

# Wellspring Calgary: What Works and How? A Case Study of Patient Engagement

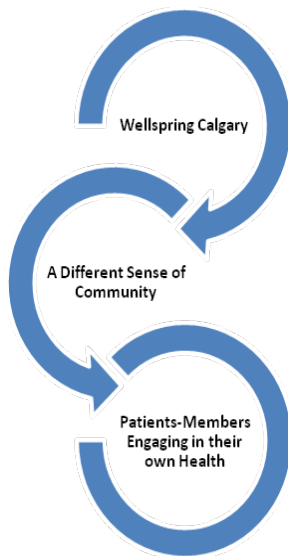
## Patient Engagement Research Study Report

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## Wellspring Calgary: What Works and How? A Case Study of Patient Engagement

### Introduction

Citizens, their families and loved ones who have experienced a cancer diagnosis and treatment are faced with a host of physical, psychological, social and emotional issues that impact their long-term wellness. By studying Wellspring Calgary we hope to add an alternative patient perspective on how attending a community-based wellness centre impacts the lives of cancer patients. The Patient and Community Engagement Research (PACER) case study methodology allowed us to engage our peers in discussions that capture ideas and emerging themes about the experience of living with cancer and attending Wellspring. The entire process of involving patients in research has been shown to be valuable “because it contains stories and knowledge shaped by human values and social contexts” (Saunders & Girgis, 2010, p 1).

This qualitative study has been undertaken to fulfill the requirements of an internship in the *Patients Matter* Project, whereby patients are taught to conduct research with other patients. The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID Number: E-25194 ). The research team – six PACER interns – had experience of cancer (four as patients and two as caregivers) and decided to embark on a case study to explore the experience of attending a community-based cancer support and wellness centre (Wellspring Calgary) and how such an organization might influence members to become more engaged in their health and wellness.

At each step of the way the researchers were advised and closely supervised by two University of Calgary instructors: Professor Nancy Marlett who conceptualized the project, and Svetlana Shklarov. Throughout the internship, the Patient and Community Engagement Researchers (PACERs) were mentored by Mary Sheridan who has previous experience of the innovative methodology through her work with the *Grey Matters* Project (Marlett & Emes, 2010).

There are several definitions of a case study that can be found in literature, and these are discussed in the Background and Literature Review section. Each definition below highlights an aspect of this case study:

- John Gerring (2004) defines case study as “an intensive study of a single unit for the purpose of understanding a larger class of (similar) units” (p. 342).
- Larry Dooley (2002) adds that “case study research emphasizes the detailed contextual analysis of a limited number of events or conditions and their relationships” (p. 335).
- Robert Yin (1984) defines the case study research method as an empirical inquiry that “investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used” (p. 23).

After much background work the underlying structure of the case emerged at the intersections of the data sources, as researchers, members, staff and volunteers explored what works and how at Wellspring. The aim of this research then, using Wellspring Calgary as an exemplar of a supportive cancer-based wellness and salutogenic (Antonovsky, 1979) centre, was to ask the seemingly simple question, “What works and how?”

Salutogenesis (Antonovsky, 1979) is a comprehensive theory about the origins of health within the continuum of health and illness. This focus on the ways to improve patient engagement in health seemed extremely important to us because it represents the public and political debate on chronic illness and human agency where constructs of the “expert patient” and “purposive collective action” are considered the key to patient self-management capacities (Taylor & Bury, 2007).

We hope that the information and data gathered herein, in line with the Alberta Health Services' Cancer Strategic Clinical Network mandate (Alberta Health Services (AHS), 2011), will be utilized to inform and add to the growing repository in the field of patient and citizen participation in their health planning and outcomes (Pivik, 2002). Using the techniques learned in the Patient and Community Engagement Research program (PACER), we firmly believe that we have a method that has “credibility, transferability, dependability, and objectivity” (Marlett & Emes, 2010, p. 25-28).

Using Wellspring Calgary as our model, comparing and contrasting the experiences of the members, their families and caregivers, this case study investigated the environment, the available programs, the experience of its staff, volunteers and members, and their perceptions in relation to its mission statement:

Wellspring Calgary is a warm and welcoming community that provides a comprehensive range of support, resources and programs for anyone living with cancer and the people who care about them, so they can improve the quality of their lives.

and vision:

No one has to face cancer alone. (Wellspring Calgary, n.d.)

As we, the researchers, are citizens living with cancer, this research methodology allows us to engage our peers in discussions that capture ideas and emerging themes about the experience of living with cancer and attending Wellspring Calgary. The entire process of involving patients in research has been shown to be valuable “because it contains stories and knowledge shaped by human values and social contexts” (Saunders & Girgis, 2010, p 1).

This case study, therefore, is in line with the Wellspring’s Research and Evaluation Committee’s mandate: “to support the development, implementation, monitoring and evaluation processes involved in research at Wellspring to ensure that programs and services correspond to Wellspring’s mission” (Wellspring Calgary, n.d.).

We hope:

- that data from this exploration will inform the Alberta Health Services' Cancer Strategic Clinical Network (SCN) mandate “to inform and add to their basic understanding of cancer experience during and after the acute phase” (AHS, 2011);
- that it will suggest further research and add to the field of patient and citizen participation in their health planning and outcomes (Pivik, 2002);

- that our findings will provide a more comprehensive understanding of the nature of community-based support during the cancer experience and how a salutogenic approach may benefit patient outcomes.

We believe this will be beneficial for community wellness centres, people who live with cancer, those who plan and provide patient care (including clinicians, health care planners, natural and community supports, and Primary Care Networks) and Alberta Health Services' Cancer SCN.

We believe that through the PACER techniques learned in the internship we have a method that has "credibility, transferability, dependability, and objectivity" (Marlett & Emes, p. 25-28) to bring a patient voice to research literature that will inform health care decisions.

### **Background and Literature Review**

This literature review begins with a short review of patient engagement literature, since this study is directly relevant to patients who, because of a social environment, are able to engage in their own health and wellbeing during and after cancer. We also discuss patient engagement within a salutogenic framework. This review then extends to include salutogenic environments. The final section outlines the literature related to case studies to understand organizations that provide a salutogenic model of holistic health support.

We have chosen to focus on the definition of patient engagement that concentrates on patients becoming more empowered to manage their own health. That is to say, "Patient engagement is a person's sustained participation in managing their health in a way that creates the necessary self-efficacy to achieve physical, mental and social well-being" (Worden, 2013).

We also draw upon a definition of health capacity from Australia, that has a long history of patient and citizen engagement because it touches the essence of patient engagement that we find appropriate to this case study: "helping individuals and groups to appreciate and manage their changing health circumstances with an objective of improving personal and social health in an ethically defensible way" (adapted from Macadam et al, 2004. p. ix). Patient engagement is, in essence, the attempt to include patients in their own health and in health care without resorting to artificial protocols and incentives.

Patient engagement is particularly important within cancer. People with cancer are living longer, and their cancer is more frequently being seen as a chronic illness. Cancer as a chronic illness places new demands on patients and families to manage their own care, and it challenges old paradigms that oncology's work is done after treatment (McCorkle et al, 2011). There has been a dramatic increase in self-management and psycho-educational programs conducted by health professionals (McCorkle et al, 2011; Taylor, 2007) but all models to date appear to replicate the traditional professional-patient relationship in that the professional provides the information, guides and motivates patients and provides feedback about success. However, cancer care studies have consistently shown that patients cannot be forced to follow a life style that is decided by others (McCarley, 2009). In keeping with this, we have chosen to study a self help model of cancer support and to focus on the natural, peer to peer guidance.

Patient empowerment and self-management are, therefore, crucial to ensure that patients know they are still in control of their lives and are motivated to become engaged partners with members of their health care team (McCarley, 2009, p. 409). Current theories related to engagement in health, such as salutogenesis (Antonovsky, 1978), and Ian Worden's (2013) recent work on a model of patient engagement that includes participation, sustainability, management, self-efficacy and wellness, suggest an alternative approach.

### **Salutogenesis**

The traditional medical model considers the health professional as the expert and the patient as a passive recipient of advice and guidance (Antonovsky, 1996) and the health care system reinforces the power differentials. Salutogenesis is the study of what makes people healthy, the converse of pathogenesis (a study of illness and what causes poor health). In this context, health represents an ever changing continuum from illness to wellness, and patients, their families and community environments are central to patient engagement in their own health. Salutogenesis is an ecological theory which informs internal and external processes and environments that are intended to help individuals and groups appreciate and manage their changing health circumstances.



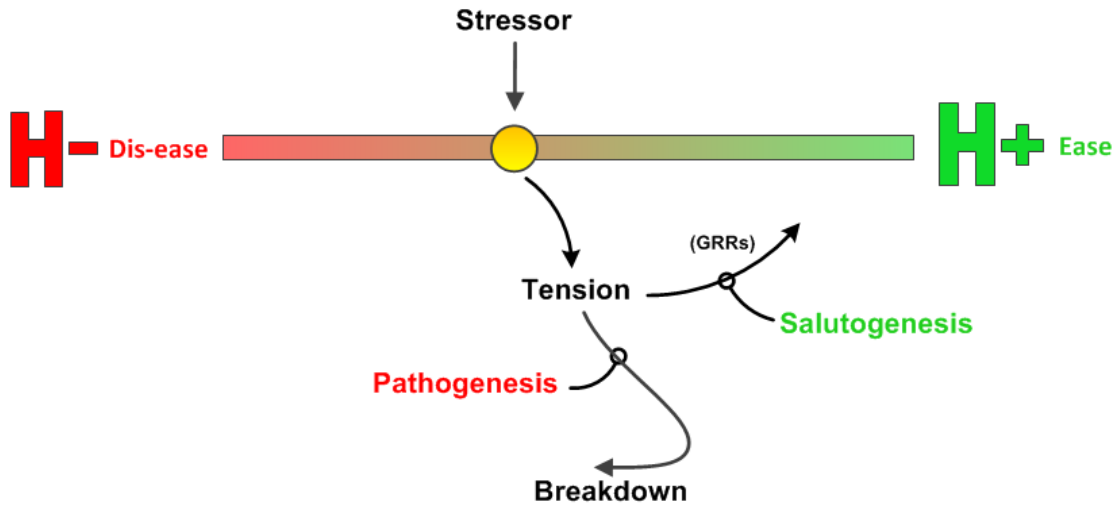
As mentioned above, a salutogenic orientation to health can be conceptualized as a continuum. Total health and total illness are the extreme poles. No one is ever at either pole; from the moment of birth till the moment of death there are forces pushing us in one direction or the other, but we are all, in this view, in part healthy, in part sick (Antonovsky, 1990).

Salutogenesis has become a recognized theory in psycho-oncology research in recent years, focusing on how the theoretical model predicts the activation and engagement of cancer patients in their own treatment. While much of the research capitalizes on the sense of coherence (SOC) scale as a measure to confirm that people with high sense of coherence experience more success than those with low scores in the SOC scale, there is a refreshing emergence in the use of the theory to explore the nature of stressors and generalized resistance resources in promising programs (Milberg & Strang, 2007). In these studies, we see how social environments and structures provide resources to avoid or overcome specific stressors.

The following short review of the elements of salutogenesis (Antonovsky, 1987) is provided for those who are unfamiliar with the overall theory. There are two primary actions in this complex and rich theory: the first focuses on the stressors that create imbalance in health, and the second describes generalized resistance resources, for example, social support and education, that provide the resources to counteract the impact of stressors.

Antonovsky himself drew out a representation of his health continuum depicting the tension caused by the stressors and the effects of generalized resistance resources (GRRs) on a pathogenic or salutogenic outcome. This is shown in the following diagram.

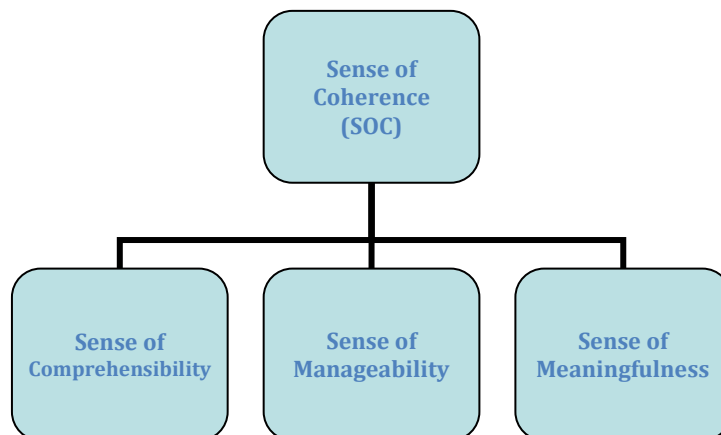
Figure 1. Action of Stressors and GRRs on Antonovsky's Health Continuum.



Source: Antonovsky, A. (1987), cited in Lindström, B. & Eriksson, M. (2010). *The Hitchhiker's Guide to Salutogenesis*. Folkhälsan Health Promotion Research Report.

The second and most widely used action relates to the development and maintenance of a sense of coherence (SOC), as depicted below.

Figure 2. The Sense of Coherence.



## **Sense of Coherence (SOC)**

Sense of coherence is an individual's general attitude to the world and his or her own life; a global orientation or character of a lasting and dynamic trust that can be understood, managed and gives meaning to their search for health (comprehensibility, manageability, meaningfulness). A strong sense of coherence makes it possible to be flexible and creative in meeting challenges. A weak sense of coherence leaves people with negative emotional responses (avoidance, depression) and rigid coping strategies. If a person believes there is no reason to persist, survive and confront challenges, then that person will have no motivation to comprehend and manage events.

