualitatively explores how the program could be enhanced in terms of content, format, delivery and marketing strategy, again primarily from a program leader's perspective. This matter has been elaborated on in the discussion of this thesis.

3.5 Knowledge Translation

The methods used for knowledge translation in this study were adopted from the CIHR's Knowledge-to-Action cycle. As shown below in Figure 2, this cycle has been adapted to illustrate this study's knowledge translation process. Initiation of this adapted knowledge-to-action cycle was planned to meet the research objective of developing recommendations in coordination with agencies and institutions that provide services to cancer survivors based on study results and ultimately to provide effective health services for rural Saskatchewan cancer survivors.

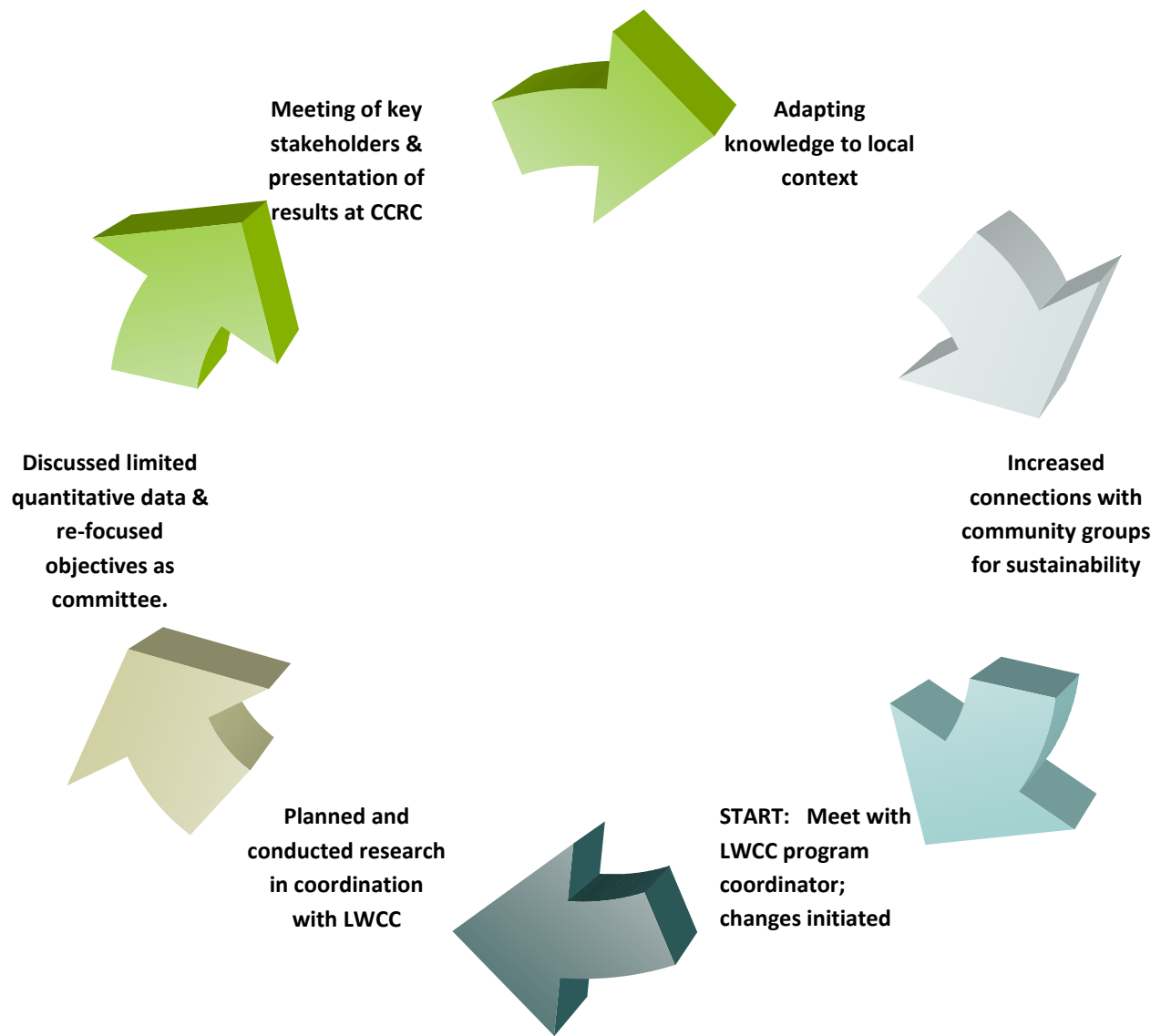


Figure 2: Knowledge Translation Process, an adapted Knowledge-to-Action Cycle

There was a need identified for this research to contribute to the knowledge base at the start of this study. Once this need had been identified, the decision makers and knowledge users in the area of LWCC programming in rural Saskatchewan communities were identified and involved in each stage of the research process from development of research objectives to dissemination of results. Following the initial meeting with the coordinator of LWCC changes to program promotion were initiated to better reach the cancer survivor population. Plans for this

research also started conversations among agencies involved with rural cancer survivor care that may not have otherwise developed.

Barriers to knowledge use were identified in the setting of this study. For example, during the data collection period, it was realized that insufficient quantitative data would constitute a barrier to producing the expected evidence. The advisory committee including the knowledge user suggested to re-focus the research objectives to adjust to the situation while ensuring that applicable knowledge was still going to be generated through this research process. Environmental factors were identified as one of the main barriers to knowledge use including time pressures, lack of resources, and organizational constraints. When working alongside public and non-profit organizations which provide services scattered across a province with a small population, insufficient time, insufficient materials or staff, and insufficient support from one or more organizations were all potential factors that could have an impact on the knowledge translation cycle (50).

In order to develop recommendations in coordination with agencies that provide cancer care, the fourth step of the knowledge translation cycle was undertaken. It consisted in selecting and implementing a knowledge translation intervention. Key stakeholders were invited to a meeting where research findings were presented and preliminary recommendations proposed. A discussion forum was then held around the topic.

This discussion forum was facilitated by the student's supervisor with a focus on how the results of this study may better inform and shape recommendations regarding future LWCC programming and rural cancer survivorship in Saskatchewan. This discussion was preceded by roundtable introductions of the individuals participating in the discussion. At that time members were invited to share resources or programming currently offered by their organization. It was within the context of this local information that recommendations were adapted by the group for future programming (step three of knowledge translation cycle).

The key stakeholders identified and invited to participate in this focus group were: provincial LWCC program coordinator Darla Walz with Leslie Worth, manager of Chronic Disease Management within the Saskatoon Health Region, regional LWCC program coordinators, representatives from the Saskatchewan Cancer Agency, Canadian Cancer Society,

HOPE Cancer Help Centre, Ovarian Cancer Canada, and the Saskatchewan Network for Health Services in French. See invitation letter in Appendix 4.

The meeting provided education and developed networking by involving formal and informal leaders in the area of rural cancer survivorship programming. Education was provided to improve motivational factors for the stakeholders, and key individuals were identified to attend with the objective of building inter-professional inter-agency partnerships (50). During the knowledge translation intervention of the meeting of key stakeholders, knowledge was adapted as a group to the local context. This step was important to avoid duplication of efforts and to optimize use of existing resources. An additional knowledge translation activity was carried out as results were presented at a national cancer research conference.

Sustaining knowledge use was the final step of the knowledge translation process undertaken throughout the course of this study. An effort was made to support sustainability by increasing connections and partnerships with community groups. Actions to sustain knowledge use were planned for at the meeting.

Given that the final steps of monitoring and evaluating knowledge use to complete the cycle as described by CIHR were not completed within the methods and timeline of this research, these final steps have been discussed in section 5.5.

3.6 Researcher's Journey

In qualitative research, the researcher can be viewed as a study tool. In this section, my background and how the study came to be has been outlined to provide a personal description of myself as a data collection tool for this study (57). In this section some key issues that evolved throughout this research process are presented for the reader to gain understanding of the obstacles of this particular case study.

Prior to starting graduate studies I practiced as a Registered Dietitian for two years. I spent one year working as a community dietitian in rural Saskatchewan in the Saskatoon area working in small town hospitals, medical clinics, and long term care facilities. I have now been working in an urban clinical setting as a dietitian on a hospital ward for three years. As a nutrition undergraduate student, one of my first degree-related work experiences was as a summer student with a palliative care program. It was in this position that I developed an interest in oncology nutrition and I have been able to continue to pursue this interest through

working on a hospital oncology ward as well as facilitating annual oncology nutrition workshops for *HOPE* Cancer Help Centre, a non-profit community organization in Saskatoon, Saskatchewan. In my role facilitating workshops for *HOPE* I found that many of the workshop participants had completed their cancer treatment and had been living with their cancer diagnosis for years. They attended these workshops to gain nutrition information primarily on preventing cancer recurrence and re-gaining their health following cancer treatment. There appeared to be a need for oncology nutrition information for cancer survivors.

In my work as a community dietitian I was trained to be a leader for *LiveWell with Chronic Conditions*. This training and my review of the literature gave me the knowledge and understanding that LWCC covers many topics of cancer survivorship programs offered in places outside of Saskatchewan.

I met with Darla Walz, Provincial Coordinator for the LWCC program early on in my graduate studies. Through this relationship I was able to gain access to the LWCC program. Darla had also been connecting with the cancer community in Saskatchewan prior to our meeting and I found that these intersecting relationships were helpful in conducting this research. My supervisor was supportive in these partnerships and provided further connections to the cancer community and cancer health programming in the province for both Darla and I.

It was my goal to choose a research project that would allow me to gain skills in conducting practical research and a deeper knowledge of the research process. I wanted to choose an area of research that was related to my primary area of interest which is oncology nutrition; specifically nutrition for cancer survivorship. It also was my goal to conduct research that contributes new information to the current knowledge base and provides applicable information for health care programming in Saskatchewan. As well, the research project seemed feasible within the time and resource constraints of a Master's program.

I chose to conduct this case study research for several personal reasons: 1) to gain skills in qualitative research, 2) to gain experience in conducting practical research and the research process, and 3) to increase my knowledge in the area of cancer survivorship. These reasons are still relevant to my role as a clinical dietitian and as a facilitator of oncology nutrition workshops and define my personal agenda for conducting this study.

I believe that nutrition, exercise, and mental wellbeing are essential components to regain one's health following cancer treatment. I believe that stress reduction, healthy eating and increased physical activity can improve an individual's quality of life following cancer treatment. I believe that in order for a person to make healthy lifestyle changes they psychologically need to be ready for and not resisting change. I believe it is the responsibility of an individual through guidance from their health care provider to ensure that they are living a healthy life. It is because of these underlying beliefs that I see value in *LiveWell with Chronic Conditions* as a program to provide guidance for cancer survivors who want to make healthy lifestyle changes. I understand that interpretation of my findings is shaped by my background therefore peer debriefing has been used to ensure the findings will resonate with people other than myself and that the study is grounded in the data rather than completely in my beliefs.

I have worked as an undergraduate summer research student collecting quantitative data and have a knowledge base in quantitative research. I learned more about quantitative data analysis while taking a graduate level statistics course. I did not have previous exposure to qualitative research before starting graduate studies. Studying research methods including a qualitative research methods course have provided me with comprehensive knowledge of qualitative research. These courses also gave me practical experiences in observational research and developing semi-structured interview guides. I piloted the interview guide developed for this research on two occasions and improved my skills at conducting these interviews as the study proceeded.

This graduate research journey did not happen without having to overcome some obstacles. In the design of this study it was decided to proceed with a mixed methods case study methodology using both quantitative questionnaires and qualitative semi-structured interviews. With Darla's and my experiences with the LWCC program and rural health programming it was estimated that up to 100 rural cancer survivors would participate in rural LWCC programs during the study period and that we would receive 50-75 completed questionnaires from these participants. During the data collection period I realized that few cancer survivors were in fact participating in the groups thus there were not sufficient numbers to recruit from. At that point I had to take a step back and change the design and one of the initial objectives of the study to a

more qualitatively focused endeavor which gleaned information on how LWCC responds to the needs of cancer survivors more from a program leader's perspective.

As a rural community dietitian I worked with health care professionals who are both cancer survivors and LWCC leaders and I decided to turn to these individuals to offer their unique perspectives in hopes of expanding my data obtained from cancer survivors. I acknowledge that I had a previous relationship with these individuals and was able to provide a relaxed and more conversational setting during these interviews. My rural work experience with LWCC allowed me to relate to program leaders on a deeper level than with the two cancer survivor participants interviewed. I was familiar with how the rural health system functions and had felt similar frustrations and experiences to those expressed by rural LWCC leaders in this research.

3.7 Ethical Considerations

Ethics approval was received from the Behavioural Research Ethics Board at the University of Saskatchewan and operational approval was received from the Saskatoon Health Region. See appendix 5 for the ethical approval certificate and Saskatoon Health Region letter of operational approval.

Participants' rights were respected and their anonymity was preserved in both quantitative and qualitative data collection, analysis and dissemination processes. Data collected in this study was in the form of anonymously completed questionnaires, audio-tapes from interviews, interview notes, and interview transcripts. Although direct quotations were reported from the interview, participants were given a pseudonym, and identifying information was removed from the final report. Participants were given the opportunity to review their transcript and quotations taken from their interviews and to add, alter, or delete information as they saw fit. After reviewing the quotations it was up to the participant to grant permission for their use.

There were no known risks associated with completing the study questionnaire or interviews. Participation in interviews and discussion of a cancer diagnosis may cause emotional distress. If needed and desired by the participant, an appropriate referral to a psychosocial health professional at the Saskatchewan Cancer Agency to assist the participant in coping with this emotional distress would have been made.

Data has been securely stored in a locked drawer at the University of Saskatchewan for a minimum of five years. When the data is no longer needed it will be appropriately destroyed.

CHAPTER 4: RESULTS

4.1 Introduction

An overall rhetorical structure for reporting case study research described by Creswell has been used to present the results of this mixed methods case study (57). A vignette is presented at the start of this chapter to enable the reader to develop a vicarious experience and get a feel for time and place of the study (57). Themes are presented and provide in-depth descriptive information for this case study (54). Quantitative descriptive data is provided to support the qualitative findings of this study, and finally, results and recommendations from the knowledge translation piece of this research have been presented.

4.2 A cancer survivor's experience with LiveWell with Chronic Conditions

I am a 62 year old woman and I have lung cancer. I live alone in my house in a small town of about 950 people in Saskatchewan. Even though I live alone, I have a few people who are my support system. These have been the people that I've been able to discuss my health problems with through this cancer diagnosis. I continue to have follow-up appointments and treatment for my cancer as it is not curable. I have a place to go and get chemo somewhat closer to home, but I have to travel 2 hours to get to the Cancer Centre for my follow-ups. When I get there, the oncologist never seems to have any time for my questions. If I'm not feeling well there is a doctor in my town's clinic I can go see which is nice, but even my family doctor doesn't have time to discuss or answer my questions.

About a year after I was diagnosed with lung cancer a family member who is a leader for *LiveWell with Chronic Conditions* told me about the program. It felt like a good time for me to participate in it. I had gotten used to the idea of living with cancer and had come to terms with the fact that my cancer is not curable and even if it goes into remission it will still be a chronic thing. It sounded worthwhile so I registered for a class that was offered in a nearby town. It would have been nice if it was offered in my town, but the travel was manageable because it was only about a half hour away. If it was any further I don't think I would've gone.

The sessions were held in the boardroom at the hospital which was convenient for everybody. If they couldn't do the stairs, they could use the elevator downstairs to the room it

was held. I was still receiving some cancer treatment while I was taking *LiveWell with Chronic Conditions*, and I ended up missing one session because of that.

I was the only one in my group with cancer. I understand that they need to teach a wide variety of people with different diseases but it seemed to be more focused on fibromyalgia and arthritis, probably because those are the more common chronic conditions. It would have been nice to see another person there with cancer. I think cancer could be included a little bit more in the program material, now that I've been down that road. Even still, I thought that all of the information was applicable to me and my health situation in some aspects.

I was feeling tired and fatigued from my cancer and this program helped me to deal with that. Sometimes I get discouraged and frustrated by my health and I worry about my future health. Since taking this program, I feel better able to deal with feeling stressed and better able to deal with being worried about whether my cancer treatment has worked and my fears about my cancer spreading. Since participating in the program, I feel fairly confident that I can keep any physical discomfort, emotions, and fatigue from interfering with the things I want to do. If I'm feeling down in the dumps or having some pain sometimes I will practice muscle relaxation which is something I learned at the *LiveWell with Chronic Conditions* program. This program also gave me information on making healthy food choices and ways to improve my physical activity level for me to maintain a healthy body weight. I found there was a large focus on setting action plans in the program which helped me to create a plan to move forward in life. This program gave an outlet for discussions that I would never have time for with my doctor. Nobody else has time to cover things like that and there were caring people there that you could share with. It has been about six months since I've taken the program and I still find myself reflecting back on some things that were said or a phrase coming back that proves helpful.

I would recommend this program to other cancer survivors living in a rural community if they are looking for a healthy lifestyle program. There were posters and bulletins promoting the program around town, but word of mouth seems to work best to get people out. I think that more health care professionals like my chemo nurse need to get information about the program so that they can recommend it to their patients.

4.3 Demographics of Participant Sample

Table 4: Participant Demographics

	Program leaders who are not cancer survivors	Program leaders who are cancer survivors	LiveWell Participants who are cancer survivors
Total	4	4	4
Interview completed	4	4	2
age	Not Identified	Not Identified	69 (57-83)
Location of Program Involvement	1 Prince Albert 1 Regina 1 Weyburn 1 Carlyle	1 Humboldt 1 Prince Albert 2 Saskatoon	1 Meadow Lake 1 Kipling 2 Not Identified
sex	4 female	4 female	4 female
diagnosis	NA	4 breast cancer	2 breast cancer 1 lung cancer 1 lymphoma
education	3 University Degree 1 Not Identified	2 University Degrees 2 Not Identified	2 High School Diplomas 1 Registered Apprenticeship Diploma 1 Registered Apprenticeship Diploma and College Diploma
occupation	1 Occupational Therapist 1 Diabetes Nurse Educator 1 Nurse Practitioner 1 Not Identified	2 Dietitians 2 Volunteers	Not Identified
relationship	Not Identified	Not Identified	1 Single 1 Married 2 Widowed
Language spoken in home	Not Identified	2 English 2 Not Identified	4 English

The type of demographic information collected varied among participants. Demographic data was collected on the questionnaire through demographic questions adopted from the Survivor Unmet Needs Survey (SUNS) (30) therefore more information was collected from the LWCC program participants because they each had completed the questionnaire which included a demographic section. Demographics were not discussed in great detail during the semi-structured interviews.

The participants in this study were all female. This was expected among program leader participants prior to the initiation of the study as ~85-90% of LWCC program leaders are female. The majority of cancer survivors who contributed to this research had experienced breast cancer. The participant sample in this study represented a varied geographical area from the southeast corner of the province (Carlyle) to the central western region (Meadow Lake). The three northern Saskatchewan health regions of Mamaweehan Churchill River, Kewatin Yatte, and Athabasca were not represented in the sample. Research participants came from a range of community sizes as well. Excluding Regina and Saskatoon, rural communities that were represented had populations ranging from 1,100-34,000 people. Education backgrounds were more advanced among program leaders compared with program participants.

Additional program participant demographic data specific to being diagnosed with cancer has been presented here. The years of first diagnosis with cancer were found to be 1987, 2000, 2009 and 2010. There was quite a large range in length of time from time of diagnosis to time of LWCC program attendance. The participant that was diagnosed in the year 2000 identified on her questionnaire that it would have been beneficial to take the program sooner after her cancer diagnosis. There was also a range in the stages of the participants' cancer journey. One identified herself as cancer free, 2 were having follow-up appointments and taking medication, and one was in the palliative stage. It took 2-4 hours for three of these people to travel to the nearest location where they received cancer treatment. It took 1-2 hours for the fourth person to travel for cancer treatment. Three participants identified that they usually go to their family doctor's office when they are sick with other than cancer related issues and one of the participants would go to the hospital outpatient clinic in that situation. All 4 of these participants stated that there is someone they can confide in or discuss problems with and each of them had 2-4 people that they felt they could confide in. Answers to specific questions on the LWCC program with respect to cancer survivorship are also presented here.

All four of these participants found out about the LWCC program from a friend or family member. One noted that there was information about the program in a local monthly newsletter and one had also received information from an allied health professional. Three were able to attend all 6 of the LWCC sessions in the programs they were enrolled in. The fourth participant

had to miss 1 of the 6 sessions. All respondents indicated that they would recommend the LWCC program to other cancer survivors living in a rural community.

This table does not include demographics of the two key informants who were interviewed. A representative from the Saskatchewan division of the CCS and a representative from the Ontario Division of the CCS were interviewed to learn more of cancer survivorship programs offered through the CCS in these two provinces.

4.4 Themes

Themes that convey multiple perspectives from participants have emerged from the coded data (54). See table 5 for a list of these themes and the corresponding codes that aligned with these themes. Six general themes were identified through repeated interactions with the data and the following sections of this chapter provide detailed descriptions of them.

Table 5: Schematic of Coding and Themes

Theme	Codes
Perceptions of the program Sub-themes: Provincial Program Delivery Program Leadership Program Content	The People, Generic Content, Leader Knowledge and Background, Appropriate Topics, Providing Educational Material**
Surviving cancer as a chronic condition	Side effects of cancer, Chronic Illness, Cancer is not Chronic, Cancer is Chronic
Surviving cancer in a small town	Survivor Needs, Rural Survivor Needs, Small Town and Rurality, Managing the Transition to 'New Normal'
Participation and Recruitment Methods Sub-themes: Attendance Program promotion	Getting the Numbers, Accessibility, Sense of Belonging in a Group Program Promotion, Recruitment, Timing of Delivery, End of Life
Program supports cancer survivors	Application of Information, Symptom Relief, Benefits and Highlights, Shared Experience and Group Dynamic, Building Relationships
Program enhancement Sub-themes: Gaps in Service Suggestions for change	Missing Information, Name and Theme, Continued Support, Providing Educational Material** Health Care Issues and Gaps, Changes to Program

**in two themes

4.4.1 Perceptions of the Program

Elements of the LWCC program were discussed during the semi-structured interviews in conversation separate from discussing the program with respect to rural cancer survivorship. The following three subthemes describe how leaders and participants interviewed perceive features of the program as it is run in Saskatchewan.

4.4.1a Provincial Program Delivery

During the study period in Saskatchewan, LWCC programs were offered in both urban and rural communities as a program in which anyone with any type of chronic condition can attend along with their caregiver. Some of the most common chronic conditions of participants in these programs identified by interviews with program leaders were cardiac disease, diabetes, musculoskeletal issues, COPD, arthritis, multiple sclerosis, blood disorders, mental illness, or more than one of the above. In September 2010 the program evaluation form used for this program was amended so that participants would indicate their chronic condition. The majority indicated 'other' followed by diabetes, rheumatology, cardiac, and pulmonary. It was also identified that the majority of participants who attend the program are over 65 and retired.

Since LWCC programs are run in every health region of Saskatchewan, many small communities have access to this program within a short driving distance. The following is a small list of some of those small communities that host this program. Six program leaders were interviewed for this research that have led programs in various regions of rural Saskatchewan including Birch Hills, Kinistino, Shellbrook, Rosthern, Wakaw, Cudworth, Carlyle, Kipling, Wawota, Humboldt, Imperial and Meadow Lake. Two program leaders were also interviewed who have led programs in Saskatoon which is considered an urban centre in this case study.

4.4.1b Program Leadership

Teaching this course is based on Bandura's self-efficacy theory and when possible it is taught by lay leaders often who are coping with a chronic condition themselves. In some rural areas of Saskatchewan this is not always possible because there are not enough volunteer community members to facilitate the program. When this happens, the course is co-facilitated by a trained health care provider and a trained volunteer. A variety of health care providers have been trained and are program leaders in rural Saskatchewan including but not limited to

dietitians, nurse practitioners, occupational therapists, physical therapists and exercise therapists. In the interviews, the pros and cons were weighed for having the program facilitated by a health professional or a volunteer with a chronic condition. On one hand a health professional would be able to make appropriate referrals for participants to other health care services when needed. They also may be able to better answer participants' questions about their health more appropriately or accurately. On the other hand, one leader said:

“It is stressed in our training that we are not doctors and we are not qualified to provide any disease specific information or answer disease specific questions from participants. This is important because there is concern that leaders may add their own opinions.” (B.P.-cancer survivor, program leader)

Volunteers who are trained to lead the program in Saskatchewan typically have a chronic condition themselves. There is no preferred chronic condition that a program leader should have as it is thought that there are similar experiences across all chronic conditions. However; a difference of opinion was found among program leaders interviewed on the topic of if a program leader should be a cancer survivor when facilitating this program for a group of cancer survivors.

“It may not necessarily be good to have a leader who has had cancer themselves to facilitate a group of cancer survivors because they may become more of a participant themselves than a leader.”(B.P.-cancer survivor and program leader)

“If it (LWCC) is for cancer then I think you need someone who knows something about it. It doesn't mean they have to have had cancer but they should get some sort of training.” (N.R.-program leader, cancer survivor)

“To have the program delivered by somebody who has been through that similar experience really contributes to its success.” (R.S.-program leader)

4.4.1c Program Content

Basic and general information is presented over 6 weeks at the LWCC program. Group leaders shared that they don't get into condition specific things and don't usually have disease specific resources to provide to participants. One participant found the program touched on many topics. The content included in the program was considered appropriate and applicable to cancer survivors by all who were interviewed.

"It's so generic, I mean having people design their own exercise program, pay attention to nutrition using Canada's Food Guide, relaxation, stress management, communication, really I can't think of anything that's inappropriate (for cancer survivors) necessarily." (T.F.-rural program leader)

"I think pretty well all of it is applicable (for cancer survivors). The chronic symptomology, management of symptoms and distractions, action planning, dealing with difficult emotions-that was huge. Physical activity and exercise I think is applicable to anyone surviving cancer. The relaxation, pain/fatigue management, planning for healthy eating, communication skills, pretty well everything." (J.W.-cancer survivor and program leader)

Although she agreed that the information of the program was applicable to cancer survivors, one leader did express some concern regarding the nutrition section of the program.

"I am not so sure how helpful the nutrition part is because often times when people are living with and coping with a cancer diagnosis and especially if they are going through chemo it is important for them to have a little extra weight. They probably focus on what tastes good to them so that they are getting some nutrition rather than what is always the healthiest for them to eat." (E.L.-program leader and cancer survivor)

Part of the information provided in this program is a section on planning for living wills and advanced health care directives. Although none of the leaders interviewed expressed any difficulty facilitating this section, one of the leaders did suggest additional training for program

leaders on leading this section for a group made up of cancer survivors as this would be a particularly important topic for them and could become quite emotional.

Participants in this program receive a free reference book titled *Living a Healthy Life with Chronic Conditions* that they are able to refer to during and following completion of the program. In Saskatchewan, a few other resources that are provided to group participants may include Eating Well with Canada's Food Guide, Canada's Exercise Guidelines, and Advanced Care Directives. In Ontario where the CDSMP program is used as a self-management program for only cancer survivors the *Living a Healthy Life with Chronic Conditions* book is provided and cancer specific resources are available through a way that supports self-management. A table is set up with resources available but attention is not drawn to it and since participants are supposed to be managing their own illness they can help themselves to brochures, etc. if they find them appropriate for their individual case. Some leaders allowed program participants to bring in resources for sharing because that demonstrated positive self-efficacy and self-management.