**Comprehensibility.** Comprehensibility is the *cognitive* component which describes the expectation and ability of a person to process familiar and unfamiliar stimuli as ordered, consistent, structured information and not as chaotic, random, accidental or inexplicable.

**Manageability.** Manageability is the *instrumental* component that looks to how concepts are put into action: acquiring and practicing skills, tools and pathways to achieve goals: "the extent to which one perceives that resources are at one's disposal and that they are adequate to meet the demands posed by the threatening stimuli that bombard one" (Antonovsky, 1987, p. 17). This means that the resources are under the person's own control or are controlled by legitimate others.

**Meaningfulness.** Meaningfulness is the *motivational* component, "the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement" (Antonovsky, 1987, p. 18).

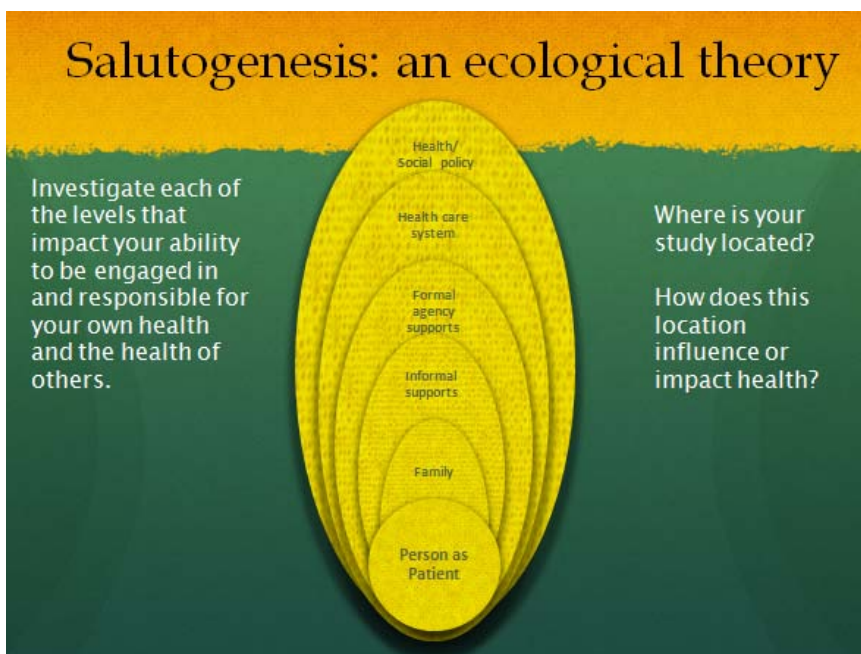
**Stressors.** Stressors are considered to be a natural part of life, expected if unpredictable. They act to unbalance and overwhelm individuals, families, groups and system and, if not managed, they can lead to "dis-ease." Salutogenesis encourages people and groups to learn to recognize and deal with stressors "upstream" rather than waiting for our health to be compromised. Stressors are not considered to be threats but opportunities to practice the use of our resources, to learn about tension, and to develop our coping skills.

## Generalized Resistance Resources (GRRs)

The search for the answer to the question, “What explains movement toward the health end of the health – illness continuum?” led to the study of resistance resources. GRRs are intrinsic to the salutogenic concept and play an important role in mitigating life’s stressors. Antonovsky (1987) describes their use as follows: “What the person with a strong SOC does, is to select the particular coping strategy that seems most appropriate to deal with the stressors being confronted” (p. 138). Those who have access to GRRs early in life have the opportunities to develop a sense of coherence and well-being. GRRs, socio-cultural, educational, and personal (biological and genetic) factors act in unison. “Activating GRRs enables the SOC to successfully manage strain, thereby contributing to a dynamic balance and homeostasis” (Mayer, 2011, p. 63).

Formal GRR examples are socio-cultural (consistent beliefs, religion), psycho-social and interpersonal relationships (support, close relationships), genetic (physical and bio-chemical), cognitive (contingent in knowledge gain and education), artefactual (capital, money, education, networks), and generalized coping strategies (as overall plans for overcoming stressors).

Figure 3. *Salutogenesis as an Ecological Theory.*



This diagram from our course material depicts the “locations of support” in rings extending from the self, through social networks, and to the wider spectrum of cultural social health policy.

These ideas (salutogenic approaches, social support, healing environments and psychosocially supportive design) are particularly relevant to the etiology of our case study and helped to define our avenues of exploration.

### **Salutogenic Environments**

There is growing evidence that the design of a healthcare facility will directly affect people's healthcare outcomes (Ulrich, 2006). Dilani (2009) delivered a paper on a psycho-social approach to building design, stating: "Health processes could be strengthened and promoted by implementing design that is salutogenic – i.e., that focuses on the factors that keep us well, rather than those that make us unwell" (p. 55). The aim is to stimulate the mind in order to create pleasure, creativity, satisfaction, and enjoyment. There is an important relationship between an individual's sense of coherence and the characteristics of the physical environment.

In order to create supportive physical environments it is crucial to engage with the individual or group to understand their fundamental needs. It is also necessary for different professional disciplines to cooperate willingly. It is this multi-disciplined approach that will produce the best outcome. To use Dilani's own example:

Before a zoo is built, it is common practice for architects, designers, biologists, landscape architects, animal psychologists and building specialists to collaborate in creating an environment that optimizes the living conditions for the animals. Factors such as materials, vegetation and lighting are taken into consideration; animals need enough space to eat, sleep and decide when to be social or seek solitude, and even their need for control and choice have been noticed. The aim is to create an environment that will support the animal's physical, psychological and social wellbeing. Ironically, humans do not seem to make the same demands when a workplace is going to be designed. (p. 57)

The World Health Organization (1978) defines holistic environments as:

viewing man in his totality within a large ecological spectrum, and ... emphasizing the view that ill health or disease is brought about by an imbalance, or disequilibrium, of man in his total ecological system and not only the causative agent and pathogenic evolution. (p.13)

Wellspring Calgary could be considered a holistic program because of the range of opportunities for people affected by cancer. The sample of programs shown in Table 1 emphasizes the holistic nature of this cancer-based wellness centre.

Table 1. *Sample of Wellspring Programming.*

<p><b>Caregiver and Bereavement Programs</b> Food for Care and Comfort Grief and Bereavement Reflection Practical Tools for Caregivers Saturday Self Care Tea gathering</p>	<p><b>Movement Programs</b> Cancervive-a-tri Exercise and Educate Healthy Steps Moves in Rhythm Qi gong Tai Chi Tango</p>
<p><b>Expressive Arts Programs: visual, tactile, written and auditory media</b> Art Bee / Open Studio Creative Journaling Music: house music concerts and workshops, singing circle, drumming Storytelling Watercolour Writing: Healing Word Visual Arts samplers: beading, ceramics, Chinese brush stroke, mixed media, mosaics</p>	<p><b>Outdoor Programs</b> Wellspring Community Garden Mindful Mountain Hiking Re-discover Biking Urban Walks: naturalist, photography X-country skiing</p> <p><b>Core Programs</b> Return to Work Brain Fog Healing Journey Money Matters</p>
<p><b>Individual Support (certified volunteer practitioners)</b> Healing Touch Patient / Caregiver Peer Support Reflexology Reiki Therapeutic Touch</p>	<p><b>Yoga and Meditation</b> Gentle Yoga I-Rest Yoga Nidra Meditation Sampler Restorative Yoga Visualization and Relaxation</p>

Source: Wellspring Calgary, <http://www.wellspringcalgary.com/offerings.asp>

Wellspring Calgary also offers one-to-one support, peer support and a venue for a number of support groups (Ussher, 2006).

In a systematic review on the use of art and healing therapies by those with chronic health conditions, Stuckey et al. (2010) concluded that artistic expression has significantly positive effects on health. With a diagnosis of cancer, art helps people to express feelings that they would otherwise not be able to do or have great difficulty with. Furthermore, Stuckey et al. determined that there are four primary therapies extensively being used globally. These therapies are: music engagement, visual arts therapy, movement-based creative expression, and expressive writing. All these therapies can be found at the core of the programs offered at Wellspring Calgary.

## **Case Studies**

We were drawn to using case study as an overall framework because it seemed to capture our interest in researching health engagement within a social environment. We were aware that there were few Wellspring models in Canada to date and because the Calgary program was well established it seemed appropriate to use it as the “case.” We are informed by John Gerring’s (2004) understanding of a case study as “an intensive study of a single unit for the purpose of understanding a larger class of (similar) units” (p. 342). This intensive study of Wellspring invites connections between Wellspring Calgary and other wellness centres and psycho-oncology hospital programs.

Larry Dooley (2002) adds that “case study research emphasizes the detailed contextual analysis of a limited number of events or conditions and their relationships” (p. 335). In our study we were conscious of our dual focus on the social environment and how the environment influenced the relationships between members, volunteers, staff and family. And finally, Robert Yin (1984) cautions that case study “investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used” (p. 23). This case study was a constant dialogue between the subtle and complex social environment as seen in documents, media, observations, conversations, focus groups, and shared analysis of the data. The underlying structure of the case emerged at the intersections of the data sources as researchers, members, staff and volunteers explored what works and how in Wellspring as an exemplar of a salutogenic cancer wellness centre.

## **Engagement Methods**

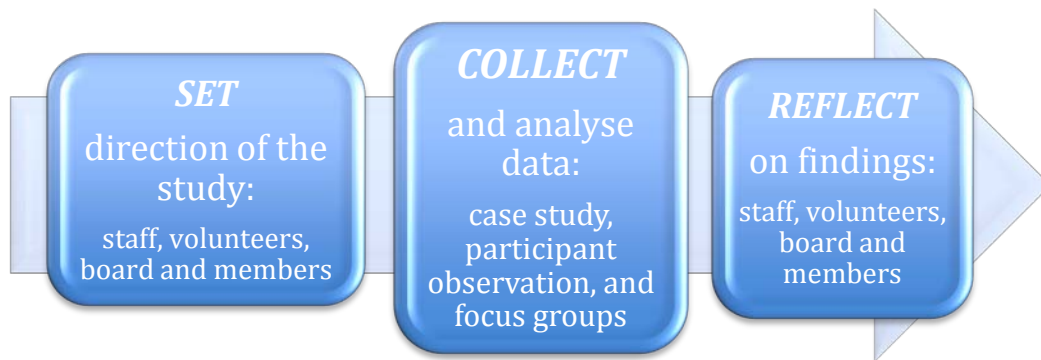
In this section on engagement methods we try to capture the challenges that led to adapting approaches in order to address the challenges inherent in engagement. We use the first person plural to indicate the research team, and when we are including participants (members, volunteers and staff) we also use the adaptation of “we.” We begin with a narrative of the method followed by the issues that we anticipate may arise with this novel approach to research. In this we cover: quality standards, recruitment of participants, roles in engagement, confidentiality, and transparency.

## Overview of Engagement Methods

As students in the *Patients Matter* Project we combined Patient and Community Engagement Research (PACER) methods (Marlett & Emes, 2010) with an experiential or phenomenological gaze as outlined by Patton (1990), Bogdan and Taylor (1975), Lincoln and Guba (1986), Kirk and Miller (1986), and Berg (1989) to identify common experiences and how the environment and the activities seemed to work.

The research study's design followed the SET COLLECT REFLECT structure outlined in the *Grey Matters* book (Marlett & Emes, 2010), as shown in Figure 4, using engagement techniques that are only possible in peer-to-peer research. SET and REFLECT are the hallmarks of the patient engagement research (PER) method, serving to ensure a meaningful patient involvement and contextual validity.

Figure 4. *SET, COLLECT, REFLECT Methodology.*



**SET:** Prior to the SET focus group, we completed an initial document review of reports, media, and program documents to ensure that we were well versed in the organizational goals and values. In addition, members of the research team had met with administration, the program committee and board members to ensure their cooperation and agreement with the general direction.

Fourteen people attended the SET focus group for the all-day session: members, staff, volunteers, board members and researchers. We were prepared with our specific tasks and our agenda, but it soon became clear that the group had come to be heard, to contribute and to ensure that Wellspring would be safe in the hands of members who were becoming researchers. The



highlights of the meeting included a vigorous debate about confidentiality, how to ensure that members were not worried about the presence of “researchers,” which activities could be observed, what would be done with the research after it was finished.

At the end of the day, we had committed to creating an ethics framework that would honour the particular ethical concerns of a self help organization, we had a list of activities to observe, we had a list of what to look for in uncovering “the different sense of community” that was Wellspring. Perhaps, most of all we were all very aware that we were no longer members, we had morphed into researchers.

**COLLECT:** Particular techniques of data collection and analysis depend on the specifics of research questions and purposes of each given study. Data are analyzed in parallel with the collection processes, so each of the steps feeds into another.

**Document review.** A second document analysis took place before the participant observations. The documents were provided by the administration or were available on line. We used a modified document analysis format from the US Library of Congress (Marlett & Emes, 2010) that allowed us to look at the type of document, the audience, the message, language used, recommendations and links to our research.

**Participant observation.** We conducted 17 participant observation events, which included 28 observations by individual researchers. The observations covered the programs and general milieu, activities, and interactions that take place there (Table 2).

Choosing the programs and activities to observe was, at times, quite contentious as the staff and board were concerned about disrupting important processes for individuals. Tough negotiations were necessary to agree on a list that represented a cross section of the activities at Wellspring. Even after this negotiation at the SET focus group, extensive negotiations took place with several of the program leaders before the actual observations took place, and changes still had to be made to where observers would sit and in what activities they could participate.

A list of ideas or themes resulting from our initial document analysis and SET focus group formed a base for what we might look for in our observations. One of the strongest of these ideas

was “the different sense of community experienced” (fg.080513) at Wellspring Calgary. These items were used to cross check our observations to make sure that we had looked for all possible behaviors and actions.

Table 2. *Observations.*

Program Observed	Date	Observation Events	Observations by Individual Researchers
Tai Chi	April 16	1	2
Ultimate Road Trip	April 16	1	2
Healing Journey 1	April 17	1	2
Healing Journey 4	April 17	1	2
Going Deep: Mono Prints	April 17	1	2
Restorative Yoga	April 22	1	2
Tea Gathering	April 23	1	2
Detox Your Home	April 24	2	4
Spring Forest Qigong	April 25	1	2
Open Art Studio	April 26	1	2
General Observations	April 14 - 27	6	6
<b>TOTAL</b>	April 14 - 27	17	28

Over 250 people were observed over the two-week period. After completing the first week of observations, we met to discuss and compare findings and re-focus before a second round of observations. At this point we embarked on several rounds of formal data analysis to make sure we had captured the nuances of the observations

The most robust themes were identified, enabling us to refine our agenda and questions for the next stage in our research, the COLLECT focus groups.

The data from the participant observations were surprisingly rich and detailed, consisting of process recordings of each of 17 observations and detailed analysis protocols done by each observer in each observation session. These observations were compared by each pair of observers. Each observation event was initially analyzed to capture the location of the observers, the negotiations needed, the flow of the activity or event, and the topics and ideas discussed.

**Focus groups.** In the COLLECT phase we used data from two focus groups. We conducted one focus group as part of the COLLECT phase, and discovered that we also needed to analyze the data from a previous, preparatory focus group. The preparatory focus group had been conducted as a class assignment in our course, prior to the initiation of this study, with a group of class

participants on their return from the yearly fundraising Cancervive bike tour, and contained rich data that added an important perspective to our work. Cancervive is an annual event and the major fundraiser for Wellspring programs across the country. We discovered once again that the idea of sub-communities and the sense of coherence theory could be applied. Comprehensibility was expressed by their love of Wellspring, and their participation was supporting a good cause (Acceptance and Shared Energy). Manageability was illustrated by the participants recounting how they pushed themselves and each other through each stage of the ride (Shared Energy, Humour and Joy, Encouragement). Meaningfulness was revealed in their recollection of how each experienced personal inspiration, growth, and overcoming the challenging conditions (Self Worth and Contribution). The participants said that it was an honour and privilege to be part of Cancervive. They found it to be a “very deep emotional and heart filling experience” (fg.291012). As researchers we were in a state of absolute awe listening to their experiences and felt that it was a real privilege to have had them share this with us.

The first focus group consisted of six people (participants and researchers) and the second group consisted of twelve (participants and researchers). The focus group method and approach, as described by Marlett and Emes (2010), was adapted for our participants who felt that meeting from 10 a.m. to 3 p.m. would be too tiring. An example agenda from one of the focus groups is presented in Appendix B.

We created a set of questions that arose from our participant observations, but the emphasis was on allowing a free-flowing dialog. All focus groups were recorded and process notes were taken. The questions evolved from our analysis of document review and observations (the first stages of our COLLECT phase).

***Narrative Interviews.*** In our proposal we had estimated that we would need to conduct narrative interviews following the participant observations and the focus groups. In fact, to our surprise, we reached a theoretical saturation point without the interviews. This meant “that no additional data are being found whereby the researcher can develop properties of that category [...] as he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated” (Glaser & Strauss, 1999. p. 61).

**REFLECT:** At this stage, participants from the initial SET focus group reviewed findings and analysis with the PACER team and suggested ways to share the information and make recommendations for further research. This stage completed the circle of PACER procedures and prepared the data to be shared with the relevant health system and submitted for publication.

Unfortunately, four members of the original focus group were unable to attend, so we invited additional participants fitting the criteria of staff, member, volunteer, or family member, to attend. This worked well as we had enough of the original core group to provide continuity, and we also had representation from the COLLECT focus groups.

We began by summarizing the flow of the research: from the SET expectations, the findings from the COLLECT phase, and especially the findings that surprised us. We then presented the data as themes and sub-communities, each researcher presenting a theme that he or she had focused on. We asked each participant to choose the emerging themes that they believed were the most important and to explain their choices.

There was an openness present among us, as group members told how their experiences related to the themes we were uncovering. As we spoke, the members of the reflect group were attentive, showing understanding and engagement in what we had found from our research. It was satisfying to share new knowledge and be understood, as we spoke about the emerging themes and their ideas with respect to “What Works and How?” This completed the circle and gave us the opportunity to ensure the findings were a true reflection of the experience of the Wellspring community. This also served to increase our understanding of the findings and how this understanding could be used. The agenda and questions for this REFLECT focus group followed the same format as that of the SET focus group (see Appendix B).

Thus, there were three sets of data, each feeding into the other: the SET focus group giving pointers on the field observations; these observations, in turn, feeding into the focus groups’ data of the COLLECT stage, and finally, the follow-up REFLECT focus group data. The data arising from the first round of COLLECT focus groups helped to refine our knowledge and understanding; to give us the depth we needed to extrapolate the underlying factors that made up the experience of being part of this Wellness Centre’s community; to understand “What works

and how?” The processes in the final, REFLECT focus group and the data gathered therein ensured that we thoroughly attended to the views of our participants, and will lead us to a resultant report that reflects participants’ views as accurately as possible.

### **Issues Arising from Patient Engagement Methods**

This section has been included because the methods described above challenge many of our assumptions about research. This is not a linear method where set questions and protocols require compliance on the part of subjects. It is interactive, organic and collaborative. We hope that by sharing our debates about engagement we start an open dialogue about this new and, at times, confusing and challenging method. The issues we address are: the search for quality data, negotiating the engagement process, confidentiality and referencing, and finally, transparency.

#### ***Quality of the data***

Underlying all of our analysis was an adherence to the strategies of “phenomenological reduction” (Patton 1990, p. 408) wherein each piece of data was shared with the group, with pairs, and by a key researcher responsible for the theme. Those categories that did not have sufficient confirmation – at least three observations – were eliminated.

The second strategy to raise trustworthiness and credibility is an integral requirement of patient engagement research. Patient engagement research (PER) is a natural method to combine with a phenomenological perspective. As noted above, patient engagement researchers are in a unique position to engage with participants, and the unique perspectives of the research interns created many vigorous debates about meaning and challenges to find the data to support ideas.

Research colleagues examined the coding of the data to eliminate researcher bias and to increase confirmability of the results (Lincoln & Guba, 1986). We also kept returning to the audio recordings, flip-charts, analytical memos and note-takings to see if “the constructs, categories, explanations and interpretations made sense and really reflected the nature of the phenomenon” (Patton, 1990, p. 462). We looked at the data from different perspectives to uncover the essence of the experience, and questioned the possibility of rival hypothesis (Berg, 1989). Since the PER structure calls for a REFLECT focus group, we were able to check that we had asked the correct

questions and that the emerging themes were “recognizable as adequate representations of their [Wellspring members] own ... realities” (Lincoln & Guba, 1985, p. 314).

### ***Engagement boundaries and negotiating roles***

The patient engagement research methodology, in which patients are interviewing patients, means that the researcher is both the instrument in the study and a participant. It becomes very important that any issues that might influence the collection or analysis of data are noted and transparent (Bogdan & Taylor, 1975; Kirk & Miller, 1986; Patton, 1990).

Patient engagement research (where “patient” includes the patient, their family and community) introduces an important variant on patient engagement and research relationships. It introduces the potential for co-creation of knowledge wherein all parties share, learn and benefit from the research process. This is possible because patient researchers come from the culture and experience of health seeking and health care and thereby share understanding with patients.

What we came to realize was that there was a different quality to the research; we were treated like comrades in arms and allowed into a private world that few researchers could have accessed, but it took considerable negotiation to establish an initial foundation of trust. Being members and insiders did not guarantee collaboration and automatic acceptance by the staff and board of Wellspring. As one of our research team members (a caregiver and volunteer at Wellspring) explains in her process notes, she felt that she was perceived differently at the Program Committee Meeting (29.10.2012):

To begin the formal research process two of us were invited to sit down with board members to discuss how we would proceed. Used to familiarity with everyone at Wellspring I was surprised by the constraint that seemed to be present. People who would normally smile at me held straight faces and I felt quite anxious. Most questions, directed towards my fellow researcher, concerned ethical procedures. It took me a while to realize that we were being treated differently because we had changed roles. Upon reflection I understood that when people have created something that they cherish, it's natural to take a protective stance and in their position I might do the same. Although high ethical standards were built into our proposal, it is wise to reinforce this need.  
(pc.PhG)

Because there had been concerns about disrupting programs and because the observations seemed difficult to negotiate in some activities, the research team came up with a variant on the initial method proposed. While we had intended to have two participant observers at each

observation, we decided to minimize the impact while still ensuring that we had two observers in the area to enable us to do inter-rater reliability and comparisons. One of the researchers became an observer and found an unobtrusive place to record what was happening using process recording techniques with a focus on activity and interactions. The other researcher was a participant in the activity and after the session was complete, filled out a form based on his or her experience of the participation. The two researchers were then able to discuss their finding, noting similarities and especially differences from their distinctly different perspectives. This was a powerful tool in challenging the integrity of the data.

### ***Confidentiality and referencing***

We have protected the confidentiality of the participants by simply recording the time, place, date and the context of our data (observations, focus groups, and personal communications) rather than record information that may identify a specific individual. All identifying data such as consent forms and demographic information were stored separately from all the raw data and analysis.

As we observed members both in the open spaces during their daily comings and goings, along with attending programs, it is difficult to put an exact number on the number of participants we had in the study. All the participants, as they were active Wellspring members, were considered as “self-identified” as having experience of cancer.

Participants for the focus groups came forward in response to an e-blast from the Wellspring, in-situ posters, information at the Wellspring’s front desk, and word of mouth from participants. In alignment with Wellspring’s confidentiality agreement and our agreement to work within these parameters, specific member (participant) demographics were not recorded for the purpose of our study.

Our data collection did not involve any personal or identifiable health-related information such as health records. It was coded for abstract concepts and themes, and summarized into a research report for anticipated publication and presentations. As such, individual names were not used, and other potential identifying markers such as age, geographic location,

socioeconomic status, detailed health care provider or agency information, or cultural affiliation were aggregated so as to preserve anonymity.

The following chart provides a guide to the reference codes used in this report.

Table 3. *Descriptions of Reference Codes.*

Reference Code	Description	Date Format	Examples
fg	Focus Group	DD/MM/YY	fg.23.05.13
pc	Personal Communication	DD/MM/YY	pc.XY*
po	Participant Observation	DD/MM/YY	po.22.04.13

\*Note: Personal Communication category represents reporting and referencing patient engagement researchers' comments in conversations and meetings. XY are researcher's initials.

### ***Transparency***

The difference in this study from a more traditional phenomenological approach is that the questions asked all come directly from the sample of patients. The researchers, themselves patients, decide on an area to be researched, the SET focus group directed the next step of the study by showing the researchers which topics are of greatest interest to those engaging in the study. The researchers take this information and conduct the COLLECT phase. The REFLECT focus group decides: a) if the researchers have represented their concerns and goals as indicated by the SET focus group, and b) if the emerging themes and their components accurately reflect the experience of attending Wellspring Calgary.

In engagement research, we the researchers are also a source of data – whatever input we bring as patients is also data. By reporting and referencing our comments in conversations and meetings (referred to as “personal communication” in Table 3), we hope to remain transparent. We have attempted also to describe in detail the process that we have used. Even the analysis of the data and the emergence of theory are described in detail in the following (Articulating Experience) section. Throughout the study we have attempted to be transparent in method, analysis, and our role in the process.