4.4.2 Surviving cancer as a chronic condition

Study participants shared their views on whether they consider cancer to be chronic or acute. The term "chronic condition" was not found have a clear-cut definition throughout the interviews with program leaders and participants. Having to do something over the long-term, perhaps for the rest of your life, was one defining factor of a chronic condition for some. A chronic condition was defined by one program leader as "a condition that physically limits a person". It was noted that during the first session of the CDSMP there is discussion about acute and chronic illness defining these terms, and program leaders interviewed would have knowledge of these definitions thus likely having similar understandings of what chronic conditions are. The Stanford CDSMP defines a chronic condition as a condition that begins slowly and proceeds slowly. Chronic conditions have multiple causes that vary over time including heredity, lifestyle factors, exposure to environmental and physiological factors. Chronic conditions usually lead to more symptoms and loss of physical functioning (18).

All nine of the program leaders interviewed, whether they had been diagnosed with cancer in their past or not, agreed that the diagnosis of cancer results in one or more chronic

conditions. A common perspective among this group was that chronic conditions arise from cancer treatment.

“Chemotherapy, radiation, some hormonal therapies and things have side effects that can result in long term chronic conditions as a result of their treatments for cancer. Conditions that you know they can live with for the rest of their life.” (R.S.-program leader)

Others found that difficult emotions following a cancer diagnosis such as fear of recurrence or grief from the cancer diagnosis persist throughout their life and contribute to the thought that cancer is chronic.

“There are all sorts of chronic conditions as a result of living with cancer. Some as a result of their cancer treatment and some as a result of the loss of being diagnosed with cancer.”(R.S.-program leader)

The fact of having continual monitoring for disease recurrence with follow-up appointments can make a cancer diagnosis a long-term health situation which would not allow a person to go back to the way their life was before cancer.

“It impacts more than just the physical aspect of the disease. There’s treatment and follow-up, but there’s also an impact on our whole body so emotionally, mentally, physically and spiritually it makes a difference.”(E.L.-program leader and cancer survivor)

“Life has changed on account of having cancer regardless of what type of cancer and regardless of the treatment.”(S.D.-rural program leader)

Interestingly, most of the interview respondents who have had cancer suggest that many people do not consider cancer a chronic condition. Various stages of cancer potentially could not be seen as chronic to some people. Those people who are totally cancer-free and whose cancer treatment consisted of solely surgical tumor removal, those who are in remission, or those with a

terminal diagnosis may not consider their cancer diagnosis as a chronic condition. One cancer survivor participant did not consider cancer as chronic. She suggested that instead of labeling a physical condition as chronic, the idea of having a chronic condition is all psychological, and that it is up to the individual to live with a chronic condition or not.

“I don’t consider it (cancer) as such (chronic). Cause you just handle it and that’s all there is to it. I think it’s mostly attitude. It’s just how you look at it. You can let it become a chronic thing that will take you down or you can just go along and deal with it day by day” (H.K.-rural cancer survivor)

All interview participants seemed to have experienced cancer in some capacity whether it was them who was diagnosed with cancer or a friend, family member or client that they had seen through their cancer, and these participants shared many stories of their cancer experiences. Regardless of whether cancer is considered a chronic condition or not, debilitating side effects of cancer were evident. Side effects mentioned that had an impact on quality of life included lymphedema and arm weakness in breast cancer survivors, tinnitus from tonsillar cancer treatment, taste changes from chemotherapy, fatigue from radiation and “chemo brain”.

4.4.3 Surviving Cancer in a Small Town

Being diagnosed with cancer in a rural community is a socially different situation. There is more of a ‘gossip’ element of small towns in that everybody knows everybody’s business.

“A lot of rural people, they just don’t up and tell everybody that they have cancer when they first get it, their neighbors, you know, it takes a while.” (N.R.-cancer survivor, rural program leader)

It was identified that overall awareness of what is available in rural programming is poor, and there is a lack of rural support for cancer survivors. The Canadian Cancer Society’s cancer information line was identified as the source that people with cancer are going to contact immediately after a diagnosis for information. This is a telephone service connecting a person with a new cancer diagnosis with someone who has had the same diagnosis and treatment

protocol. If they are able they would also find a best match for demographics like age, gender, location, and personal concerns. Appealing factors of this service are that you don't have to leave home to receive it and it maintains anonymity for people who aren't ready to reveal to members of their small community that they have cancer.

Responsibilities may be prioritized differently by rural people. A breast cancer survivor suffering from severe lymphedema explained to one of the group leaders interviewed about why it had taken her so long to participate in a group: "I was needed on the field, I was needed driving the truck, I was needed making the meals for the harvest crew".

"Often times the rural woman has so many extra responsibilities and demands; especially if she is a farm woman. Just because she has cancer, it doesn't mean that they are going to put seeding on hold or harvesting on hold." (E.L.-Program leader, cancer survivor)

It was heard that there is a need for cancer survivor support in rural communities. One participant identified her need for understanding how to be your own advocate when you go to the cancer clinic. She felt the section on communicating with health professionals in the LWCC program met this need. A cancer survivor participant explained that the CDSMP brought to the forefront a need to be in control of her own health. A breast cancer survivor identified that learning how to cope with lymphedema is a very important need of breast cancer survivors and is not addressed in the CDSMP program. Managing the adjustment of finishing treatment and living with a "new normal" was a unique need of cancer survivors represented in the interview responses.

"Once you're done treatment you feel like you're just kind of let alone in the world. Like they were keeping such a close eye on you and then all of a sudden everything stops and you just feel, yeah, it's a very uncomfortable feeling." (J.W.-cancer survivor, rural program leader)

"You know the diagnosis, that was hard, and the treatment was hard. My oncologist kind of warned me about the transition period but I thought it would be easy and it was probably even harder."(J.W.-cancer survivor, rural program leader)

One leader who is a cancer survivor acknowledged that the section on difficult emotions in the LWCC would be a good start to get cancer survivors to look at the difficult emotions that come along with a cancer diagnosis. Leaders could not identify an existing forum in rural Saskatchewan specifically designed for cancer survivors to talk about other survivorship topics including fatigue, healthy living or setting action plans.

4.4.4 Participation and Recruitment Methods

The number of rural cancer survivors currently participating in the LWCC program are far below the numbers projected by the researchers prior to data collection in this case study. From the initially estimated 100 rural cancer survivors that would participate in the 47 programs run in rural Saskatchewan during the study period, only 7 participants were identified by program leaders as cancer survivors. The small number of cancer survivor participants was identified as a finding in itself. Questions were asked during the semi-structured interviews about participant attendance and recruitment. The responses to these questions may shed light on reasons why cancer survivors were not participating or identified as participating in the LWCC program during the study period however, the researcher was not able to obtain a great depth of qualitative data to present this information solely from the cancer survivor participant's perspective. Current attendance and methods for program promotion are presented in the following two subthemes.

4.4.4a Attendance

In the interviews, the researcher asked if cancer survivors felt a sense of belonging in a group program amongst other chronic conditions.

“I can see cancer survivors thinking it was acute and that maybe they didn't fit into the program.” (C.K.-rural program leader)

“Whether a cancer survivor feels comfortable in a group of different chronic conditions I think depends on the person” explained a program leader who is a cancer survivor herself. *“Some people are very open with their diagnosis”*.

This comment relates to the issue of being wary of diagnosis disclosure in a small town (section 4.5.3) and is looked at in further detail in the discussion section addressing rural values.

Both cancer survivor program participants interviewed felt comfortable being mixed in a group with other chronic conditions and program leaders also noted that survivors were appreciative of being in a group setting even though they weren't with other cancer survivors. The support of another fellow cancer survivor in a LWCC program may also be appreciated explained a participant.

"I found that I was the only one there with cancer. It would have been nice to see another person there with cancer. It seemed to be more focused on fibromyalgia, arthritis and chronic things like those." (L.M.-cancer survivor program participant)

Running a LWCC program solely made up of cancer survivor participants may be preferable but not necessary to some people. Interview responses did not indicate that this would be feasible in rural Saskatchewan communities.

"I think in the rural you have to combine all chronic conditions, because otherwise you're not going to get enough numbers of enough people ready at the same time to do it."(N.R.-rural program leader and cancer survivor)

"Here in the rural, I see it as you would have everyone in the same room not just for cancer survivors, because the numbers are so low." (J.W.-rural program leader and cancer survivor)

The small number of participants in rural programming was commented on by 3 program leaders. It appears difficult to have 10-15 people signed up for a rural LWCC program, and also difficult to maintain two trained leaders in each community that hosts the program. These leaders indicated that if there are not enough participants registered or don't have 2 trained leaders available the LWCC program will get cancelled in that community.

Program accessibility was one issue discussed in the interviews as a possible reason for limited numbers of participants including cancer survivors in rural LWCC groups.

Consideration of transportation and travel time to the location of the program is important in rural communities. People may be willing to drive fifteen minutes to half an hour for a group session and it is easiest if you are living in the town that the program is running in. A couple of interview participants mentioned that a driving distance over an hour would be unacceptable and chances of them attending a program that is further than a one hour drive away are low. The difficulty driving a longer distance for a one-time event was also brought to my attention in these interviews.

“Coming together in the rural community for 2 ½ hours once a week for 6 weeks is probably a realistic time that a rural woman could manage. Whereas driving in to Saskatoon to go to a workshop and home again, puts more stress on the woman trying to get to the weekly session.”
(E.L.-Program Leader and Cancer Survivor)

“There were things that were offered but I didn’t go because of the travelling.”(J.W.-Rural program leader and cancer survivor)

To reduce the amount of travel time, the idea of using *Telehealth* to provide LWCC programs came up during the interviews. Although travel distances may be shorter which was preferable, experienced program leaders did not feel that attending the program over *Telehealth* would be as beneficial because you would be missing the personal interactions. Their experiences using *Telehealth* were that it’s hard to hear and participants end up watching rather than actively participating. Because this technology is not available in all small towns of Saskatchewan, participants would still have to drive to a *Telehealth* site. In rural communities, people also would have to be well enough to make the drive to the community where the LWCC program is being held.

“How do you get off the farm to go to something if you’re not feeling well, your spouse is working, and you’re it? So I guess maybe you’d have to find people willing to pick them up and take them. That’s the other thing is transportation, because lots of people who are mobile when

they're coping are not mobile while they're in treatment."(N.R.-Rural Program Leader and Cancer Survivor)

4.4.4b Program Promotion

Conversations and word of mouth appeared to be the most successful and common way to recruit a program participant. Both program participants who were interviewed were recommended to the program by family members. Participants in small communities seemed likely to invite others to attend the group with them or would recommend to other friends after completion of the program. One dietitian who is a program leader found that the majority of referrals to the programs she facilitated were coming from other team members and that this was more successful for recruitment than advertising. The CCS Ontario Division has also recognized that the support of health care professionals is important for programming and has started to develop presentations for this group. In Saskatchewan, there are regular opportunities for health care professionals to attend an information session on LWCC including support services staff at the Saskatchewan Cancer Agency.

Other methods of program promotion in rural communities that are used include: posters, brochures, newspaper, information on a website, flyers handed out with medication refills, Healthline, and bulletins in store windows.

At the start of the study period (September 2010) some promotional areas specific to cancer survivors were added to previous promotional strategies (see Methods section 3.3b). Not all interview participants were aware of these new promotional strategies and many made similar suggestions for adding the word cancer to promotional material, encouraging the Canadian Cancer Society and the Saskatchewan Cancer Agency to recommend this program to cancer survivors.

Other ideas that came out of the interviews to promote the LWCC program to cancer survivors and are not currently in practice were: presenting to local cancer support groups, mail-outs by the Saskatchewan Cancer Agency, a follow-up phone call from cancer connection making people aware of the program, presenting at the annual provincial cancer conference, and oncologists, palliative care staff, and chemo nurses recommending the program. Ideas for promoting the program in a rural community included advertising and displays at the community

Co-op store, health days, or community drop-in information days. The CCS Ontario division has found a successful model for recruitment over the past few years. A letter including a CDSMP flyer is sent out to clients who have finished receiving support from their peer support program. They found this to be successful because the client has finished peer support and has a relationship with the volunteers and staff who run the CDSMP program.

Group leaders and cancer survivor participants were asked for their thoughts on timing of delivery of the LWCC program for cancer survivors. Those who had experienced a cancer diagnosis felt that a person would need to accept the idea of living with cancer before being referred to the program and that initially after a cancer diagnosis a person would be too overwhelmed to participate. All respondents who have had cancer also felt that this program would be inappropriate during the acute treatment phase because if they are going through chemo they may not feel well enough, would have a lack of energy, too many stressful psychological demands, and would have too many other competing medical appointments etc. going on.

“Early diagnosis, early treatment and just getting through the treatment are kind of your priority. That probably wouldn’t be timely. It’s that transitional state that I think the program would benefit most.” (J.W.-rural program leader, cancer survivor)

The idea of an individual who has a terminal cancer diagnosis or who is palliative attending the LWCC was discussed on several occasions during the interview process with no clear recommendations or conclusions. Interestingly both cancer survivor participants who were interviewed had non-curative cancers. This issue will be examined further in the discussion section.

4.4.5 Program Supports Cancer Survivors

Interviews revealed this program potentially has multiple benefits for cancer survivors. The benefits of being involved in a group program and having commonality of experience echoed among group leaders and a cancer survivor participant. Responses validated that

although LWCC is not intended for support group purposes, it still may have a ‘support group’ sense to it.