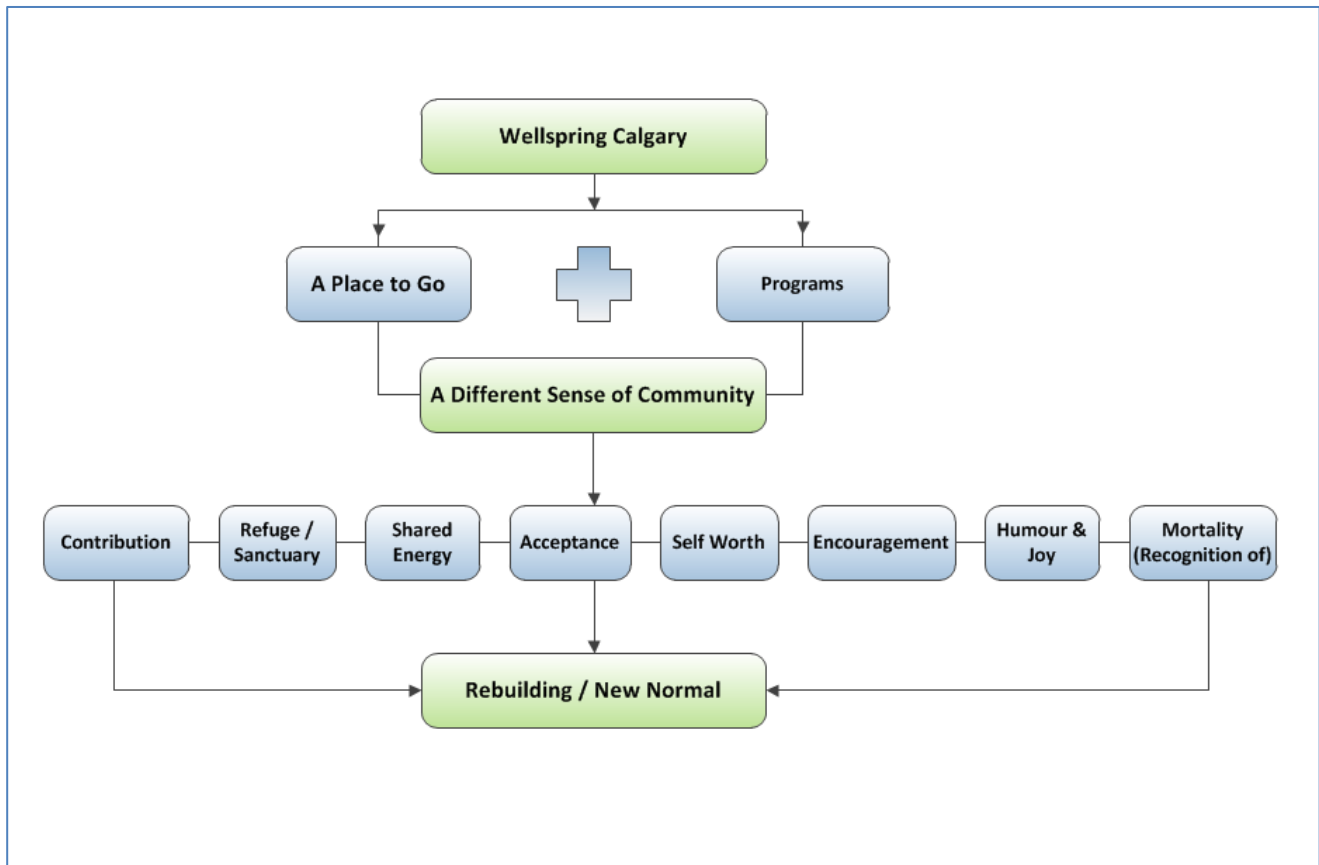
**Articulating Experience:  
A Narrative of Finding Theory Through Analysis**

We have chosen to present a narrative of our analysis because the case study format provides a way to understand the movement from data to theory. The final stages of analysis took almost four months of intensive team work. We moved from an initial reading and analysis that produced 10 general themes which we called sub-communities, through to a salutogenic theory of how a community-based wellness centre influences engagement in health.

Once we had identified our initial group of themes, we chose one of the themes – Acceptance – to understand how the theme was working to engage the members in their quest for health. This was very animated and creative, as it can only happen with a research team of seven people, each with very different backgrounds and interests. We came up with many ideas and options and, by the end of the day, we began to see the power of the stories and metaphors in the data and had devised a analytic frame for the remaining themes.

As this was an internship, and because of the time involved in group analysis, we agreed that the researchers would work in pairs with the academic advisor to analyze and write up the themes for discussion as a group. We have included a brief introduction to each theme by one of the researchers, which highlights their relationship to the topic and/or includes an exemplar from our study. We were also able to add quotes from the focus group that was held after the observations were complete. Those categories that did not have sufficient confirmation – at least three observations – were eliminated. At this point, working within the framework of a “different type of community” that had arisen from our first meetings at Wellspring, we had consolidated the themes (now called sub-communities) to eight: Sanctuary, Shared Energy, Humour and Joy, Mortality, Acceptance, Encouragement, Self Worth, and Contribution.

Figure 5. *Initial Analysis – A Different Sense of Community.*



Several of the researchers took the lead in working with the themes to construct a diagram of how Wellspring might be represented in light of the findings. Several schematics were drawn that represented the interactions between the various themes.

The first theme, a “Place to Go,” is an invitation to persons diagnosed, in treatment, or survivors of cancer to be with others on the journey to wellness. The “sub-communities” within this theme are present in the physical building, in the programs offered, and in the general atmosphere.

As we were compiling our results into the final report, two of our researchers were invited to present at the Cancer Strategic Clinical Network. They prepared slides of the process and the findings that were received politely, but they felt that the presentation was missing something. In discussion with the research team we decided to take a fresh look at the potential links to a theory of salutogenesis beyond the general descriptions provided at the end of each of the

themes. We were looking for theoretical links and models that would take the case study beyond a celebration of Wellspring as an exemplary holistic cancer wellness program to a salutogenic model of cancer wellness that could inform a variety of bodies and programs. The following description attempts to track how we interacted with the theoretical elements of salutogenesis over the span of the study.

When designing the case study, we were intrigued with how Wellspring seemed to capture the essence of a salutogenic (wellness-based) option. The construct of salutogenesis provided a useful, if unconscious frame of reference, in looking at what was happening at Wellspring. In some sense, we were sensitized to look at the environment, activities and interactions as they supported members in moving from a pathogenic, illness-based understanding of who they were to a salutogenic understanding of themselves and their desire to move towards wellness. This focus proved productive.

From the early analysis we discovered examples of activities and interactions that supported the components of a sense of coherence: comprehensibility (learning, accessing knowledge, seeking guidance); manageability (coping skills, risking, trying new activities), and meaningfulness (finding purpose, contributing to others). This was an exciting finding because it seemed to answer the questions about how people and groups were becoming engaged in their own health.

We knew from the theory that sense of coherence develops as people counteract the inevitable but unpredictable stressors that come with cancer, but there was little evidence that stressors were being overtly identified or used to organize the experiences within Wellspring. We had to interpret what stressors were in play in what we saw and heard. We could sense that there was something in play that enabled members and volunteers to re-establish a sense of coherence in lives that had been impacted by the overwhelming stressors associated with cancer.

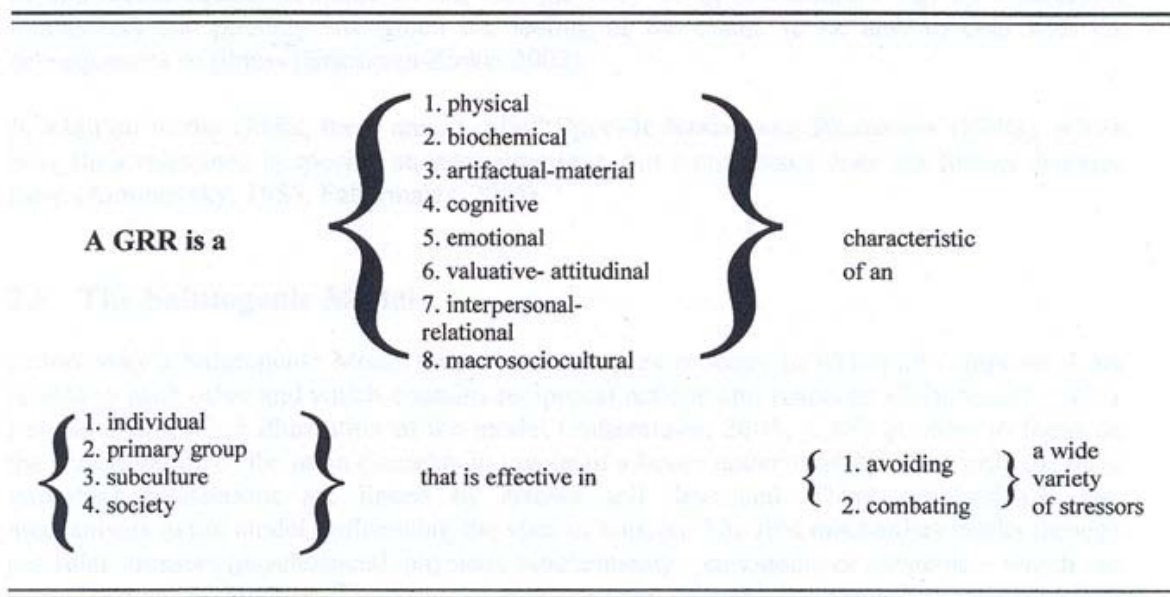
It seemed that our eight general concepts or sub-communities were acting to enable people to engage in their health, but it wasn't until the last stage of the analysis that the process fell into place. When we were attempting to classify how the stressors and the characteristics of sense of coherence interacted, we realized that the sub-committees we had uncovered to explain what worked and how, were actually working as generalized resistance resources (GRRs). Our eight

“sub-communities” were acting as “resources” that enabled people to rebuild their sense of coherence.

Wellspring had unconsciously created and nourished a number of resources that people could draw on to challenge and manage their individual stressors. In many small acts of resistance, they used these resources to overcome the tensions associated with cancer, they became more confident, competent, in control. The quantity and quality of the resources at Wellspring begins to identify what makes this a place of health and healing.

The following schema is proposed to explore what works at Wellspring and how. It is drawn from Antonovsky’s work in classifying GRRs in a Mapping Sentence (1985, p 103).

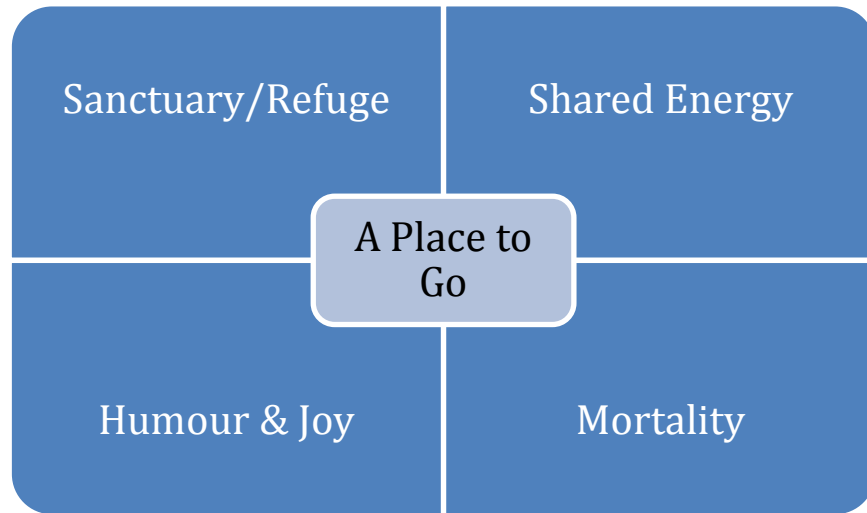
Figure 6. *GRRs in a Mapping Sentence. Source: Antonovsky (1985), p. 103.*



In the context of this case study, we propose that Wellspring has generated a unique set of GRRs, that combine physical, emotional, attitudinal, relational and sociocultural characteristics that are effective in avoiding and combating a wide variety of stressors associated with the experience of cancer at the individual, group and environmental level. These resources are drawn upon by members, staff and volunteers as they attempt to “avoid” or “combat” the stressors associated with the experiences of cancer.

- The first category of resources relate to the provision of having a “A Place to Go.” These resources are the physical, emotional and social environments that make it possible for members to engage in their health.

Figure 7. *A Place to Go (Foundational GRRs).*



- The second category of resources relate directly to the internal mechanisms that enable engagement in one’s health. We have called this group of resources “Give it a Go.”

Figure 8. *Give it a Go (Internal GRRs).*



As we continued to review our data and findings we came to understand that that Self Worth was not working as a resource but was indeed an outcome, and it related very closely to our topic – engagement and Antonovsky’s construct of a sense of coherence.

### **The Evolution of Self Worth (Sense of Coherence as Path to Engagement)**

The following section tracks the evolution of the themes identified into our understanding of them as generalized resistance resources acting as powerful, yet sometimes subtle, tools that enable the overcoming of the stressors impacting the patients and their loved ones. They are often subtle and seemingly obvious but the impact is great. This alignment with sense of coherence was uncovered when we realized that our initial theme of Self Worth was not a resource but an outcome and, in the context of Wellspring self worth seemed to speak to engagement. It was only then that we connected engagement with sense of coherence. This can be seen in our initial description of the theme of Self Worth. The cancer journey in itself is a resource, a process to reclaim and rediscover the strengths and capacities you already have and re-engage in your own health.

We now had a salutogenic model of cancer wellness that could inform a variety of bodies and programs, and the report was re-cast to reflect our findings.

As the impact of disequilibrium is being lessened by having a “Place to Go” (Wellspring Calgary), members are able to draw upon the GRRs that are present, and “Give it a Go” to rebuild their sense of coherence and in the process develop a sense of self worth and become engaged in their health.

Let us look at the links between Sense of Coherence, Self Worth and Engagement. Wellspring rebuilds a person’s self worth through a program called “healing journey” designed specifically to reclaim and rediscover self worth. Engagement is uniquely possible at Wellspring because cancer is common ground and Wellspring is a new experience for everyone. People from all walks of life come together as beginners. Self worth is not determined by what you were or had. In this place you have achieved worth because you have come. You have earned the right to membership. The main membership expectation is to try to be good to yourself and learn to be

your authentic self. You may be sad, upset, overwhelmed, shy, elated or anxious, but members understand because everyone has been there too.

There is something very unique and down to earth about discovery of self worth. At first glance it might seem to be an inner personality shift. However, self worth is also concrete; an obvious yet unspoken process to build competence. Members learn about themselves and that it is possible to find a “new normal,” new routines, make different lifestyle choices (e. g., better or different diet, exercise, alternative therapies), and establish or reset personal boundaries, all while finding meaning in their self discovery and engagement.

It is as if loss of self worth is just like loss of hair, energy, or a job, and like those other aspects of cancer. Wellspring seems to treat loss of self worth as a normal part of having cancer, and like loss of hair, it can be reversed by helping people understand that it is not their fault but a normal part of being diagnosed.

This is done by sharing stories of common experiences so that people realize it is not personal, unique or an unexpected occurrence. For instance, if everyone experiences loss of self worth then it must be common. This also implies that others have lost and regained self worth, and can change.

As one of our research team members explains,

I was attracted to writing about self worth because of how my cancer diagnosis affected this part of me. Childhood trauma later coupled with society’s expectations of how a woman could now “have it all” (work and raise kids) left me filled with a lot of personal fears and self-doubt. After many years of raising kids and getting to a point in life where I could really take time for myself I was diagnosed with cancer. Any ambitions I harboured were put on hold while I fought the disease. Everything I knew and believed in went out the window. I was crushed. There was nothing left. I turned to outside resources to help rebuild my sense of coherence/self worth. One of those resources was the Healing Journey program at Wellspring Calgary. The different levels of this program help you rebuild and make sense of your cancer experience. My personal experience with this was later validated by going back to the program as a PER observer and again hearing focus group participants speak of the “arsenal of tools” (fg.080513) gained by participating in this program.” (pc.SN)

This is a critical piece of encouraging members to treat loss of self worth as something to overcome, to practice seeing self worth, doing things to see oneself as worthy. “Freedom to experiment with who you are” (pc.NJM) enables you to “connect the dots.” It is a very sophisticated and yet hidden coping strategy that underlies engagement.

Through our case study research, we have uncovered that self worth is achieved through the interaction of the components of sense of coherence: comprehensibility, manageability and meaning:

- Comprehensibility, the cognitive aspect, seems directly related to what we have called Acceptance. In this the member comes to understand herself as a person with cancer through watching and being part of Wellspring. Here others also have cancer but are living full lives.
- Manageability, the coping aspect, related directly to what we have called Encouragement, because it relates to trying new things, finding ways to explore and to risk in a positive environment.
- Meaningfulness, the motivational or purpose aspect, relates directly to what we have called Contribution, where people make commitments to others, through volunteering and reaching out.

We discovered these relationships as we returned to our sub-communities. These sub-communities had evolved into common ways of acting or speaking, expectations and rituals that acted to create a sense of community. Seen from another perspective, the sub-communities seemed to represent repertoires or ways of acting and speaking that encouraged members to engage in their own health. Table 6 in the next section clarifies strong links within the relationships between sense of coherence and our sub-communities.

Yet again we returned to our analysis and the data, and in reworking our findings we discovered that the first four themes were indeed GRRs, and the remaining three themes were working as repertoires (ways of working and understanding work through common and often unconscious actions and language). These repertoires were acting in alignment with the three repertoires of



sense of coherence. We were now ready to look at a full salutogenic theory about what works at Wellspring and how does it work.

### Stressors Identified by Participants

The following tables present our work in “locating” the unspoken presence of stressors in the data and the relationship between stressors and the sub-communities identified above.

Table 4. *Stressors Categorized by Fear, Loss and Emotions.*

<b>Fear (of)</b>	<b>Loss (of)</b>	<b>Emotions</b>
Death	Energy	Shock of diagnosis
Being taken over by cancer	Independence	Uncertainty
Stigma, being different	No place to be yourself	Depression, sadness
Pain	Self	Guilt about getting cancer
Taking risks	Loss of expectation of what you expected death to be	Guilt about impacting others
Planning ahead	Connectedness, friends, work	Constant vigilance and anxiety
	Comfort in roles	
	Ability to contribute	

Given the profound disequilibrium caused by the cascade of stressors associated with cancer and the loss of control over these stressors, it is surprising that Wellspring and the programs associated with it have enforced a wellness environment. It is not that stressors are not recognized, they take second place to working towards wellness.

Table 5. *Stressors Related to Sub-Communities.*

<b>Sub-communities</b>	<b>Stressors</b>
<b>Sanctuary</b>	no place to be self, shock/panic; guilt (feelings), constant anxiety, fear of death
<b>Shared Energy</b>	low energy
<b>Humour &amp; Joy</b>	constant anxiety, feeling different, guilt, depression, sadness
<b>Mortality</b>	fear of death, uncertainty

<b>Acceptance</b>	being different, occupied by cancer, loss of roles and other losses, guilt
<b>Encouragement</b>	fear of risk taking, being different, planning ahead, being humourous
<b>Self Worth</b>	Losses of identity, connectedness, role changes, engagement with life and health
<b>Contribution</b>	loss of roles, ability to contribute, energy

It was very powerful to map the connections between the sub-committees and the stressors that are reduced through the actions of the sub-committees. This simple exercise opened the door to thinking about the potential connections between our sub-committees and a sense of coherence.

Table 6. *Relationship between Sub-Communities and Sense of Coherence Factors.*

Sub-Communities (GRRs)	Sense of Coherence Factors		
	Comprehensibility	Manageability	Meaningfulness
<b>A Place to Go</b>			
<b>Sanctuary</b>			<b>YES</b>
<b>Shared Energy</b>	yes	<b>YES</b>	
<b>Humour &amp; Joy</b>	yes	<b>YES</b>	
<b>Mortality</b>	yes		<b>YES</b>
<b>Give it a Go</b>			
<b>Acceptance</b>	<b>YES</b>		
<b>Encouragement</b>		<b>YES</b>	
<b>Self-Worth</b>	<b>YES</b>	<b>YES</b>	<b>YES</b>
<b>Contribution</b>			<b>YES</b>

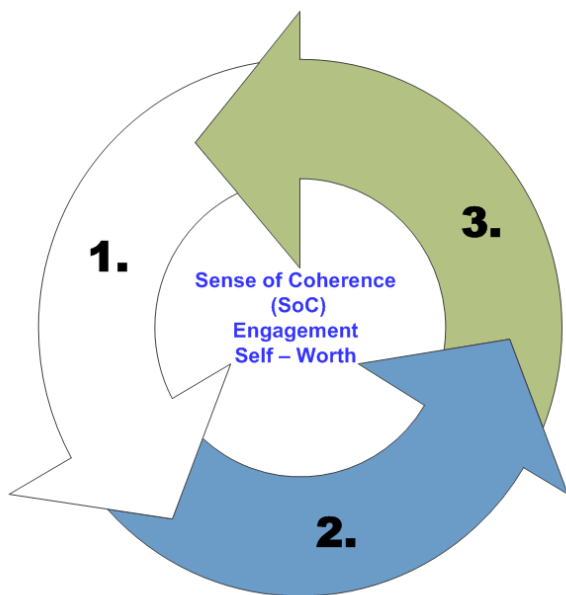
\*Note: UPPER CASE (YES) indicates the SOC category where we thought it fit best, lower case (yes) indicates a more minor fit.

Through mapping our data and themes onto the theoretical framework of salutogenesis, we moved to a more abstract and comprehensive understanding of our findings. The sub-communities we had uncovered to explain what worked and how, were actually working as generalized resistance resources (GRRs).

Wellspring as an organisation acts as a social and physical environment that has created unique resources (physical, emotional, attitudinal, relational and socio-cultural) and these are effective in avoiding or combating a wide variety of stressors associated with the experience of cancer. These unique sets of GRRs, found in the grouped themes of A Place to Go and Give it a Go and the resources therein, are drawn upon by members, staff and volunteers as they attempt to avoid or combat the stressors associated with the experiences of cancer. In many small acts of resistance, they used these resources to overcome the tensions associated with cancer, they became more confident, competent, in control. In effect the existence of these resources increased or regained individual sense of coherence as evident in their engagement in their own health.

Yet again we returned to our analysis and the data and in reworking our findings we discovered that the first four resources were “foundational” GRRs related to the physical space, whereas the remaining three GRRs from the second theme (Give it a Go) were the “individual and internal” mechanisms drawn upon, and were directly related to the factors of sense of coherence. Each of these three resources appears to be directly related to one of the factors that comprise sense of coherence as presented below.

Figure 9. *Wellspring Resources and a Sense of Coherence.*



### The “Evolution” of Self Worth at Wellspring and a Sense of Coherence

1. “Meaningfulness” through **Contribution**

2. “Comprehensibility” through **Acceptance**

3. “Manageability” through **Encouragement**

With this revelation, we were now ready to look at a full salutogenic theory about what works at Wellspring and how.

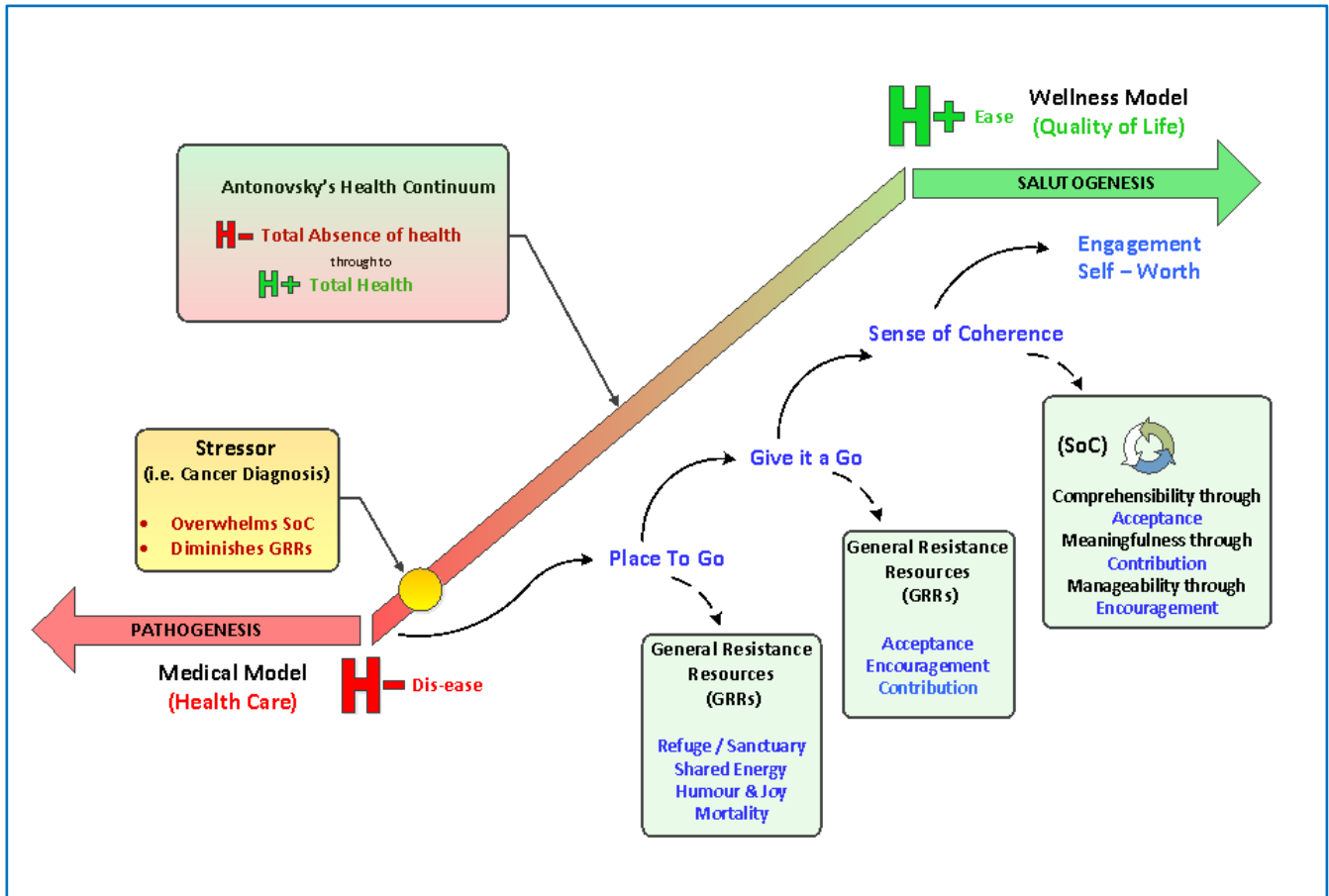
### **A Salutogenic Theory of Cancer Wellness**

This section presents the themes, sub-communities and analysis of the data collected in the case study within the structure of the theory of salutogenesis. The first component outlines the destabilizing of SOC and GRRs due to the overwhelming influence of stressors associated with cancer. The second section looks to Wellspring as an example of a “different sense of community” that has created unique and powerful GRRs that act as resources for cancer patients and their families. The third section looks to the reestablished equilibrium through three components of SOC, which relates to development of self worth and patient engagement.

The diagram below is a pictorial representation of the theory. The basic premise is that what we call health is actually a continuous dance between two poles: Ease, the pull to find wellness, and Dis-Ease, the struggle to avoid or overcome illness. The illness end of the continuum is well understood, but the wellness end remains overshadowed by the urgent pull of ill health.

Salutogenesis, the origins of health, considers that stressors (challenges to health) are to be expected. The onset of cancer causes a catastrophic disequilibrium and a rare chance to see the act of seeking health. The theory we present takes each component of the diagram in turn. First we deal with the destabilizing force of a cancer diagnosis and the stressors associated with it. This is followed by the description of the unique set of resistance resources that greet a newcomer to Wellspring. In the final section we discuss how the underlying actions of Wellspring not only are generalized resistance resources, but also act to rebuild a new normal sense of coherence.