“This program has caring people that you can share with” (L.M.-rural cancer survivor)

“It’s that process of working through it as a group and then individualizing like the action plans and that whole support, yeah, it’s very powerful” (R.S.-Program Leader)

“The socialization and being around other people with chronic health conditions would be the best part of the program.” (T.F.-rural program leader)

“I think that’s part of it is to see how other people cope with things.” (N.R.-rural program leader and cancer survivor)

“It’s a case of asking questions and they ask it of each other. Often women have a wealth of information because of our experience living with cancer and we’re willing to share it with someone else. (E.L.-cancer survivor-program leader)

Given the range of topics presented at LWCC, it is suggested that all topics would not be equally applicable to everyone. The sections that are the most important to an individual are those that specifically target what that participant’s major symptom from their chronic condition is. Major symptoms of cancer survivors were identified as emotional issues, physical issues, fatigue and pain. Cancer survivors attending the program and their program leaders explained that LWCC helps them deal with these symptoms. A cancer survivor participant and leader provided examples of how the LWCC information has been helpful in managing her cancer-related chronic conditions.

“The coping strategies such as the deep breathing and the guided imagery and some of the other pain management techniques that we worked on, were probably highlights for me that I felt workable and beneficial.” (E.L.-program leader and cancer survivor)

“Some of the coping strategies with regards to the guided imagery and the use of deep breathing. I continue to do that on a regular basis. Especially when there’s a stressful situation.” (E.L.-program leader and cancer survivor)

“I find myself thinking once in a while what was said or a phrase coming back that proves to be helpful. This program helped you maybe channel your thoughts in a way they should go regarding your illness.” (H.K.-cancer survivor)

The length of time that this program remains helpful after participating in it was not identified through these interviews. One leader indicated that this program can have an impact and outcomes over the six short weeks. Leaders who are cancer survivors continue to use self-management techniques learned from the program and one believes these strategies will be helpful for the rest of her life. A cancer survivor who participated in the program nine months after attending it still found the information useful.

Program satisfaction and recommendations were plentiful not only for cancer survivors but for anyone with chronic conditions. Leaders had the impression that people really liked the program, participants find value in it, and believe it is an excellent program for promoting a healthy lifestyle. Cancer survivor participants also were satisfied with the program as they found it very helpful and would recommend it to other cancer survivors.

“I think it’s really good. It gives a lot of ideas and different ways of looking at things so I think that’s really good. Just different ways of dealing with it helped me.” (R.S.-cancer survivor)

4.4.6 Program Enhancement

Qualitative interviews were used to meet the research objective of exploring how the program could be enhanced in terms of content, format, delivery and marketing strategy. Results have been presented regarding marketing strategies however there were some overlapping results in the coding of this theme. This theme has been divided into two sub-themes. One describing issues in health care that were identified by interview participants. These have been presented as

these factors may identify additional areas that this program could be enhanced to resolve these issues. This will be addressed further in the discussion section. The other subtheme presents suggestions for program enhancement that came out of the interviews.

4.4.6a Gaps in Service

A main concept that a cancer survivor found was lacking from her care was discussion time with her doctor. She felt the way this program was given provided the time to cover topics that wouldn't be covered by a physician.

“It’s lacking in the community because even your doctor doesn’t have time to discuss or answer your questions. I found the oncologists didn’t have time for you at all. They came in said “Hi. You’re looking good. Everything’s fine. Goodbye”.”(H.K.-rural cancer survivor)

There were topics of interest to the cancer survivor that were identified as not part of the LWCC program content. Dealing with the arm at risk with lymphedema for breast cancer survivors and more information on sexuality, and how to test or know if a cancer has come back were a few of the missing topics identified. A cancer survivor thought it should address the emotional concerns of cancer. The fear of cancer recurrence was described by a program leader and cancer survivor and she felt that it is important for the cancer survivor to learn how to cope with this fear.

“That feeling that I had all of a sudden that you’re just so intensely in treatment and then all of a sudden you’re not. I don’t know how to describe that feeling. Like, it was a fear.”(J.W.-rural program leader and cancer survivor)

The *Living a Healthy life with Chronic Conditions* manual did not really mention cancer in it at all. The researchers at Stanford have developed a Living a Healthy Life book specifically for HIV AIDS, blood disorders and pain management. Two program leaders thought being able to have a more cancer-focused Living a Healthy Life workbook would enhance the content already being provided.

To enhance program content, the idea of a seventh session or an add-on session was brought up by either the interviewer or the interviewee where the facilitator could let the participant know what other program options there are, provide CCS information, and going more in-depth into those transition issues such as cancer recurrence.

The name of the program is usually the first thing a person comes in contact with. A leader felt that the *LiveWell with Chronic Conditions* program could have a different name as the word chronic has a negative connotation to it. The group in Ontario that runs the CDSMP specifically for cancer survivors struggled with finding an appropriate name but has settled on *Living Well beyond Cancer* after trialing the names *Chronic Disease Self-Management Program* and *Surviving Cancer and Living Well*.

4.4.6b Suggestions for Change

Several items that may enhance the delivery of the program were brought to light. Webinars or delivering the program over *Telehealth* might be useful for reaching a larger population especially those living in rural that were younger and working or those with a computer that are not able to travel. The length of time that an individual attends LWCC weekly may be too long for the cancer survivor.

“For the cancer patient who is going through treatment and opts to take part in the LiveWell program, as it is the only time it will be offered, 2 ½ hours may be too much time for them. It may be necessary for the leader of the LiveWell program to take into account that the cancer patient may not be able to stay 2 ½ hours”. (E.L.-program leader and cancer survivor)

The program format currently used previously mentioned in the description of the case is a 6-week program with 2 ½ hour sessions weekly. The follow-up piece after the 6 weeks has ended was a concern two leaders shared. Their comments suggested that it may be beneficial to have supports in place for follow-up or for people who participated in the program to carry on with the skills they have learned.

“One thing that does kind of concern me a bit is that follow-up. Where are they in 3 months and 6 months? Does it still have the impact like a year away?” (R.S.-program leader)

Some CDSMP programs have had hiking groups start after the 6 weeks are completed or participants would send around a phone list and meet socially. One-on-one friendships would sometimes develop. A suggestion made by a leader to keep the group going after the 6 weeks have been completed was for the participants to take it over and if there is a topic that they are interested in, then they could bring in a guest speaker, or everyone could look for information on a topic and share it with the group.

4.5 Quantitative Results

A questionnaire was created to quantitatively assess how the existing LWCC program meets the needs of rural cancer survivors who seek support to make healthier lifestyle choices. Limited quantitative data collected from cancer survivors who participated in the program unfortunately prevented the research team to meet this research objective. Descriptive quantitative results are presented in this section from the four completed questionnaires received. They tell parts of the story and give examples of experiences which have enhanced the understanding gained through qualitative analysis. However these quantitative results do not provide conclusive evidence or answers.

An aim of the questionnaire was to evaluate the effectiveness of this particular program among rural cancer survivors. As determined in the literature review, it was found that important areas of cancer survivorship programming were exercise, nutrition, fatigue, and psychosocial concerns including stress and fear. Stanford University acknowledged they had not found or developed a scale to measure nutrition information that was brief (62). In this questionnaire general questions were asked of the participants regarding their feeling of the impact LWCC had on their nutrition, physical activity level, and body weight. Three of the four participants agreed or strongly agreed that the LWCC program provided the information and/or skills they needed to make healthy food choices and improve their physical activity level whereas the fourth participant was in strong disagreement on this topic. Two of the participants agreed that LWCC

provided information and/or skills to achieve or maintain a healthy body weight and the other two participants felt this topic was not applicable to them.

The questionnaire asks participants if they feel they have an improved ability to cope with or address the top 10 unmet cancer survivor needs as defined through the development of the SUNS after attending the LWCC program. This question was intended to determine if the LWCC program meets the needs of rural cancer survivors in this study. Four other questions on the questionnaire were derived from SUNS questions. Although these were not among the top ten needs as identified by SUNS researchers, they were important topics to ask participants within the context of this study because they addressed the ‘transitioning’ process of cancer survivorship, a topic that has been included in many recently developed cancer survivorship programs. The responses to these questions from the 4 participants who completed this questionnaire are provided in the table below. Numbers 1-10 correspond to the top 10 unmet needs of survivors identified in SUNS and numbers 11-14 correspond to the additional questions included in the questionnaire that were found important to this study.

Table 6 Responses to Statements:

By participating in the LiveWell with Chronic Conditions program, I feel better able to...

#		Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
1	Deal with feeling stressed.	1		3		
2	Deal with feeling tired.			3	1	
3	Deal with feeling worried (anxious).	1		3		
4	Cope with bad memory, lack of focus.			3		1
5	Deal with fears about cancer spreading.		2	2		
6	Deal with not feeling sure that the cancer has gone.		1	2		1
7	Deal with worry about whether the treatment has worked.			2		2
8	Cope with being told I have cancer.		1	1		2
9	Find information about complementary and alternative therapies.		2	1		1
10	Find what type of financial assistance is available and how to obtain it.		2	1		1
11	Deal with people who expect me to be 'back to normal'	1	1	1	1	
12	Deal with not being able to feel 'normal'.	1		1	1	1

The LiveWell with Chronic Conditions program has given me adequate support...

#		Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
13	For finding meaning or a new purpose in life.			3		1
14	To create a plan to move forward.			3	1	

By using previously developed and validated subscales by Stanford University Research Centre, the researcher measured outcomes that would be desired in a cancer survivorship program. The three validated scales developed by Stanford Research Centre included in this

questionnaire were the health distress scale, the cognitive symptom management scale and the self-efficacy scale.

The health distress scale was used with the intention that it would provide the researcher with the level of distress caused by illness during the month the participant was enrolled in LWCC. As described previously, the number of cancer survivors enrolled in LWCC during participant sampling was very limited. When this was discovered, cancer survivors who had participated in the program up to 6 months earlier were contacted to complete the questionnaire. Therefore, not all participants who completed the questionnaire did so at the last session. The results of the responses to the health distress scale were no longer useful for the purpose of this study as they do not indicate health distress during the time of the LWCC program and therefore they have not been presented.

The cognitive symptom management scale is a behaviour change measure to find out if people have been practicing any cognitive stress and/or pain reduction techniques (62). Scores for this scale can range from 0-5 and higher scores indicate more practice of these techniques. The self-efficacy scale was used to understand rural cancer survivors' self-efficacy in disease management following program participation. Scores can range from 1 (not at all) to 10 (totally), a higher number indicates higher self-efficacy.

Table 7 Self-management Outcomes

Scale	n	Range	Mean
Cognitive Symptom Management	4	1.17-2.17	1.63
Self-efficacy	4	6.83-9.83	8.58

The sample size of this study is far too small to produce evidence or arrive at any conclusions regarding the impact of LWCC on self-efficacy and cognitive symptom management among rural cancer survivors. However, it was identified that all four participants who completed this questionnaire had a high level of self-efficacy. These participants also showed

that they practice cognitive symptom management techniques to a similar degree to the sample Stanford used to validate this scale.

4.6 Turning Knowledge into Practice

The identified significance of this research was: If *Live Well with Chronic Conditions* becomes commonly offered and marketed to rural cancer survivors; they would have access to a resource that is already available across Saskatchewan but is not necessarily perceived to be appropriate for this group. Through evaluation and program enhancement as explored by this study, preliminary recommendations were formulated by this student researcher, research supervisor Dr. Anne Leis, and LWCC provincial program coordinator and research advisory committee member Ms Darla Walz. These recommendations were categorized into three general recommendations and three specific recommendations. The results and these preliminary recommendations were presented to a group of key stakeholders followed by a discussion of current cancer survivorship programming in Saskatchewan and how these practices and knowledge could inform future recommendations. This method of knowledge translation was planned to meet the research objective to develop recommendations in coordination with agencies and institutions that provide services to cancer survivors based on study results.

This group met on October 26th, 2011 and connected in person, over *Telehealth*, and with teleconferencing. Stakeholders who were invited and able to attend included representatives from the Saskatchewan Division of the CCS, SCA, Saskatchewan Network for Health Services in French, LWCC rural program leaders, the LWCC Provincial Program Coordinator and the manager of Chronic Disease Management with the Saskatoon Health Region. Study results were presented by this student researcher and the discussion was facilitated by research supervisor, Dr. Anne Leis. One goal of having a discussion with this group of individuals was to provide a forum for those attending to apprise others of current cancer survivorship programming they provide which may not have been mentioned in the research presentation. See Appendix 6 for the minutes of this discussion.

Resources, presentations, and programs available through the CCS were described by members from this agency. A representative from the SCA at this meeting of key stakeholders presented additional information regarding survivorship programming in Saskatchewan provided by the agency. The manager of Chronic Disease Management (CDM) for the Saskatoon Health

Region discussed a number of exercise programs that are offered in Saskatoon and in rural communities of the Saskatoon Health Region including Humboldt, Wakaw, Rosthern, and Wynyard.

The preliminary recommendation to broaden the awareness of LWCC among cancer care providers was discussed by this group of key stakeholders. Promoting this program through word-of-mouth or conversations between cancer care providers and cancer survivors may increase the number of cancer survivors participating in LWCC in rural Saskatchewan. Rural LWCC leaders agreed that cancer care practitioners would be an excellent source of referral to the program because their words of recommendation to clients or patients may have more weight than from a lay individual. These leaders felt that COPS staff should know or learn about the LWCC program as they provide cancer treatment in 16 rural Saskatchewan communities. During this discussion the provincial LWCC program coordinator reinforced that the program will continue to offer LWCC orientation for SCA and CCS staff and/or volunteers to further broaden the awareness of the program.