Figure 10. *Salutogenic Theory of Engagement in Health at Wellspring.*



### ***Cancer as Disequilibrium***

This section has been informed by a secondary reading of the data to identify and categorize the stressors from our research as in Table 4 above. While the stressors were not part of the original question of “what works and how at Wellspring,” we found that, in order to understand how Wellspring represented a salutogenic organization, we needed to develop a more comprehensive understanding of the stressors that members bring with them to Wellspring.

The catastrophic impact of cancer is signaled by a flood of stressors. The fear of death, uncertainty and being occupied by cancer seem to capture the initial shock of diagnosis. The stressors associated with illness and treatment reflect pain, depression, and low energy. While these are a reality, the stressors most discussed are related to the losses and ongoing impact of living with cancer and “grieving life changes” (fg.08.05.13).

The stress of stigma or loss of acceptance includes personal loss of self, self-image, and roles. We noticed the pervasive nature of loss as a stressor in the many references to hair, loss of hair, and hair coverings that suggest that the shared experience of losing hair is a confirmation that someone is sick. While the impact of cancer is not visible, the loss of hair is visible. Some of the comments included: “it blows your mind,” “physical changes cause self-loathing like with hair loss,” “family doesn’t want to see a bald head.” This is particularly noticeable with women but one man talked about losing hair as a confirmation of sickness, “you can’t deny you have cancer any longer” (pc.JC). The other stressors related to stigma include self blame and guilt, being seen as different, having no place to be yourself, even loss of self.

There is also the experience of social losses, loss of your family role, your friends and colleagues. Becoming defined by cancer and weakness signals that you are no longer part of your former world. Your social life is defined by people associated with your illness, and your medical appointments and routines cause you to withdraw from former activities or friends. There is tension between your former world and from others who don’t know how to stay connected or to react.

You can’t talk to your friends, they just don’t understand, they just haven’t gone through it. They talk about getting a good support network. My friends are great, fabulous but they are useless. They don’t understand what you are going through especially when you look ok. I looked alright so they want to believe that you are ok... So how are you? (laughs) and they nod, and if you say, actually I am feeling horrible, they ask the question but you can’t answer or they are upset. (fg.08.05.13)

There are also pressures to protect family from the loss of your role in the family. Families have expectations about who you are supposed to be. When you have cancer you see yourself through the eyes of your loved ones who look at you with fear that you may be dying. So you pretend to be the old you and, in the metaphor of wearing a hat to hide your loss of hair, you don’t take off

the hat when family is around. However, at home “spouses want you to get past it,” and children expect the mom they are used to. This produces the feeling of “speaking to people who are not listening.” Home life changes completely because a couple who loved an active outdoor life together can’t do this anymore. The outcome is that the “spouse resents lack of participation in normal life activities” and continues alone. Both are “grieving life changes” (fg.08.05.13g).

In other words, the disequilibrium associated with cancer causes patients to be overwhelmed, they have no place to be themselves, they are in constant anxiety because of the uncertainty and the subsequent loss of expectations and anticipation of what life (and death) is supposed to be like. Their lack of connectedness and the inability to contribute lead to a fear of taking risks. The impact of being overwhelmed and lost in their cancer is often associated with depression and isolation.

### ***Generalized Resistance Resources***

The resources found in our two grouped themes, listed below, act to lessen the impact of stressors experienced by the members. One could consider that Wellspring itself is a GRR as a social environment that provides stabilizing resources to members and their families. It is a “Place to Go” to begin the process of engagement in health.

**The resources associated with a *Place to Go*.** We identified four stable (foundational) resources that make it possible for members to begin their journey to Wellness. These are:

- ✓ *Sanctuary/Refuge*. The physical building is indeed a foundation resource, the antithesis of a hospital or clinic, yet not a home or a place of work.
- ✓ *Shared Energy*. Opportunities to experiment and practice with physical, emotional and spiritual energy, alone and with others, is an essential antidote to the crushing loss of energy that produce many of the stressors associated with cancer.
- ✓ *Humour and Joy*. The light in this resource is a respite from the serious attention to the fears and stressors and a chance to practice being happy.
- ✓ *Mortality* is a resource because it exists along with cancer at Wellspring, but by its very presence it decreases its ability to create tension and stress.

**The resources associated with *Give it a Go*.** We identified three stable (individual) resources that make it possible for members to begin their journey to wellness. These are:

- ✓ *Acceptance.* Members learn from being with others who are like them that “I am not alone, others have cancer and they seem to be active and involved.” This relates to comprehensibility, the cognitive aspect of sense of coherence.
- ✓ *Encouragement.* Programs, volunteers and members create a “give it a go” atmosphere that implies the permission to try, to risk, to fail, and through this relearn strategies to cope and new activities to pursue and new supports in the learning process. This repertoire relates to manageability.
- ✓ *Contribution.* Volunteering is an essential opportunity in all peer support models. Belonging to a group implies responsibilities, you become closer to others and the program through giving what you can. You find meaning in belonging and finding ways to give back. This relates to meaningfulness in sense of coherence.

### **Sanctuary / Refuge**

*“I knew I needed somewhere: I wasn’t sure what that was at the time, but I knew I had found it at Wellspring. Here was a place where you could just go; talk to people or not talk to people. I could just sit and enjoy the space and enjoy time spent. A time when I wasn’t at home maudlin or at the hospital feeling sorry for myself or feeling sick. I came here and I got energized. I walked in through the doors to find a great atmosphere; and when I walked out the doors I felt better.” (Welcome Video, Wellspringcalgary.ca)*

*These are my words. The challenge for me throughout this research was in not leading the participants towards an opinion that mirrored my own; to let the data come out of the work and evolve freely. I had never really thought about what it was that worked in the Wellspring environment before carrying out this research or understood how it could be understood as a sanctuary.*

*(NO. PER researcher and Wellspring member)*

Wellspring Calgary, Carma House, Home Road; can it be coincidence that this building has been built with a great “karma” and is situated in “home” road? Here is a sanctuary built out of love by the many hands of volunteers (Annual General Report Year 2012). As a reminder to one and all, the very bricks on the paths to and from the door have words and slogans such as: “True to



Yourself,” “Live, Love & Laughter,” “Be The Cure,” “Mind Over Matter,” “A Brother Found” and “Empower Yourself” etched into them. Other stones have the names of departed loved ones.

Not unlike cathedrals and places of worship from all around the globe, it has large windows on the south, west and east sides allowing the sun’s warm energy in to the building. You step through the doors in to a warm central “nave” running east/west with doors at each end. You are reminded of Wellspring’s purpose as you see an oil painting of the Cancervive experience; two riders on their bikes, each with one hand placed on the back of a central rider, helping and offering support on their journey. You are also reminded of Wellspring’s history as, at the front door, there is a nod to one of the founders whose battle with cancer is over now but not before he helped establish Wellspring. In the centre of this building is the communal kitchen area where we see a large photograph showing all those people who helped build Carma House along with their names and signatures and comments of hope handwritten in the margins. This purpose is reinforced throughout the building in subtle ways.

### **Analysis:**

A refuge or sanctuary is a place of peace and simplicity that enables you to focus and replenish your strength. Wellspring is a safe-haven; a port offering shelter during the cancer storm. Cancer complicates already complicated lives, and to heal, simplicity is needed. The refuge is simple and yet comfortable, with elements of home. No expectations; “Wellspring is to me the creation of a safe-haven, for people to come and find the tools to heal themselves. It’s a place of peace, calm and hope” (Wellspring Welcome Video, [wellspringcalgary.ca](http://wellspringcalgary.ca)). Wellspring is a place to go, to find enough energy within you to just get there, to be quiet and let things be, a place to leave behind your load, your cares of the hospital, home or work; to decompress after news (fg.08.05.13). People break bread together in the centrally located communal kitchen. This space is open and laughter from here often permeates the whole main level. There are places you can sit or have tea, watch people or be with people enjoying themselves. The energy of the place can “wash” over you; no need to vent but you could, no need for commitments but you can. By simply showing up and you have accomplished all you have set out to do (fg.08.05.13).

## Relationship to Salutogenesis and GRRs:

As sanctuary it is a place away from other expectations, it holds cancer as present but not the focus. It is a place for you and your cancer, away from home. “Wellspring is a home front for me and my cancer,” “You are valued for just coming in the door,” “It was like people already knew me” (fg.08.05.13).

Refuge/Sanctuary acts as a generalized resistance resource to neutralize any and all the stressors members bring with them; by having a breathing space, it enables the externalization of feelings (stressors within), putting distance between yourself and them so they can be more easily managed.

### Shared Energy

*When I (Phyllis) was 8 years old people gathered in my street to celebrate the end of war. Seeing the exultant faces around me created an inner sensation of waves of joy. Perhaps this early memory drew me to the topic of Shared Energy.*

*I was invited to join Wellspring as a caregiver to a young friend who was having a reoccurrence of cancer. The caring energy seemed to flow through everything and everybody, inviting us to feel comfortable and at home. At the first opportunity I took a training session to become a front desk volunteer.*

*In doing my research I found that although I thought I had a pretty good take on Wellspring having sampled classes and attended longer seminars in a caregiving capacity I had not fully appreciated the level of attentive awareness in the teachers or in the levels of engagement of the members. I have gained a deeper understanding and appreciation of the scope and power of shared energy. Now I see it everywhere, in hugs, gestures, gentle touches, laughter, communication, as well as in yoga, meditation and movement classes. I understand myself better too, noticing what fills me up and energizes me, and on the other hand what depletes or drains my energy. With this knowledge I can make choices that keep me healthier and more balanced. (PhG. PER researcher and Wellspring member)*

When people come together for a purpose, energy is created and shared. The concept of Wellspring itself was developed by people with new ideas of how the needs of cancer patients and their families could be better served. The building also was created through the energy of volunteer workers. It's hardly surprising then that shared energy is a foundation of Wellspring.

To illustrate this, we share with you a sampling of the many energy options available at Wellspring.

**Restorative Yoga** invites you to “Move into the body with effortless, supported poses and gentle breath for deep relaxation and rest” (Wellspring Program Brochure, 2013). In our observations we noted that:

In this relaxation and restorative movement class the participants all seemed “to know what to do.” As participants arrived, they set up their equipment, and on understanding that one observer was going to take part, someone set up the equipment needed for the class. One lady was already in deep relaxation with a little bag shielding her eyes from the light. As participants arrived they communicated quietly through smiles and whispers (po.22.04.13). In doing this they were acknowledging the quiet meditative atmosphere already being created, and supporting it. Someone had also prepared a place for the teacher (pc.PhG). When the teacher arrived she was welcomed by smiles and nods that did not disturb the current of relaxation energy already present (po.22.04.13). The teacher was welcoming to our presence as observers also, knowing that we were going to be there (pc.PhG). The teacher visited quietly with one person, listening to her and giving comfort by stroking her shoulder (po.22.04.13). When the work began everyone was deeply engaged. As the teacher guided the movements she also moved among the participants, gently adjusting parts of the body (po.22.04.13). In doing so she seemed attuned to the level of comfort each person was experiencing (pc.PhG). Even just sitting in a chair observing an inner response can be felt followed by relaxed attentiveness. In reflection the energy contained in the level of attentiveness and engagement of the teacher influenced the experience of the participants. (pc.PhG)

**Spring Forest Qigong** creates energy through practicing together (po.25.04.13). “Balance physical, emotional and spiritual energy, use breathing, visualization, simple movement and sound to relieve pain, stress, depression and more” (Wellspring Program Brochure, 2013). From our observation:

From the outset the teacher spoke to the value of the energy created by practicing together. Since participants can work at their own pace and level of movement, they are able to own and manage their bodies in this class. Some stood and some sat on chairs. They also worked with energy, creating energy and shaping it into a ball that they could hold in front of them (po.25.04.13). As an observer I had difficulties resisting doing the class along with other members. This class creates a different sense of self, a sense of going beyond oneself (pc.PhG). At the conclusion of the class participants appeared content with the class and thankful to the teacher, some putting their hands together and bowing gently. (po.25.04.13)

**Tai chi** promotes balance, coordination and a healthy immune system and may relieve pain and brain fog. An excellent stress relief tool, Tai Chi brings peace and calmness to your day” (Wellspring Program Brochure, 2013).

One of the researchers who was participating in the class noted that the experience of “internal heat.” When the “internal heat” sensation did arise, the experience was quite awe-inspiring. This was not about physically perspiring, but a heat that emits and radiates from the inside out. I had not been experienced this heat in other Tai Chi classes I had attended. It lasted approximately 36 hours and brought with it a peace, calmness and a profound sense of wellbeing for that time. (pc.JC)

**Personally challenging movement classes** where practicing together creates a shared inner experience of both exhaustion and pleasure. In the Healthy Steps class, a vibrant teacher leads a group of participants in a variety of movements that are stimulating and energizing. Some parts require concentration and exertion and it all adds to the shared energy of fun and laughter. You end up feeling like you’ve done something good for yourself and attended a party (pc.PhG). The moves in rhythm class has provided another ingredient.

The Moves in Rhythm class is initially challenging, but you gradually pick up the moves and they become a part of you. This is not without personal effort, which gives way frequently to both laughter and humorous despair. However, there is a great payoff. Besides creating a sense of joy in practicing the movements together, the participants regain and maintain flexibility that enhances their overall sense of wellness. Another component of this class is that it winds down with a meditation which participants greatly appreciate. (pc.PhG)

**Healing touch energy sessions** do not rely on meditation per se, but focus on shared energy. Tired people come and leave with energy.