To fill the gap of missing cancer-specific information of the CDSMP it was recommended to refer rural cancer survivors on to the Saskatchewan CCS “The Transition from Treatment to Living Well” program. This recommendation and the idea of offering an additional 7th cancer specific session were explored in detail among key stakeholders. An arthritis-specific session has been developed by the Arthritis Society and has been used in a similar way as a disease-specific information session in addition to the LWCC program. Regional LWCC coordinators have organized this by keeping a list of people with arthritis who attend LWCC and are interested in this session. When enough people have been identified the LWCC coordinator then contacts the Arthritis Society and requests this arthritis-specific workshop be facilitated in their community. The CCS has 10 ‘units’ in Saskatchewan and they felt it would be sensible to provide the CCS units with individual’s names and contact information who were interested in participating in “The Transition from Treatment to Living Well” program. When 10 names have been collected for a region near one of these 10 units, the CCS would plan to hold a workshop there. There was agreement in the discussion that it would be helpful for LWCC leaders to be informed of this workshop available through the CCS in order for them to make appropriate

referrals and one way of achieving this may be for an individual from the CCS to present to leaders who are attending LWCC orientation sessions.

If LWCC leaders are successful in promoting this workshop to LWCC program participants who are cancer survivors, it is thought that more people participating in this workshop will have previously participated in LWCC. The members from the CCS acknowledged this and plan to review the workshop as it is currently designed and will tailor it to reduce overlapping information that a person may have already learned and covered by participating in LWCC.

At the conclusion of this discussion group participants planned to strengthen their inter-agency partnerships and to provide survivorship programming in rural communities by enhancing programming that is already in place but not widely accessed by rural survivors and limiting programming overlap between agencies.

The summary of the discussion consensus includes recommendations for adjustments to be made to the preliminary recommendations. Three broad recommendations made were to:

1. Continue to recommend the program to rural Saskatchewan cancer survivors.
2. Broaden the awareness of the program among cancer care providers since they are a trusted source of referral.
3. Target program promotion to cancer survivors who have recently finished acute cancer treatment.

Changes were made to the three specific recommendations only and it is now specifically recommended to:

1. Refer rural cancer survivors enrolled in LWCC to "The Transition from Treatment to Living Well" single-day workshop.
2. Tailor the "Transition from Treatment to Living Well" workshop to reduce overlapping material with LWCC.
3. Provide a cancer survivor specific book to cancer survivors participating in LWCC. "Life after Cancer" CCS book was recommended to be used for this purpose.

Including the knowledge users and decision makers throughout the research process was found to be essential to support strengthening a network within the community of health care providers to cancer survivors in Saskatchewan. The knowledge translation intervention was

successful in making a concise plan to move forward in health care programming with the aim of improving healthy living support for rural cancer survivors in the province.

CHAPTER 5: DISCUSSION

This chapter presents a summary of what is understood about the case by comparing and contrasting findings with previous knowledge and information gleaned from the literature (57). The scientific merit and limitations of this research are identified and suggestions for future research direction are proposed.

5.1 Summary

A person's life changes forever following a cancer diagnosis and the transition to a 'new normal' is a unique reality among cancer survivors. Chronic conditions commonly arise from cancer treatment, and many consider cancer as chronic for this reason. Rural support for Saskatchewan cancer survivors has been lacking. *LiveWell with Chronic Conditions*, a chronic disease self-management program run in many rural areas of Saskatchewan is uncommonly attended by cancer survivors. It is typically facilitated by two volunteers though due to limited numbers of volunteer leaders in rural Saskatchewan these programs are often facilitated by a health professional and a volunteer. The content of this program was found to be appropriate and applicable to cancer survivors however some cancer survivors may be interested in learning additional cancer specific information. This information could be provided by an additional session or by providing a cancer specific resource book for reference during the CDSMP sessions. Cancer survivors found this program had many benefits including providing a supportive atmosphere, improved self-efficacy, and managing emotional and physical issues resulting from their cancer including fatigue and pain. The content of this program was found to be most appropriate for managing the transition period to a 'new normal' rather than offering it to those newly diagnosed or in active acute cancer treatment. Cancer survivors felt comfortable participating in a group with others experiencing other chronic diseases although support of another person with cancer in the group would be appreciated. Cancer survivor participation in the program is low as no one had self-identified as a survivor and few were identified as a survivor by their leader. The reason cancer survivors have not been participating in LWCC remains unknown. Conversation and word of mouth, particularly in rural communities, appears to be a successful way to recruit participants to the program therefore individuals involved in cancer care (rural chemo nurses, oncologists, Peer Support, etc.) could discuss this program with

their clients in an attempt to increase program participation by cancer survivors in the future. Preliminary recommendations of program content, promotion, and recruitment were discussed among key stakeholders in rural cancer survivor care. They have been adapted to fit within the context of local programming and adopted by these organizations with the aim of responding to the health programming needs of rural Saskatchewan cancer survivors.

5.2 Values of Rural Cancer Survivors

Through this research project, it was learned that rural values and priorities with respect to health can differ quite significantly from the values and priorities of urban dwellers. In the literature, rural men have defined health as being able to work and to do what needs to be done and rural women have defined health as adapting and coping with whatever life brings (64). Rural people may more often tend to delay treatment. Perceiving that work is more important than health care, they tend to use health care more when there are lower demands on their time from seasonal work (65). This research provides support to these views by giving examples of situations where farming families do not have the opportunity to take time away from work when someone in the family has a cancer diagnosis. One story was shared of a farm woman who was a cancer survivor. She coped independently, as well as she could, with breast cancer-related lymphedema until an opportunity to access health care services presented itself at a time when she could get away from commitments on the farm. This story emphasized the fact that farming is a time sensitive livelihood and, in many cases, farming responsibilities may take precedence over caring for one's health.

Unique aspects of rural living may interact with the experiences of a cancer diagnosis, treatment and recovery (66). Research has indicated a need for improved rural survivorship care through focusing on interpersonal relationship problems, stigma associated with diagnosis, emotional challenges related to self-image and lack of adequate support from healthcare professionals (67). Factors of rural life can impact the cancer journey, resulting in rural cancer survivors experiencing poorer mental health outcomes than urban cancer survivors (66). Because of the intertwined nature of rural social networks and lack of anonymity, stigma may be a barrier to help-seeking for mental health concerns in rural communities (68,68) and could contribute to rural residents using fewer supports in this area than urban residents (66). Research

has reported greater anxiety, depressive symptoms, distress and emotional problems, poorer mental functioning and significantly lower life satisfaction among rural cancer survivors compared to urban cancer survivors (66).

Responses from interviews highlighted the fact that maintaining anonymity is difficult in a small town. A cancer diagnosis might be more difficult to discuss in rural areas due to social norms regarding disclosure of one's emotional or psychological problems to other individuals (66). Kenny et al demonstrated that rural cancer survivors were not as comfortable in expressing their psychological and social needs because they had a personal relationship with their health care provider (67). One interview respondent identified that individuals in rural communities take time for careful consideration before disclosing a disease diagnosis. Word travels fast in small towns and a person needs to be prepared for many people to find out about their disease diagnosis once it has been discussed outside of immediate family members. Cancer Connection (now recognized as Peer Support), a phone service offered by the Canadian Cancer Society (CCS), was greatly valued by rural Saskatchewan survivors. It was common for survivors to access Peer Support in rural Saskatchewan communities. Through Peer Support, rural cancer survivors were able to discuss their cancer diagnosis with CCS volunteers while maintaining confidentiality of their diagnosis until a time when they were ready for people in their town to know about it. This issue of maintaining anonymity in rural communities because of emotional energy required with disclosing a cancer diagnosis is important to reflect upon when implementing and planning for future rural health programs and support groups.

5.3 Rural Health Programming for Cancer Survivors

5.3a Self-management Program Delivery

Enhancement of LWCC program delivery was discussed to improve accessibility for rural residents. Novel ways of offering this program using modern technology were mentioned in several interviews. Telemedicine and e-Health are terms for the use of internet for providing medical care to patients. They have been described as the single most important way to equalize the differential in resource availability between rural and urban areas (65). Some researchers argue that for rural residents frequent and direct contact with health professionals may be undesirable and that health education to improve self-efficacy and informal health delivery may be more acceptable in rural communities (68). It is therefore suggested that one possible means

of delivering education and self-help skills to rural residents is over the internet (68). Making the program accessible electronically either via webinars or *Telehealth* was identified as a mode of program delivery that may be acceptable to maintain anonymity for those not wishing to disclose their disease diagnosis openly in their community and to decrease travel time to get to the program. *Telehealth* began in Saskatchewan in 1999 to help address the need for improved health services in rural and remote areas of the province and since then *Telehealth* has expanded its services to be present in 60 Saskatchewan communities (69). In Saskatchewan offering a health program using *Telehealth* technology can reduce travel distances however it does not eliminate the need to travel as *Telehealth* is not available in all rural communities, and anonymity is not able to be maintained. In comparison, an internet based program accessible from home would have the potential to eliminate need for travel and maintain participant anonymity. There were concerns expressed by several program leaders that attending the program in person would be ideal to have more personal interactions and they wondered if the program would be as effective if offered over *Telehealth* or the internet. A systematic review of 85 studies including a total of 43,236 participants looked at efficacy of internet based healthy lifestyle programs (70). Internet-based programs were shown to have a significant effect on health-related behaviour and the efficacy of the programs improved with use of theory and inclusion of behaviour change techniques (70). A randomized trial of an internet based CDSMP has indicated that it can significantly improve health status compared to the usual care group and would be a viable alternative (71). It is recognized that the internet would only be adopted as a part of usual health care if this venue improves self-management and enhances health outcomes (72).

Distance to health services has been shown to affect a cancer survivor's access to long-term follow-up care and rural dwellers are more frequently called on to be independent and self-reliant (64). There is also evidence that expressing negative feelings or thoughts is considered inappropriate within farming communities and that a person should seek to solve, rather than talk about, their problems (68). Providing self-management programming for rural cancer survivors may be one way to address this need of self-reliance and self-sufficiency and may provide methods for one to 'seek to solve' (68). Pan-Canadian practice guidelines of best practices for adult survivorship care and services have recently been created. These guidelines acknowledge

that within the cancer survivor population there is a need for access to self-management focused education and support to facilitate tailored adoption of healthy lifestyle behaviours including daily physical activity, balanced nutrition, and smoking cessation (29) . These programs should be designed to improve health related quality-of-life and physiological outcomes, reduce distress and risk of recurrence (29). This research provided examples of improved self-management skills gained by both leaders and participants. Participants indicated that they continue to reflect on things learned in the LWCC sessions and apply strategies to their everyday life. Examples include a survivor who learned to channel her thoughts in a more helpful way, and a leader and cancer survivor who continues to use deep breathing and guided imagery years after learning these skills from LWCC. Through application of these self-management skills, improved coping with chronic symptoms including pain and fatigue was achieved.

This case study and previous research has identified that providing internet-based education for cancer survivors in rural communities may improve program accessibility. It also appears important that online programming for cancer survivors should have a self-management component to it. With this information, online self-management programs were explored further. Stanford University has adopted the internet as an alternative venue for offering an online self-management program titled *Better Choices, Better Health*TM. Through discussions with the provincial LWCC coordinator, it has been identified that bringing *Better Choices, Better Health*TM to Saskatchewan is a very real option and planning is in place for this program to be available. During the creation of Stanford's online self-management programs randomized controlled trials were conducted in an attempt to learn if the sharing and support that is essential to the success of their community-based programs could be transferred to the online community (73). Nine hundred and fifty-eight people with chronic diseases were randomized into an internet intervention group or a usual care group. The intervention group had similar improvements in health status to the small CDSMP group (71). Results from Stanford's research also suggest that a combination of information and support largely offered through an internet discussion group improves health status and health care utilization for up to 1 year (74). Stanford has recently developed an online self-management program specifically for cancer survivors titled *Cancer: Thriving and Surviving Workshop*. This is an online workshop for adult cancer survivors led by cancer survivors. Clinical trials of this program are currently underway

(75). If results show effectiveness of this program, this may be a viable option for enhancing cancer survivorship care in rural Saskatchewan.

While there appear to be many benefits to implementing an online self-management program, it is important to consider that while these e-Health technologies have the potential to reduce disparities in rural health care, some groups who could benefit from e-Health initiatives including seniors and low income groups may be less likely to have access to such technologies (72).

5.3b Rural program marketing

Effective modes of program promotion in rural communities were explored. It was learned that in rural communities talking with community members is likely the most efficient and effective way to communicate information about health programming. An example of word-of-mouth program recruitment was given by an LWCC participant. She shared stories of going around her apartment building or the community senior's centre to recruit friends to come to the LWCC program with her, making LWCC more of a social outing than a health care appointment. Interestingly, the best program turnout was in those very small communities with a population of less than 2000 people. It was suggested that the smaller communities may bring stronger connections between all community members and more successful program promotion through word-of-mouth. Facilitating more word-of-mouth promotion could be an important way to reach and recruit cancer survivors to the LWCC program. This word-of-mouth promotion could be between the cancer care provider and the cancer survivor i.e. oncologists, oncology nurses, oncology social workers and dietitians, volunteers with Cancer Connection, and Healthline staff. As LWCC continues to work with the Saskatchewan health regions by orientating health professionals, including the above mentioned cancer care providers, to the program, the cancer health care system will become empowered to be able to offer survivorship care for rural cancer survivors through recommending the LWCC program.

5.4 LWCC as a rural survivorship program

In the pan-Canadian guideline of best practices for adult survivorship care and services it was identified that while ongoing high-quality research is needed to optimize services for cancer

survivors, interventions that promote healthy lifestyle behaviours or those that address psychosocial concerns or distress, appear to improve survivors' physical functioning, psychosocial well-being, and quality of life (29). It is also recommended that survivors have access to self-management focused education and support to facilitate tailored adoption of healthy lifestyle behaviours.

There are many important topics that need to be addressed in cancer survivorship interventions to improve outcomes and quality of life which begs the question: Does the CDSMP meet the needs of cancer survivors by addressing these issues that are so important to the cancer survivor population? The CDSMP had not been created specific to cancer survivorship and it was identified that there is content missing that cancer survivors are interested in, thus enhancement of the CDSMP program content appears important to better meet the needs of cancer survivors. Fear of cancer recurrence, managing lymphedema, and sexuality were identified as key topics missing from LWCC that are of interest to cancer survivors. This information may be able to be provided by the addition of a seventh session for cancer survivors to attend after they have completed the LWCC program.

Many of the results found in this study have echoed results found by Beckmann et al who conducted a similar pilot study in an urban Australian setting where 29 cancer survivors who participated in the CDSMP program were interviewed (11). They found that cancer survivor participants felt that the CDSMP could be improved by providing more detail in relation to cancer-specific topics including dietary advice, complementary therapies, dealing with mortality, and depression (11). Following the Australian pilot study, the Cancer Council South Australia (CCSA) offered a chronic disease self-management program specifically targeted toward people affected by cancer by incorporating the original six-week CDSMP course structure developed by Stanford and following it with an additional module focused on cancer specific issues (11). They named this program "Staying Healthy after Cancer". The coordinator of this program was contacted and their experiences with facilitating this additional session were discussed. The CCSA received feedback from their peer leaders and these leaders felt that leaving the cancer session until the 7th session was a heavy topic to finish on, whereas the final Stanford session is lighter and more of a celebration. They now run the program by providing the first three sessions of the Stanford program, then the cancer specific session, then the final three Stanford

sessions. The information provided in the cancer specific session includes terminology around cancer, risk factors, and the shared experience of survivorship. This program is only available in an urban setting, and so the CCSA are looking into options for providing a similar online program.

A single-day workshop titled “The Transition from Treatment to Living Well” focused on survivorship issues has been created and is available to cancer survivors in Saskatchewan addressing topics of managing change and transition, phases of recovery, relationships, recovering a sense of control, energy builders and energy drains, envisioning wellness, creating a personalized healing plan, and defining a new normal. Through discussions with one of the facilitators of this program with the Saskatchewan division of the CCS, it was identified that the program can be made available to some rural communities in Saskatchewan. Key stakeholders in cancer survivorship programming may wish to pursue using this program as an additional session to enhance the LWCC and address important issues identified by rural cancer survivors. This would require continued cooperation and partnership building between these two agencies in order to provide rural cancer survivors with continuity of care. Interviews also revealed that seeing the word ‘cancer’ in the *Living a Healthy Life* book would have been appreciated as it would make the program seem more inclusive of cancer. Through the literature review process and qualitative interviews it has been brought to the researcher’s attention that the Stanford University online cancer module *Cancer: Surviving and Thriving* may include a cancer-specific reference book. Saskatchewan program providers may also find the inclusion of this book in current LWCC programming can address this need of more cancer-specific information.

As cancer patients go through treatment, they are often overwhelmed by the demands of treatment and put many other things on hold. The end of acute treatment may trigger different worries. Relationships with family, intimate partners, friends, and co-workers may change following cancer treatment. These factors can make it even more challenging for survivors to cope (76). Literature indicates that cancer survivors do benefit from ongoing post-treatment survivorship interventions designed to improve survivor outcomes (29). The pan-Canadian practice guideline of best practices for adult survivorship care and services recommends that survivors should have access to coordinated interdisciplinary, multicomponent psychosocial and supportive care services during the transition from active treatment to extended survival (29).

Research has evaluated when the appropriate timing would be to provide the CDSMP as a cancer survivorship program. It indicated that the CDSMP is less beneficial to those who are still in acute cancer treatment compared to those who are beginning to 'move on' in this transition from active treatment to extended survival. These researchers suggest that soon after finishing acute treatment would be the preferred time to attend the program (11). The LWCC case study research responses were very similar as many expressed this same opinion. Interview participants described the transitional period as a difficult time and that transition support has been lacking in rural Saskatchewan, therefore following acute cancer treatment would be the preferred time to attend the LWCC program.

The CCS Ontario Division provides the CDSMP for cancer survivors specifically, and has developed registration criteria for their program. This group also found that the transition period following acute cancer treatment would be the most appropriate time to deliver the program. Their criteria are outlined as follows: cancer survivors that attend must be adults >18 years of age who are survivors of cancer or have cared for a loved one with cancer. The experience is post-treatment but the survivor may be on maintenance chemotherapy and/or hormonal treatment. They commit to attending the full 6 week program. The survivor must not be palliative. The CCS Ontario Division found that when people who have end-stage cancer participated, it altered the expectations of their peer leaders, the dynamic of working through the processes, and that it put a focus on those end-stage people.

Beckmann et al compared two variations of the CDSMP. One group was comprised of only cancer survivors and one group had cancer survivors mixed in with other chronic diseases. They found that offering a cancer-specific CDSMP would be the model of choice because the cancer survivors appreciated having a shared experience (11). A cancer survivor in the LWCC research study expressed that they would have this same appreciation if there was at least one other cancer survivor participating in their program. In theory a cancer-specific CDSMP program in rural Saskatchewan would also be ideal but the reality is that even with all chronic conditions combined, the LWCC program struggles to recruit enough program participants and volunteers to run the program in many rural communities. It does not seem likely that a cancer-specific CDSMP program would be sustainable in rural Saskatchewan and that a program

encompassing all chronic conditions including cancer would be the best option for providing support to rural cancer survivors.

Although the literature has indicated that cancer is more commonly considered a chronic condition (17,19) and interview participants in this study acknowledged cancer to be a chronic condition, they also suggested that perhaps other cancer survivors do not consider it as such. When planning a health program inclusive of all chronic health conditions in rural Saskatchewan titled “*LiveWell with Chronic Conditions*” it will be important to learn more around how cancer survivors perceive their illness. Do cancer survivors perceive their illness to be chronic? Do cancer survivors perceive a program for all chronic conditions as something applicable to them? Gaining further understanding of how cancer survivors perceive their illness is important because this can be a determinant of health-related quality of life (77). The Brief Illness Perception Questionnaire was recently completed by 3080 cancer survivors (77). This questionnaire was based on the self-regulation model which assumes that patients respond to symptoms of illness by forming cognitive and emotional representations of the illness. A few dimensions of these representations include the anticipated and experienced consequences of the illness on the patient’s life, the perceived duration of the illness and the perception of having self-control (77). Empowerment of patients by teaching them adequate coping skills and self-management training will translate into illness perceptions reflecting greater sense of control (77) therefore a self-management program such as CDSMP could be appropriate. However Husson et al’s study indicated that receipt of information about other services was associated with worse consequences and symptoms of the illness, more concerns, and higher emotional impact. These negative conceptualizations of the illness can lead to maladaptive responses to the illness. These maladaptive responses and perceptions could be changed by giving information meeting patient’s needs in combination with individualized behavioural intervention (77) . These researchers encourage health care providers to move from a generic method of information provision to an approach that considers the unique information needs of cancer survivors (77). This case study has shown that cancer-specific information is desired by LWCC participants. The basic information provided in a standard chronic disease self-management program does not meet the disease-specific information needs of cancer survivors, and the research by Husson et al

gives further evidence of the importance to finding ways of providing this patient-centered disease-specific information.

5.5 Sharing Results with Stakeholders

A randomized controlled trial has evaluated the effectiveness of three knowledge translation and exchange strategies in the incorporation of research evidence into public health programs (78). The results support the hypothesis that tailored, targeted messages can be part of an effective strategy for facilitating evidence-informed decision making (78). The results also demonstrate involvement of a decision-maker working in an organization supportive of evidence-informed decision making (such as a health region) leads to outcomes in the hypothesized direction (78). As outlined in Figure 2, these knowledge-users and decision-makers were involved at the very start of this study. It was hoped that their involvement would result in achieving the greatest impact (50) and to achieve the goal set out of conducting research that contributes applicable information for health care programming in Saskatchewan.

As a practicing dietitian both in community and clinical settings, I have attended many presentations of research results. Presentations of research are interesting; however it is the presentations that come with a tailored, targeted message or those that provide guidance for implementing the evidence into practice that are the most practical. This method of knowledge dissemination has proven effective in my practice as a dietitian and has been the life experience which directed the selection of the knowledge translation intervention in this study. The tailored, targeted messages provided in the presentation of this research were in the form of preliminary recommendations and were presented at a meeting of key stakeholders. Agencies and organizations were able to adapt them as a consensus into recommendations that made sense within the rural Saskatchewan context and the current situations within their organizations.

Informal, unplanned knowledge translation also took place over the course of this study. The act of completing a study in the area of rural cancer survivorship programming contributed to a conversation about the topic between several organizations that had not yet happened or only just begun at the start of this research. The conversation between the Saskatchewan Cancer Agency and the LWCC program was initiated and strategies were implemented to promote this program to rural cancer survivors. As the study proceeded the partnership grew, and continues

to develop beyond this study. Impacts of this discussion and partnership building have been seen by an increased awareness of LWCC among SCA care providers, and an increased number of referrals from the SCA to the LWCC program.

The LWCC and CCS had started to connect prior to this study with the idea to build a partnership for resource sharing between the two agencies. Following the knowledge translation intervention in this study the three specific recommendations were adapted. All three of these specific recommendations involve the LWCC and CCS agencies working together to enhance health care for cancer survivors living in rural Saskatchewan, therefore the knowledge translation activities have a large impact on programming by both LWCC and the CCS.

As described in section 3.5, steps of the knowledge-translation cycle were not completed during the course of this case study research. These steps include monitoring, evaluating, and sustaining knowledge use. Health promotion research has demonstrated that increased connections with community groups and partners are essential to sustainability (79). Several factors including community links or networks, leadership, and knowledge integration need to be considered when developing plan for sustainability (80). Although it is not known if the knowledge-use will be continued following this study, these factors were addressed in an effort to support this. Agencies that needed to be engaged were identified and these groups had the opportunity to network at the meeting of key stakeholders. Actions that leaders and program managers needed to take to sustain knowledge-use were discussed among this group and agencies had the opportunity to talk about how recommendations may be integrated into current health programming available in rural Saskatchewan (80). A forum for this group of key stakeholders to meet and discuss programming on a regular basis could be planned to support sustainability of knowledge use and maintain inter-agency partnerships.

Following implementation of these recommendations it will be important for the LWCC program, CCS, SCA and others involved to evaluate if recommendations made and implemented have in fact made a difference in reaching and responding to the needs of cancer survivors living in rural communities. This evaluation should aim to connect with more cancer survivors than this study was able to do in order to truly understand the issue from their perspectives.

The goal to conduct research which contributes new information to the knowledge base has been met through this knowledge translation process.

5.6 Strengths

Qualitative inquiry is subjective, interpretive, and time and context bound, subsequently researchers have argued that reliability and validity are terms that belong to the positivist paradigm and qualitative researchers should use different terms (81). *Consistency* and *dependability* are terms that would perhaps more appropriately apply to reliability in qualitative research (81). To ensure consistency of results, I documented as many steps as possible of the procedures of this case study. Transcripts were also checked to make sure that they do not contain obvious mistakes made during their transcription (54). Qualitative validity is based on determining whether findings are accurate from the standpoint of the researcher, the participant, or the readers of an account. *Trustworthiness*, *authenticity*, and *credibility* are terms that may be used to describe validity in qualitative research (54). Several strategies were employed to ensure validity in this research. Rich, thick description was used to convey the findings, particularly in the presentation of the cancer survivor's story which was written in an attempt to transport the readers to the setting and share in the cancer survivor's experience (54). The bias that was brought to the study by this researcher was clarified by presenting the researcher's journey in the results section. The 'researcher's journey' is a disclosure of my background and explains how that shaped my interpretation of qualitative findings. Peer debriefing was used to enhance accuracy of the account (54). The research supervisor reviewed and asked questions about the findings. The strategy of peer debriefing allows the account to resonate with people other than the researcher (54).

5.7 Limitations

Some limitations in this study have been identified. The limitation of participant sampling had major implications on this research study. Purposeful sampling of cancer survivors who were actively participating in rural LWCC programs and their program leaders was initially planned. It was determined that this group of individuals would provide data to best answer the research questions at hand. A very limited number of cancer survivors participated in LWCC during the study period and so purposeful sampling was then directed towards cancer survivors who had participated in the program in the past, and program leaders who are cancer survivors themselves. By interviewing program leaders who were cancer survivors I was able to obtain a unique perspective of the case and because they had such a unique situation of being a health

care professional in a rural community the question of if the program meets a rural cancer survivor's needs could not be answered solely from this data. Interviews with cancer survivors who had participated in the past provided interesting data but their recollection of the program itself may not be as clear or precise as it would have been had the interview been conducted immediately following their completion of the LWCC program.

The participant sample of this research was all female and consequently results are solely from the female perspective. I was thus unable to explore the experience and perspectives of male cancer survivors and their participation in LWCC.

Another limitation identified was the interview setting. All interviews were conducted over the telephone and all discussions were held over speaker phone. I found this setting more challenging to develop a rapport with interview participants, especially those that I had never previously met in person. Interview participants may not have found this interview setting to be a warm, welcoming one and may not have felt comfortable to discuss topics in great detail. I had met several program leaders prior to conducting this research and had already established rapport with them. It was noted that the interviews with these people were more relaxed and topics were delved into on a deeper level. Results are more heavily weighted on data from the interview responses where I had a prior relationship and rapport with the interview participant.

The quality of qualitative research is dependent on the researcher's experience and skills. My experience with conducting research prior to starting this graduate research was limited.

Although quantitative data collected is not statistically significant to the findings of this research, limitations of the data collection tool should be noted. Portions of the questionnaire had previously been validated but the questionnaire as a whole had not.