**Meditation.** It may be counter-intuitive, but it seems that energy is augmented with controlled breathing, focus and relaxation. The foundation of meditation practice brings quiet and stillness that grounds you and enables you to be deeply with yourself. This enables you to be open to sharing energy with others in the class, group meditation combines individual energy into a wholeness that is more powerful.

There’s a lot of hugging at Wellspring. Physical touch is often lacking in our society. The energy it transmits is therapeutic and reassuring in its ability to envelop the person. There are no “pretend hugs.” Sometimes a person you know just walks over and reaches out with a hug. On

other occasions you may get an invitation. Someone might say, “Have we had our hug today?” or, “I feel I need to hug you.” People at Wellspring may be very busy but still stop and hug you. It’s like saying, “I may not have time for a tea and a chat right now, but I can always give you a hug.”

Besides hugs, there are other physical gestures that exude warmth. A person might hold your hand and notice that you feel cold. You find your cold hand being warmed by someone who tends to be too warm. Warm hands are embracing your cold one and two people are receiving what they need. Someone is speaking of a difficulty and a comforting arm is extended across their shoulder. There is a need for physical touch at Wellspring. Perhaps it’s a way of exchanging understanding without talking about details. It could be happening because we have experienced shared energy through classes we have taken together and we have found ways to communicate that are comfortable for us.

### **Analysis:**

The focus on energy is natural at a cancer program because the treatments deplete your energy; people feel extreme stress at the loss of energy and fear that it may never return. Members are aware that they may have to take care of their energy, manage, conserve, and build energy. In response, the program has many alternative energy classes so that people can experiment and uncover/discover their own way to connect with their energy. You can find what feeds your energy naturally. The sessions and the classes facilitate the sharing of energy through sharing experience. There is a commonality of cancer at Wellspring that makes it easier to share experience and energy.

### **Relationship to Salutogenesis:**

Shared energy as a generalized resistance resource is a well; people come to draw on the shared energy to replenish individual and collective energy. In doing so, it can quiet anxiety about the stress of low energy. The acknowledgment of the existence of collective energy brings hope that the stress caused by low energy, can be balanced by the group’s energy.

The generalized resistance resource is the abundance and expectation of energy that comes from purposeful engagement and connection with others. When you try an energy activity, you notice

a difference in yourself. You feel some kind of an inner response and you feel fresher, newer, and more hopeful. You hear some words spoken and you personally relate to what has been said. “This is good for me,” you say to yourself and you feel invigorated by the thought. The group energy supports and balances you.

### **Humour and Joy**

*I was anxious to report on the community of humour and joy at Wellspring because I had used humour extensively in my lengthy nursing career as a means to connect with my patients and get them actively engaged and contributing to their wellness. As an author I wrote a book about leveling life's playing field through humour. I believe humour gives birth to joy which nurtures hope, which ultimately changes the filter through which we view the world and our place in it. It seems capable of softening the blow of reality.*

*As a Wellspring volunteer I saw hope acting like a brace to shore up the member, the family and the caregivers who were making the cancer recovery journey together. Because my point of reference had previously been grounded entirely in the clinical presentation, it was very gratifying to me to actually see how effectively members used humour as a coping strategy to release stress in a non clinical, community setting! Being able to put a humorous spin on hair loss, brain fog, loss of employment and relationships attested to that. (CM. PER researcher and Wellspring member)*

In an art class a member explains how she has been spending so much money on supplies and paint:

Each time she learned a new art form she went out and purchased everything she needed to do the project at home. Finally one day her husband looks at her work and says, “You have to stop buying paint. You are not good,” so she bought more paint (po.17.04.13). There is a constant flow of humorous remarks during the art class as the group viewed each other's work. A high comfort level and a keen desire to have fun is demonstrated by another member who says, “I come here just to play.” (po. 17.04.13)

A front desk volunteer chats with family members who stay on and wait for their spouses to complete their class. One gentleman would sit near the desk and share jokes and humorous stories to anyone coming by who stayed to talk with him. He seemed able to find humor or link it to almost every facet of his life. His wife explained that she did not see him sit and chat and laugh anywhere else like he did at Wellspring and she was so appreciative that we allowed him to do this. (pc.CN)

Joy starts at the front door where each person is greeted with smiling eyes and hugs. Humor is used often as a structure, activities start and end with humor. As observed in the Tea Gathering Group,

Laughter began this one and a half hour gathering, easing nervousness as the group came together for another week of discussion. Throughout the time were small humorous comments lightening the dark conversation about coping with cancer in members' everyday lives, happy chatter about women and hair color. The topic continued with hair and curlers and memories of youth, hair dying, hair curling, hair straightening and lovely laughter although of the nervous kind. The members seemed eager to talk, with exciting and happy voices as if they hadn't talked for years. Some now, reflecting on gray hair and as well success through stressful times. Laughter still, but on "thoughts of tougher times." More serious conversation begins about cancer and hair loss, change of color, frizzy, curly and each person having a clear experience that is different from the other. Most members are very animated. Now someone talks about slow hair growth, thinning hair, and talk is of more concern about "hair accidents at the hospital mostly embarrassing ones." All sounds stop and there seems to be a release into quietness. It has only been 13 minutes into the group. (po.23.04.13)

Although there was serious talk, the group ended with a funny story; a way to physically laugh, to leave with a fun memory, and to share something new and happy together. Members seem relaxed now. The tensions that had risen have now fallen.

The facilitator asks if the group could now have "the Reading Story" component of the group, which appears to be a winding down task asked by a different member each week. The story is about a wedding and a duplicate dress that another family member is also wearing. The result is lots of laughter from the members and similar member stories of "expensive dresses flaunted by others and a bird pooping on it." There is lots of laughter again. The member says, "this story makes her laugh every time she thinks of it." Members appear to be satisfied to end class now. Members from the Tea Gathering Group are now in the kitchen with members from other groups contributing to the cleanup and share time in the kitchen. The kitchen area is open and communal ... everyone is welcome there. It is like the hub or engine of the house and usually hums with sounds of the joyful sharing. (po.23.04.13)

Like the farm kitchen, this is where the laughter reigns. (po.23.04.13)

Members report, "There is joy and humor here. My special joy is that members allow themselves to be known. People are authentic and real here" (fg.08.05.13).

### **Analysis:**

As cancer survivors we are wired to be vigilant to be prepared to walk into the war. Humour gives us a place to live where there isn't a need to be vigilant. It allows us to be softer with our life, to smile, to provide a time to heal, a buffer within our vigilance. We can put the cancer to one side and enjoy life's gentle humour. At Wellspring on the main floor you can tune into gentle

humour in the kitchen. Gentle laughter lives in the creative classes, shy giggles about our shared inadequacies in art. The humour would come in waves in the Open Art Session as everyone appeared to be “on the same page when a task was completed ... they could relax. The humour seemed to take everyone out of 'cancer' and if only for that morning, put them in a 'new zone'” (po.26.04.13).

Humour lets us join in through our shared amusement at our accidents, shortcomings and embarrassments. Through laughing at the little things we get to practice laughing and build up to laughing at the bigger things. It is a way to master the art of humour as a recovery tool or a means to resilience.

Humour can be dark when it comes close to our fears and loss, and in the process humour can reduce the stress and anger about cancer, treatment and even death. You can spend time talking about your illness and using it to connect with people who are like minded through humour. It takes the critical out of critical.

### **Relationship to Salutogenesis:**

Humour and laughter act as a simple, profound resource and one difficult to use in clinical or professional settings. The opportunity to laugh at a funny story, our own foibles, cancer and death is a scarce resource for most cancer patients but one that is sorely needed. This resource is insider humour, a humour not appropriate with outsiders. It is used to diminish the enemy, the pain, the power of the system and in the process act and take action, feel reward and power.

Humour is also an effective resource to use in making connections, or reconnections with those around us. Because it is the opposite of pain and loss, it offers a feeling of hope that pain and loss can be navigated and survived. At Wellspring it is used as a coping strategy, and a release... a way to diffuse the intensity of feelings that have the potential to sabotage going forward. Humour at Wellspring does not suggest a lack of awareness of the gravity of life's situations but does suggest a desire to put a new spin on them!



## Mortality

*I didn't choose this topic. In fact I fought against doing it at all. Therefore it was deemed to be a good exercise for me. I rejected it because our focus at Wellspring is to "celebrate life" so that's where I come from. However, I can see that mortality does happen at Wellspring, and that when it happens we cannot deny it. I am not at odds with death as I have attended grief classes at Wellspring in a caregiving role. My research about mortality has expanded my senses. It's as though I have a new lens to view the world through. My husband gets the same feeling from hiking and scrambling up mountains. We often wonder which of us will die first and each talk of how we might manage. I always assumed it would be me since I am the less fit. However, having survived a year-long course and finding myself with some exiting new understanding and skills, I am renewed and forward looking. (PhG. PER researcher and Wellspring member)*

This resource was a source of much emotion and confusion during the long analysis process. We found very few direct quotes or references to mortality in our observations and the focus groups and yet, the topic continued to haunt us. In order to handle this difficult topic, Phyllis and James were asked to return to data collection about the presence of death. This involved a number of interviews with staff, volunteers and members.

When people die from cancer, their obituaries often speak of having fought bravely, the idea being that cancer is an enemy that we struggle with and resist to the end. So the obituary quote "She lived successfully with cancer" suggests something different. Although death is a reality for everyone, not everyone who experiences cancer dies of it, so the focus at Wellspring is clearly on the celebration of life.

Members who come to Wellspring have spoken of feeling resistant at first. "I returned to work with reduced hours and punished myself by working too much" (fg.08.05.13). So there is some part of our nature that urges us to fight and keep going when challenged by a stressor like cancer, but there are alternative ways to respond. "Surrender is not giving up, it is opening up" (fg.08.05.13). "Whatever life is left, you don't want to waste it" (fg.08.05.13). "I can't live like this, I have to move on" (fg.08.05.13). In adapting to ideas like these, members show a willingness to discuss issues and problems, and find things that work, like becoming more open minded, trying

out new activities, accepting change and seeing new possibilities within themselves and the life being lived.

And yet, death happens to everyone and it takes its toll at Wellspring just as it does in society at large. For this reason a Memory Book was created in the early days of Wellspring Calgary at its original location in Parkdale. The book was started to honour those Wellspring Calgary members who had passed away. It was situated in the library on a stand. This worked quite well as the library was visible to everyone. In Wellspring Calgary's beginnings, some or all of the staff would attend the funeral of a deceased member. This was doable because the membership was small. As membership grew, this was no longer possible and also the workload of the staff greatly increased. Thus, the Membership Book took on greater significance. One of the Wellspring volunteers took on the task of assembling the Memory Book. It was put into a decorated binder and included the obituary of the deceased and other relevant details. There are now three Memory Books which can be found in the Peer Support Room of Wellspring's new location at Carma House.

Two years ago obituaries in the Calgary Herald were checked against the Wellspring membership list instead, ensuring family of the deceased would no longer receive mail from Wellspring. The applicable obituaries would be placed in the Memory Book.

About a year and a half ago we began taking time on the last Wednesday of each month to honour deceased members. At 4:00pm, all available staff members and volunteers and others meet in the Waterfall Room. A candle is lit and we form a circle. Someone may say a prayer, poem, or sing a song and the names of the deceased are read aloud. A rock is passed from hand to hand to ground us. Everyone present then holds hands and by squeezing hands the hand hug proceeds around the circle. This completes the ritual which is quiet and unobtrusive in nature. However, it feels valuable and satisfying to those who are present. It feels good to have spoken the names and taken a few minutes to remember that they once walked among us.

A very popular class at Wellspring is "Creative Journaling." Here members have the opportunity to create a very special book about oneself. No previous experience is necessary, but participants explore a variety of art media and powerful writer's exercises that go below the surface of day-

to-day life. “The blank page will fill with personal words and imagery. This is a no pressure, guided class that shares laughter and discovery” (Wellspring Program Brochure, 2013). On the occasion of an Open House, participants can if they wish allow their journals to be exhibited. The journals are very engaging, it’s difficult to tear oneself away from them. Visitors almost seem to be hypnotized by them, they are so beautiful and special. It occasionally happens that a participant in this class sees the possibilities of the journal as a comfort to family and as a part of their funeral. If this is an expressed interest the teacher will aid in the completion of the journal outside of the class. The outcome is that it is a great comfort that plays an important part in the celebration of life, where it vividly represents the person.

### **Analysis:**

When Wellspring began it was smaller and more intimate. Almost everything was on one floor so it was easier to take in all that was happening. Members were more likely to know one another. With smaller numbers, and members mostly recently diagnosed, death was a rarity. If a death occurred Wellspring staff were more likely to be involved and members were more likely to attend the funeral. Now the idea of a community that shares a person’s dying is beyond the capacity of the staff and volunteers to maintain. This function has been taken up more informally by those who come to know each other more personally. It can happen that an exceptionally large funeral happens and many more staff and members go because Wellspring has been kept up to date on the progress of the illness, the death has received media attention and many people are expected not only from Wellspring but also from the larger community.

Since we think it’s important to keep track of our members and acknowledge their deaths, when a rumor of a death came and we couldn’t verify it through normal channels, many staff and members felt upset. The member had attended classes fairly recently and we were uncertain as to whether the person had died or not. This “not knowing” was distressing because without definite knowledge we could not reach closure.

Wellspring is a force for celebrating life in the face of death. Wellspring can be a haven for someone who is dying. There was a young woman who spent some time at Wellspring, almost every day for as long as she could. She was well known by all and much loved. In the face of

death her spirit glowed with light and life. Perhaps she was just an exceptional person, but she taught us so much, by showing what is possible, that even though death is near, it is possible to remain a vibrant, living presence until we actually depart.