5.8 Methodology Revisited

For this research, a mixed methods case study methodology was proposed to explore the research objectives at hand. Qualitative data through semi-structured interviews was collected to explore from their perspectives how the program could be enhanced in terms of content, format, delivery and marketing strategy and to gain understanding around how this program meets the needs of rural cancer survivors. A quantitative data collection tool was developed to be able to further describe how the LWCC program responds to the needs of rural cancer survivors as well

as demographic information of the rural cancer survivors that were using the LWCC program during the study period. Due to the participant demographic information, changes to participant sampling, and lack of quantitative results, this study shifted from an originally planned mixed methods case study to solely qualitative case study. Results from quantitative questionnaires were only presented in a descriptive fashion. The four questionnaires collected were then reconsidered as an alternate source of information or document which contributed to the qualitative case study. This information was used to illustrate a cancer survivor's experience with LWCC and provided some demographic information. Thus, through the process of this research the methodology changed from a mixed methods case study to a qualitative case study.

Upon reflection about the research design and knowledge translation activities, additional strategies might have added strength to both the research design and knowledge translation. Energy was directed towards including decision makers and knowledge users which enhanced knowledge uptake by health care providers; however the missing element in the research process was involvement of the cancer survivors themselves. More participation of the users' group in this study may have given more insight with regards to recruitment difficulties and may have been able to suggest further avenues for knowledge dissemination and translation.

5.9 Future Research

New research questions that need to be asked, raised by data collection and analysis that were not foreseen earlier in the study have been identified (54). Research is required to better ascertain why rural cancer survivors have not been participating in LWCC sessions. Is it because the program hadn't been actively promoted to cancer survivors until fall of 2010 and is still in the initial phases of doing so? Is it because many cancer survivors do not feel a program for people with chronic conditions is appropriate or applicable to them? Moreover this case study research did not have the opportunity to explore the male cancer survivor's perspective on the LWCC program. This is an important group of the rural cancer survivor population and their needs for support should be explored. As online programming is becoming more readily available through Stanford University and through Saskatchewan health regions, a comparison should be made between the *in-person* versus *online* versions of the LWCC program in terms of

fit for rural cancer survivors. Results from this research and previous research show promise that this program does in fact meet the needs of cancer survivors but more rural cancer survivors would need to be participating in LWCC before this question can be sufficiently answered.

CHAPTER 6: CONCLUSIONS

Cancer and treatments for cancer cause physical and emotional changes that may persist through the rest of one's life. Once acute cancer treatments have been completed, cancer survivors in Saskatchewan have reported feeling disconnected and unable to find adequate support and resources (4). The purpose of this study was to determine how the existing LWCC program reaches and responds to these needs of rural Saskatchewan cancer survivors. Cancer survivors interviewed in this study reinforced that this transition period of adapting to a 'new normal' is a time when support is essential. Very few rural Saskatchewan cancer survivors have been accessing LWCC as a healthy lifestyle program likely for the reasons that prior to this study the program had not been strongly marketed to this group, and some cancer survivors may not identify that a program addressing chronic conditions applies to their health situation. Cancer survivors interviewed in this study found LWCC had many benefits including providing a supportive atmosphere, improved self-efficacy, and managing emotional and physical issues from their cancer including fatigue and pain. This study identified program value within the cancer survivor population and hence this program will continue to be promoted to rural Saskatchewan cancer survivors.

It was beneficial to involve cancer care key stakeholders in all stages of this study. These decision-makers helped to guide the objectives and direction of this study facilitating research which produced knowledge that can directly apply to current programming in the province. Results informed recommendations for future rural cancer survivor care.

Cancer survivors found the LWCC program content to be most appropriate for those who have completed acute cancer treatment and are wishing to manage lasting treatment side effects and prevent cancer recurrence. LWCC may assist cancer survivors to navigate through this transition period and program promotion should target this demographic. Cancer survivors felt comfortable participating in a group among other chronic diseases although support of another person with cancer in the group would be appreciated. Personal referrals and word of mouth, particularly in rural communities, are effective ways to recruit participants to the LWCC program. It was recommended to broaden the awareness of LWCC among cancer care providers

who could then discuss this program with their clients in attempt to increase program participation in the future. Following discussions with cancer care providers of Saskatchewan, the LWCC program continues to provide orientation to CCS staff and volunteers, COPS staff, and continue to educate supportive care staff at the SCA in order to pursue this recommendation. Cancer-specific topics including dealing with the arm at risk with lymphedema, sexuality, dealing with the fear of cancer recurrence and other emotional concerns of cancer are topics important to cancer survivors and are missing from the LWCC program. Cancer survivors participating in LWCC can be referred to the “Transition from Treatment to Living Well” program offered through the CCS to gain cancer-specific information needed. Through continued cooperation from these key stakeholders, cancer survivors living in rural areas of Saskatchewan will have improved knowledge of and access to support for making healthy lifestyle choices and achieving a better quality of life. These inter-agency partnerships which have formed require input and support from all involved in order to sustain this positive movement towards healthy lifestyle programming for this population.

This thesis contributes to the understanding that LWCC (the CDSMP) is relevant to people affected by cancer and could potentially help fill the void that exists for many cancer survivors after leaving the acute care setting (11). It provides new knowledge to the literature applying the CDSMP to rurally located cancer survivors, demonstrating promise that it may be a useful and effective program for individuals of this specific population looking to make healthy lifestyle changes.

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Appendix 1

LiveWell with Chronic Conditions Evaluation: A questionnaire for rural cancer survivors

We would like to know how the *LiveWell with Chronic Conditions* program meets the needs of rural cancer survivors who are looking to make healthy lifestyle changes. This questionnaire includes questions about your overall health, your cancer experience, and asks for your thoughts about the *LiveWell with Chronic Conditions* program.

This questionnaire will take about 10 minutes to complete. To ensure your privacy please complete this questionnaire on your own. Remember that we will keep all your answers private. No details about you as an individual will be released to anyone. When you have finished please return it in the stamped, self-addressed envelope to the research team.

This study has been reviewed and received ethics clearance by the Research Ethics Board at the University of Saskatchewan. If you would like more information about this questionnaire or research project please feel free to contact the individuals listed below.

Thank you for taking the time to complete this questionnaire;
your information and thoughts are very much appreciated.

Heather Millar
Graduate Research Student
University of Saskatchewan
Haw205@mail.usask.ca
(306)655-6453

Anne Leis, PhD
Research Supervisor
University of Saskatchewan
Anne.Leis@usask.ca
(306)966-7878

Section 1: About *LiveWell with Chronic Conditions*

Please **place a check** beside the answer that best describes your response.

1. **How did you find out about the *LiveWell with Chronic Conditions* program?** (Please check **all** that apply)

Friend or family member

Physician

Saskatchewan Cancer Agency

Canadian Cancer Society

Someone who has attended the program in the past

Other health professional (dietitian, exercise therapist, physical therapist, etc.)

Promotional Material (brochure, poster, etc.)

Other (please specify) _____

2. **Would you recommend the *LiveWell with Chronic Conditions* program to other cancer survivors living in a rural community?**

Yes No

3. **How much of the information provided in the *LiveWell with Chronic Conditions* program did you feel was applicable to your current health situation?**

Not much

Some

Quite a bit

Most

All

4. **What information was not provided at *LiveWell with Chronic Conditions* that would be of interest and applicable to your current health situation?** (Please provide suggestions)

5. **How many of the *LiveWell with Chronic Conditions* sessions were you able to attend?** _____

6. Please check the box that best represents your response to these statements:

The *LiveWell with Chronic Conditions* program has provided the information and/or skills I need to...

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Make healthy food choices.					
Improve my physical activity level.					
Achieve or maintain a healthy body weight.					

The *LiveWell with Chronic Conditions* program has given me adequate support...

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
For finding meaning or a new purpose in life.					
To create a plan to move forward.					

By participating in the *LiveWell with Chronic Conditions* program, I feel better able to.....

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Deal with feeling stressed.					
Deal with feeling tired.					
Deal with feeling worried (anxious).					
Cope with bad memory, lack of focus.					
Deal with fears about cancer spreading.					
Deal with not feeling sure that the cancer has gone.					
Deal with worry about whether the treatment has worked.					

Cope with being told I have cancer.					
Find information about complementary and alternative therapies.					
Find what type of financial assistance is available and how to obtain it.					
Deal with people who expect me to be 'back to normal'					
Deal with not being able to feel 'normal'					

These questions are about how you feel and how things have been with you **during the past month**. For each question, please circle the **one** number that comes closest to the way you have been feeling.

How much time during the past month...	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
7. were you discouraged by your health problems?	0	1	2	3	4	5
8. were you fearful about your future health?	0	1	2	3	4	5
9. was your health a worry in your life?	0	1	2	3	4	5
10. were you frustrated by your health problems?	0	1	2	3	4	5

For each of the following questions, please **circle** the number which corresponds to your **confidence** that you can do the tasks regularly at the present time.

11. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

12. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

13. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

14. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

15. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

16. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

(Not at all) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (Totally)

When you are feeling down in the dumps, feeling pain, or having other unpleasant symptoms, how often do you do the following? (please **circle** one number for each question)

	Never	Almost Never	Sometimes	Fairly Often	Very Often	Always
17. Try to feel distant from the discomfort and pretend that it is not part of your body?	0	1	2	3	4	5
18. Don't think of it as discomfort but as some other sensation, like a warm, numb feeling?	0	1	2	3	4	5
19. Play mental games or sing songs to keep your mind off of the discomfort?	0	1	2	3	4	5
20. Practice progressive muscle relaxation?	0	1	2	3	4	5
21. Practice visualization or guided imagery, such as picturing yourself somewhere else?	0	1	2	3	4	5
22. Talk to yourself in a positive way.	0	1	2	3	4	5

9. Which of these best describes where you are now in your cancer journey?

(Please check the **ONE answer** that most closely describes where you are in the cancer journey)

- Now having treatment
- Now having follow-ups
- Follow-up visits have ended
- Am now cancer free
- Am dealing with the return of cancer or second cancer
- Palliative Care (end-of-life care)
- Other (please specify) _____

10. How long does or did it take you to travel to the nearest cancer centre, clinic or hospital where you received cancer treatment?

- Less than 30 minutes
- 30 minutes to 1 hour
- More than 1 hour but less than 2
- 2 hours or more but less than 4
- 4 hours or more
- Other (please specify): _____

11. Where do you usually go when you are sick or need advice about your health (other than cancer related issues)? (Please check only **ONE answer**)

- Family Doctor's Office
- Specialist Doctor's Office
- Other health professional's office
- Community Health Centre
- Walk-in clinic
- Appointment clinic
- Healthline
- Hospital Emergency Room
- Hospital Outpatient Clinic
- Other (please specify): _____



CONSENT FORM CONSENT FORM Program Participants

You are invited to participate in a research project entitled *Responding to the needs of rural cancer survivors: learning to LiveWell*. Please read this form carefully, and feel free to ask any questions you might have.

Researcher(s):

Heather Millar, Graduate Student, Department of Community Health and Epidemiology in College of Medicine, University of Saskatchewan, (306) 374-0562, haw205@mail.usask.ca

Dr. Anne Leis, Research Supervisor, Department of Community Health and Epidemiology in College of Medicine, University of Saskatchewan, (306) 955-7878, Anne.Leis@usask.ca

Purpose and Procedure:

The purpose of this research is to determine how 'LiveWell with Chronic Conditions' can reach and respond to the needs of rural cancer survivors in Saskatchewan. We are asking you to participate in a one on one interview. The interview will be done in a location of your choosing. The interview will take approximately 30-60 minutes. The interviewer will ask you questions about your experience as a participant of the LiveWell program, and your thoughts of the future use of this program among rural cancer survivors in Saskatchewan. The interviewer will take notes during the interview, and will use an audio-taping device. The findings from this research will be presented by the research student to a group of key stakeholders with respect to cancer survivorship programming in Saskatchewan. Results will be documented in a research thesis as well as in a journal article to be submitted for publishing in an appropriate journal selected by the research team.

Potential Benefits:

There are no anticipated direct benefits to you from participating in this study but your answers will help us to make recommendations for future cancer survivorship health programming. These benefits are not guaranteed.

Potential Risks:

There are no known risks to participating in this one-time interview.

Storage of Data:

Data collected in this study will be in the form of tapes from in-person interviews, interview notes, and interview transcripts. The researcher will know the identity of the participants while conducting the interviews. When data is entered into the database it will be coded with unique identifiers. The person who will be assuming responsibility for data storage is

the research supervisor, Dr. Anne Leis. Data will be securely stored at the University of Saskatchewan for a minimum of five years upon the completion of this study. When the data is no longer needed it will be appropriately destroyed.

Confidentiality:

At all times, your participation in this study will only be known to the student researcher and research supervisor. The data from this research will be published and presented to a group of key stakeholders; however, your identity will be kept confidential. Although we will report direct quotations from the interview, you will be given a pseudonym, and identifying information including your name and the rural community in which you live will be removed from the report.

Would you like the opportunity to review transcripts and quotations taken from your interview?:

YES NO

The information that is shared will be held in strict confidence and discussed only with the research team

Right to Withdraw:

Your participation is voluntary, and you may answer only those questions involved in the interview that you are comfortable with. You have the right to request audio-recording equipment be turned off or not to be used at all. After the interview is complete, you may withdraw your responses at any time up until April 30, 2011 when data collection will be finalized. There is no guarantee that you will personally benefit from your involvement. You will be informed of any new information that may affect your decision to participate. You may withdraw from the research project for any reason, at any time, without penalty of any sort and the decision to withdraw will not affect your future medical care. If you withdraw from the research project, any data that you have contributed will be destroyed at your request.

Questions:

If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided below if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on December 14th, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Follow-Up:

You may contact either member of the research team at any time to discuss this research project and learn of the research results.

Consent to Participate- Providing Written Consent:

I have read and understood the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)

CONSENT FORM

CONSENT FORM Program Leaders

You are invited to participate in a research project entitled *Responding to the needs of rural cancer survivors: learning to LiveWell*. Please read this form carefully, and feel free to ask any questions you might have.

Researcher(s):

Heather Millar, Graduate Student, Department of Community Health and Epidemiology in College of Medicine, University of Saskatchewan, (306) 374-0562, haw205@mail.usask.ca

Dr. Anne Leis, Research Supervisor, Department of Community Health and Epidemiology in College of Medicine, University of Saskatchewan, (306) 955-7878, Anne.Leis@usask.ca

Purpose and Procedure:

The purpose of this research is to determine how 'LiveWell with Chronic Conditions' can reach and respond to the needs of rural cancer survivors in Saskatchewan. We are asking you to participate in a one on one interview. The interview will be done in a location of your choosing. The interview will take approximately 30-60 minutes. The interviewer will ask you questions about your experience as a leader of the LiveWell program, and your thoughts of the future use of this program among rural cancer survivors in Saskatchewan. The interviewer will take notes during the interview, and will use an audio-taping device. The findings from this research will be presented by the research student to a group of key stakeholders with respect to cancer survivorship programming in Saskatchewan. Results will be documented in a research thesis as well as in a journal article to be submitted for publishing in an appropriate journal selected by the research team.

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There are no anticipated direct benefits to you from participating in this study but your answers will help us to make recommendations for future cancer survivorship health programming. These benefits are not guaranteed.

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Storage of Data:

Data collected in this study will be in the form of tapes from in-person interviews, interview notes, and interview transcripts. The researcher will know the identity of the participants while conducting the interviews. When data is entered into the database it will be coded with unique identifiers. The person who will be assuming responsibility for data storage is the research supervisor, Dr. Anne Leis. Data will be securely stored at the University of

Saskatchewan for a minimum of five years upon the completion of this study. When the data is no longer needed it will be appropriately destroyed.

Confidentiality:

At all times, your participation in this study will only be known to the student researcher and research supervisor. The data from this research will be published and presented to a group of key stakeholders; however, your identity will be kept confidential. Although we will report direct quotations from the interview, you will be given a pseudonym, and identifying information including your name and the rural community in which you live will be removed from the report.

Would you like the opportunity to review transcripts and quotations taken from your interview?:

YES NO

The information that is shared will be held in strict confidence and discussed only with the research team

Right to Withdraw:

Your participation is voluntary, and you may answer only those questions involved in the interview that you are comfortable with. You have the right to request audio-recording equipment be turned off or not to be used at all. After the interview is complete, you may withdraw your responses at any time up until April 30, 2011 when data collection will be finalized. There is no guarantee that you will personally benefit from your involvement. You will be informed of any new information that may affect your decision to participate. You may withdraw from the research project for any reason, at any time, without penalty of any sort and the decision to withdraw will not affect your future medical care or your position as a program leader. If you withdraw from the research project, any data that you have contributed will be destroyed at your request.

Questions:

If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided below if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on December 14, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Follow-Up:

You may contact either member of the research team at any time to discuss this research project and learn of the research results.

Consent to Participate:

Providing Written Consent:

I have read and understood the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)

Appendix 3

Interview Guide: LiveWell with Chronic Conditions Program Leader

Time/Date:

Place of Interview:

Name of Interviewer:

Name of interviewee:

Do you view cancer as a chronic health condition? (Please explain)

What is your overall impression of LiveWell with Chronic Conditions as a program for cancer survivors?

In previous LiveWell with Chronic Conditions programs that you've facilitated, approximately how many cancer survivors have attended your sessions?

Do you have suggestions of different ways to format or deliver this program for rural cancer survivors?

Do you feel you need other resources or material available to offer cancer survivors who are participating in your program? What would these be?

Do you feel you need additional training to be a LiveWell with Chronic Conditions program leader for a group of cancer survivors?

If so, what do you think this training should include?

What strategies would you recommend using for promoting this program to rural cancer survivors?

Do you have anything to add?

Interview Guide: LiveWell with Chronic Conditions Program Participants

Time/Date:

Place of interview:

Name of Interviewer:

Name of Interviewee:

Do you view cancer as a chronic health condition? (Please explain)

What was your overall impression of LiveWell with Chronic Conditions as a program for cancer survivors?

Do you feel this program meets your needs as a rural cancer survivor? Why or why not?

What parts of the program did you feel were most applicable to you?

Has the program helped you to manage your health concerns related to your cancer? (please explain)

What did you get out of the course that you have not been able to get elsewhere?

How could the program be improved? (discuss improvement suggestions for format and delivery)

Did you feel there was content missing from the program? If so, what would be your suggestions for additions in the future?

How did you find out about the program?

Would you recommend any marketing or promotional strategies to better reach rural cancer survivors?

Do you have anything to add



INVITATION

As someone who is involved in the health of cancer survivors, you are invited to take part in a meeting designed to hear the results of a research study entitled *Responding to the needs of rural cancer Survivors: Learning to LiveWell*. The objectives of this meeting are to discuss the findings and implications derived from that study while keeping in mind programs and resources for cancer survivors that are currently available in Saskatchewan.

This meeting will be held on Wednesday October 26th, 2011 from 3:00pm-4:45pm at the Royal University Hospital in Saskatoon in Admin Room 6625. It will also be offered over Telehealth for those who live outside of Saskatoon. The telehealth suite at your site would need to be booked for this time. If telehealth is not available you are welcome to join in through the telephone

Heather Millar, a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan has recently completed her Master's research study. Heather partnered with the *LiveWell with Chronic Conditions* provincial program to determine whether this program meets the needs of rural cancer survivors. Heather also explored ways in which this program could be enhanced in terms of format, delivery, and content.

Proposed Agenda

3:00 pm	Roundtable for introductions and brief description of attendees' involvement with rural cancer survivors
3:15 pm	Research Presentation
3:45 pm	Facilitated discussion
4:30 pm	Wrap up and next steps

Please confirm your participation by e-mailing heather.millar@saskatoonhealthregion.ca or by calling Dr. Anne Leis at (306)9667878 by October 24th, 2011.

Sincerely,

Anne Leis, PhD
Professor and Dr. Louis Schulman Research Chair
College of Medicine

Darla Walz, BSW
Provincial Program Coordinator
LiveWell with Chronic Conditions

Appendix 5



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Anne Leis

DEPARTMENT
Community Health and Epidemiology

BEH#
10-296

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
University of Saskatchewan

STUDENT RESEARCHERS
Heather Millar

SPONSOR
UNFUNDED

TITLE
Responding to the Needs of Rural Cancer Survivors: Learning to LiveWell

ORIGINAL REVIEW DATE
05-Nov-2010

APPROVAL ON
14-Dec-2010

APPROVAL OF
Ethics Application
Consent Protocol

EXPIRY DATE
14-Dec-2011

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

Expedited Review:

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/



John Rigby, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8



**UNIVERSITY OF
SASKATCHEWAN**

**Associate Vice-President Research – Health
(University of Saskatchewan)
Vice-President Research and Innovation
(Saskatoon Health Region)
Room 247-111 Research Drive
Atrium Building, Innovation Place
Saskatoon, SK S7N 3R2
Phone: (306) 966-8745**

DATE: January 4, 2011

TO: **Dr. Anne Leis**
Dept. of Community Health & Epidemiology
University of Saskatchewan

FROM: Martha E. (Beth) Horsburgh
Associate Vice-President Research – Health (University of Saskatchewan)/
Vice-President Research & Innovation (Saskatoon Health Region)

RE: **RESEARCH ETHICS BOARD (REB) #: B2010-296**
PROJECT NAME: Responding to the Needs of Rural Cancer Survivors: Learning to LiveWell
PROTOCOL #: N/A

Saskatoon Health Region is pleased to provide you with operational approval of the above-mentioned research project.

Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 655-1442 or email shawna.weeks@saskatoonhealthregion.ca



Martha E. (Beth) Horsburgh, RN, Ph.D
Associate Vice-President Research – Health (University of Saskatchewan)/
Vice-President Research & Innovation (Saskatoon Health Region)

cc: Leslie Worth, Manager, Chronic Disease Management

Catalyzing Health Research and Innovation Together

Appendix 6

Research Presentation and Discussion- Meeting Minutes

October 26th, 2011

3:00pm-4:45pm

RUH, Telehealth, Teleconference

In Attendance:

Name	Position/Organization	Location	Way of Attending
Kellie Heidel	LWCC Regional Coordinator	Prairie North Health Region	Telehealth (video)
Jodi Tweed	LWCC Regional Coordinator	Sun Country Health Region	Telehealth (video)
Jenn Brown	RD, LWCC Facilitator	PA Parkland Health Region	Telehealth (video)
Leslie Quedell	RD, LWCC Facilitator	PA Parkland Health Region	Telehealth (video)
Sylvia Martin	LWCC Regional Coordinator	Athabasca Health Region	Telehealth (phone-in)
Bernie Doepker	LWCC Regional Coordinator	Five Hills Health Region	Telehealth (video)
Leslie Worth	Manager LiveWell CDM	Saskatoon, SHR	In person
Miriam Tettler	SCA Representative	Saskatoon	In person
Laura O'Brian	Sask Division CCS	Regina	Telehealth (phone-in)
Krista Epp	Sask Division CCS	Regina	Telehealth (phone-in)
Doreen Callander	Sask Division CCS	Saskatoon	In person
Roger Gauthier	SK Network for Health Services in French	Saskatoon	In person
Agathe Gaulin	SK Network for Health Services in French	Saskatoon	In person
Darla Walz	Provincial Coordinator LWCC	Saskatoon	In person
Anne Leis	Dept. Community Health and Epidemiology	Saskatoon	In person
Heather Millar	Dept. Community Health and Epidemiology	Saskatoon	In person

Regrets: Ruth Meier LWCC Regional Coordinator Regina Qu'Appelle Health Region, Deb Bulych VP Supportive Care SCA, Donna Boyce Hope Cancer Help Centre Inc. Saskatoon

Heather Millar: Powerpoint presentation of study results

Anne Leis: Requested a roundtable discussion of resources and programs related to cancer survivorship available through the various organizations attending.

CCS Representatives: The CCS provides support services to cancer survivors over the telephone. This service was previously known as Cancer Connection. The representatives from CCS informed the group that this service is now called the Peer Support Program. It is provided by 1300 volunteers across Canada and these volunteers provide one on one emotional support

over the telephone making this service available to anyone with a telephone. The Peer Support Program came out of research studies in 2000 which indicated rural people with cancer were looking for more support. Also, there is a new online community with the CCS that has approximately 1000 people at this point. Information resources from the CCS are available in french and english, in particular a resource titled "Life After Cancer" which focuses on cancer survivorship. Programming available that was mentioned in the research includes the "Transition from Treatment to Living Well" survivorship 4 hour workshop that was designed to fill the information void of how to live with a 'new normal'. This workshop is offered to groups with a minimum of 10 participants registered. The CCS also hosts an annual Living Well with Cancer conference in either Regina or Saskatoon.

Saskatchewan Cancer Agency Representative: Information regarding the Cancer Transitions program was provided. This program is for people who have been off of cancer treatments for at least six weeks, and has a follow-up session during a period following program completion. This program has diet, exercise and psychosocial support components and is available in the cancer centres in Regina and Saskatoon. The SCA also hosts a women's metastatic support group in Saskatoon, a prostate cancer support group in Regina, a relaxation program once a week hosted at the cancer lodge in Saskatoon, and an online group support program through Cancer Chat of the BC Cancer Agency. The SCA is looking at implementing a caregiver group in the future with newly acquired resources. The SCA also provides monthly presentations for health professionals in rural COPS centres. A group that was not represented at this meeting of key stakeholders was the YWCA however it was acknowledged that the YWCA provides a program in Saskatoon titled "Encore" which is a program for breast cancer patients and has an exercise component to it.

Chronic Disease Management (CDM) representative for the Saskatoon Health Region: A number of exercise programs that are offered in Saskatoon and in rural communities of the Saskatoon Health Region including Humboldt, Wakaw, Rosthern, and Wynyard. Depending on staffing and resources available not all of these programs are supervised by an exercise

therapist. CDM also provides a program called Bosom Buddies in Saskatoon that is an exercise program for breast cancer survivors.

Regional LWCC Coordinators: Exercise programs available in their communities were mentioned. Prairie North Health Region has the Strive program or Stars in Meadow Lake. Moose Jaw is a community that uses *Telehealth* to provide exercise education to other rural areas of the Five Hills Health Region. Although a lot of practitioners may be stretched to provide this programming, it was heard that many communities are motivated to plan and provide exercise programs of their own, separate from health care providers. Sometimes these programs may be initiated by rural volunteer leaders of LWCC program.

Heather Millar: Preliminary Recommendations were repeated to the group

Anne Leis: Facilitated group input on where to go from here given the preliminary recommendations presented

Darla Walz: Will continue to offer orientation to the LWCC program for the CCS, SCA to broaden cancer care provider awareness.

Doreen Callandar: Recommended a member from CCS join Darla in these orientation sessions to present information on the Transition from Treatment to Living Well Workshop.

Krista Epp: Suggested the current CCS survivorship program be tailored to reduce program overlap with LWCC.

Kellie Heidel: Would like staff at provincial COPS centres to learn about the program.

Darla Walz: Provided information to the members from the Saskatchewan Health Network for Services in French about plans to provide LWCC in French.

Roger Gauthier: Was pleased with this information stating that real support in French other than paper resources is something the French community struggles with.

Anne Leis: Facilitated group discussion around the topic of offering a seventh cancer specific session

Krista Epp: Using the 10 units of the CCS in Saskatchewan it would make sense to keep a running list of people who are interested in the Transition from Treatment to Living Well program within each unit.

Kellie Heidel: LWCC Facilitators would be able to refer those interested to the CCS unit of their area.