In two movement classes observed there were people with quite different levels of physical ability who were able to do the movements accordingly. It was beautiful that in the moment everyone could be supported in an activity that was beneficial.

### **Relationship to Salutogenesis:**

Through familiarity death loses its interest or power. It is no longer about losing the battle to cancer, it's about living each day the best you can. Mortality as diminished by familiarity is indeed a resource, it is present, and a reality but not in control. It just is.

Resources surrounding death are naturally built within the programs at Wellspring where teachers, members and volunteers find ways to be naturally supportive and bring comfort to participants. In this way members can continue to attend classes, even in circumstances of declining health.

### **Acceptance**

*"This is the only place that I go without the hat ... It means I can sit here today without a hat. I don't go anywhere without a hat, I always have a hat on, including in my own home. But I can sit here without a hat on. ... They accept people who have gone through this. I am still emotional enough that walking around the streets ... looking like this ... I couldn't do it, I absolutely couldn't do it. I was never confident enough to do it. ..." "It's only recently that I am able to do it. I have an outdoor hat and an indoor hat, I still have my indoor hat in my purse but I haven't worn it for three weeks. There is that acceptance that ... there is common ground here." "The only place where you can go and be your true self, not hiding because there is a community of acceptance and understanding." "Wellspring has been the main contributor to transition into my new life. I made a choice to become engaged and I needed a variety of programs for support. I needed to get out of the house. People here understand, they've been through it. Friends had trouble understanding what I'd been through, expected me to be okay. My husband says, 'Wellspring is your place.'" (fg.08.05.13)*

This story became an extended metaphor/theory of the findings related to the GRR of Acceptance that exists at Wellspring. It is a metaphor of acceptance because it embraces the loss of acceptance felt by those living with cancer and the attempts to hide or control loss ... the loss of hair for example. It also captures the symbolic act of taking the hat off which here stands for feeling accepted enough to present oneself without covering the loss.

There comes a time when you realize the need to find ways to be part of the world, to connect to something or others who are like you. When you come to Wellspring you are coming to a place where you can see others who have taken their hats off and are accepted.

There is that acceptance here because others have gone through at least what I have gone through, or variations of it or worse than I have. (fg.08.05.13)

My initial reaction was 'ahh', I have arrived and I'm relaxed. It's a combination of home, church and team. Home because you are welcomed here. You're just accepted and you can do dorky things. The church aspect what like a religion you are sampling for the first time...

...I am out there hugging trees and trying to sense the energy. You are totally accepted as part of the congregation and whether you like it or not they are carrying you along. You may not know where you are going. The team, you don't have to have special skills. ... when I was in France, we had a bike with eight seats and every seat had to be filled but here you don't have to pedal. You are just carried along. When you do that, you are becoming part of the team. (fg.08.05.13)

When you see that others are being honest about their feelings you realize that there is a place to be honest to yourself without hurting or frightening others. ... When I take off the hat, I announce to myself I that I am not the person who is weak, the person who is trying to protect others first. I am saying that I and my cancer are here, and can look at the stress and the cancer that I bring to Wellspring. (fg.08.05.13)

A person comes into a group, takes her hat off putting it on the table as a way of declaring her space and feelings and experience and as if to say,

"I engage with myself to feel and share my vulnerabilities"(fg.08.05.13). "I am grappling with the new part, what comes next, so what is the new part I am feeling like the caterpillar in the cysallis waiting to emerge and I don't know what it is going to look like" (fg.08.05.13). "I am saying I have cancer, I am one of you, I am ok to be me here, I am angry, I am sad, I can laugh." (pc. NJM)

The power of sharing distressful emotions helps members confront personal blame, a common outcome of living with cancer according to some members.

It is almost as if people learn that there are shared experiences of distress that help them realize that by sharing common stress, it is not their fault or because of them. It is like realizing that other people's husbands don't know how to help so maybe it is not because I am not able to make it work but that cancer causes problems that are beyond my ability. (fg.08.05.13)

Acceptance is reciprocal and self-fulfilling: "I become part of the community and accepted because I accept," "I need to be here." It is a very personal, if unconscious act enabled by the ethos present at Wellspring Calgary. "We are all in this journey together." The job of members is to let people be who they are learning to be and to share what they can voice and name. The resource of Acceptance is powerful and confusing. One example from participant observation caused much discussion and debate. During a casual check in, a young woman said that her cancer had returned for the third time, the members nodded and moved to the next person. She was able to share this because her news was accepted without the need for comment or intervention from others.

There are expectations and boundaries that create a safe space to learn from acceptance. "I have difficulty asking for help. I was tired of trying to help myself. I came here on faith because I couldn't do it myself." "I didn't know what to expect. It was like heaven when I finally got there. It was like people already knew me. People had to encourage me to do things. I bonded with others and we talked together. Life changed. The readiness factor was huge for me – crucial" (fg.08.05.13).

At Wellspring more happens than the eye can see.

Walking in is like an embrace of loving kindness:

Persons entering Wellspring for the first time possibly have experienced very successful work lives, where their abilities and achievements have been looked up to and recognized. However, whether or not this is true, everyone who comes to Wellspring after cancer is a beginner of sorts, a newcomer entering a new field of work and play. It is hard to have to ask for help and admit to a loss that leaves you feeling alone and vulnerable. People who reflect on coming to Wellspring often say, "I didn't know what I needed, but I knew I needed something." (fg.08.05.13)

To connect with a community of unconditional acceptance and understanding is a boon. There will be many in the groups that will see you as they were in the early part of their cancer journey. We learn from their experience and they reaffirm their transformation in the process. Their encouragement and willingness to bond and share is a natural act of loving kindness. “There’s a pleasure and relief to openness” (pc.NO).

Some come to Wellspring deciding the time has come to test out who they are becoming. This would be difficult without the acceptance offered at Wellspring.

When you come to Wellspring it is like coming to a place where you can see others who have taken their hats off and are accepted, strong, and offering. Taking off the masque and to finally be the person I am. When I am taking the hat off I am expecting something new. I am saying I have cancer, I am one of you, I am ok to be vulnerable here, I am angry, I am sad, I can laugh. (fg.08.05.13)

From the Healing Journey One Class, one half were in tears and they could be free, let it out, there is no one to defend against (po.17.04.13). “Leaving the hat off I’m expecting something new. What is the new part? I feel like a caterpillar in the chrysalis” (fg.08.05.13). “I can blurt out everything and not be judged. Because of the accepting nature of everything and everyone at Wellspring no one has to be concerned about what we think, do or say. There is such freedom in that” (fg.08.05.13). “There are no 'walls' at Wellspring. Everyone is very accepting of what we have to bring. No pressure at Wellspring means a calmness that results in less pressure on the spouse and family at home. At Wellspring there is an automatic connection with others. Friendships can be forged that take us out of our isolation. People here understand, they have been through it” (fg.08.05.13).

### **Analysis:**

In many ways, acceptance is sanctuary in action, acceptance provides the safety so you can begin to believe that it is possible to travel inwards to discover yourself, the new you. This acceptance of cancer enables you to integrate cancer as a part of who you are but only a part, it no longer defines who you are. This is important because for many people, cancer has overtaken them and they actually can’t let it go, so you need a place that is identified with cancer within which you can come to own your cancer.

Along with the hope that comes with acceptance of a new reality is the removal of self blame. People learn that the stress that has invaded their life is not their fault, it is a common outcome of living with cancer. The group discovered the following examples:

It is almost as if people learn that there are shared experiences of distress that help them realize that by sharing common stress, it is not their fault or because of them. It is like realizing that other people's husbands don't know how to help so maybe it is not because I am not able to make it work but that cancer causes problems that are beyond my ability. (fg.08.05.13)

When I take off the hat, I announce to myself that I am not the person who is weak, the person who is trying to protect others first. I am saying that I and my cancer are here ... and can look at the stress and the cancer that I bring to Wellspring. (fg.08.05.13)

### **Relationship to Salutogenesis:**

Acceptance as a route to comprehensibility enables people to learn from looking at the stresses in a safe way and in the process acceptance diminishes the power of the stressors to overwhelm. When stressors are considered as a natural part of life / of the illness / of the treatment / of the stigma, the stressor is no longer personal. Acceptance brings a balance, you are not to blame for the powerful stressors that accompany cancer.

### **Encouragement**

*Encouragement is something I have been witness to all my life. As a young girl listening to stories of my family as immigrants and how they encouraged each other through trying times. Watching friends with young families struggle through cancer I was amazed that there was always someone who showed up, out of the blue, to encourage them. Encouragement is complicated and simple at the same time. There is openness about encouragement. My job has been to be present to encourage. Maybe it's a bit of a lost art that needs practice in today's society. However with openness and honesty, you notice the opportunities for people to learn from trying, at Wellspring encouragement is expected. (PG. PER researcher and Wellspring member)*

A new member who was on an orientation tour of Wellspring Calgary was shown the Art Room and was introduced to the members who were busy on their projects:

The new member made tentative eye contact while describing a deep depression she had been battling for months. She said she was "desperate to try something to help herself get going, but that she was fearful." She was feeling more and more isolated. The group and



facilitator in the Art Room began to encourage the member to attend at the Open Studio classes as a non-threatening way to meet others. The members showed the work they had been doing and reassured the new member that she could master any of these art forms because they had. This was accepted with a smile and an agreement that the new member “was going to come back next week.” (po.26.04.13)

Art class facilitators often inspired and motivated with confidence builders, for example, by saying, “Do something today you have never done before,” “Don’t keep repeating your successes,” or “Push out from what is ordinary” (po.26.04.13). Members are encouraged to try new things in an environment that ensures learning and creating without risk.

Members decide the direction they wish to take and volunteers, staff, facilitators and other members encourage. For example, the Tea Gathering Group members encourage each other to try some of the other Wellspring programs and they did this through leading by example. Resources outside Wellspring are shared by members in this group too, and sometimes friendships develop outside Wellspring (po.23.04.13).

Members are encouraged to be themselves while meeting and taking risks to try new strategies. The cancer journey is sometimes described as a “battle” by cancer survivors, so in that context, Wellspring encourages their members to take a break from the battle by changing or rebuilding focus on the everyday. One member summarized it like this: “Wellspring gets you out of your bubble. There is a rhythm and balance that you can take elsewhere. You can reflect on what happened here and connect the dots. You can learn to fill in missing pieces” (fg.08.05.13). Taking control can begin through the simplest acts of encouragement.

Encouragement by facilitators also takes many forms as noticed in a speaker session on Detox Your Home. As a volume of information is shared, the facilitator encourages members to “take in what you can and start with just one simple idea. Apply this information into your home as you can manage it” (po.24.04.13). Alternatively, encouragement by the facilitator in the Qigong class is experimental through breathing and “trying to feel the energy you share in the class, to feel something different” (po.25.04.13).

There is diversity among the members’ needs at Wellspring. A large variety of programs are provided for support. “I was amazed by the variety of programs at Wellspring and they are all

free. It is a catalogue of offerings” (fg.08.05.13). The members are grateful that the programs are all under one roof and there is no need for more travel, “one stop shopping” (fg.08.05.13).

Wellspring is ever mindful of loss of stamina in its members.

Wellspring also encourages by expanding and building on what you already know. “You can develop new skills with an arsenal of tools” (fg.08.05.13). “The community at Wellspring helps you deal with what is, and keeps it real” (fg.08.05.13).

Encouragement can also be about “powering down self-criticism”: “There is more to me than my suffering,” “The only thing I can change is the way I hold the suffering” (po.17.04.13).

### **Analysis:**

Coming to Wellspring Calgary is about the courage to try. It is a way to action, to make a decision. Encouragement provides the permission to fail or succeed, it just doesn’t matter. To try means you are automatically going forward. For example, helping women manage the appearance related side effects of cancer is encouraged by providing free makeup, free training and supervision in the space Wellspring provides for the community program Look Good Feel Better. There is a lot of trying by example, people try out new looks.

Because so much has been lost, things are so different, energy is so low, encouragement is subtle and caring and enables people to set their own limits and feel comfortable within their own boundaries. Encouragement is a personal resource; it is not about the trying for the group. Members are encouraged to find their own way.

The Wellspring Calgary public relations document (Annual Report, 2012) is also designed to encourage people to come to Wellspring through the use of stories of ordinary people with whom you can identify. They talk about trying new things. Once there, you can observe others enjoying doing things they haven’t done before. It is a gentle encouragement without pressure.

Members are often surprised with the lack of expectations about their attendance and commitment: free choice in attendance, drop in, what works for you, the programs you choose, all reduce the fear of trying. What you bring to Wellspring is good enough; you offer what you

can and do what you are interested in. It is like a bowl of jelly beans, you can keep trying until you find one that tastes like bubble gum. Because programs are free, people can try without high expectations, or loss. There are no consequences to not doing well, for example in the Watercolours Just for Fun program (Wellspring Program Brochure, 2013). Drop-in allows members to mediate their energy, come when they can. What members produce or try is celebrated naturally by others as an accomplishment. The celebration is for the trying. The celebration is not about success but about finishing something meaningful to members.

### **Relationship to Salutogenesis:**

The stressors like isolation, fearing the unknown, and the fear of trying again in the face of the limitations, losses or deficiencies are lessened with encouragement that supports learning to risk without fear of failure. When people come to Wellspring they have decided they can't do it on their own and they know what hasn't worked. Wellspring provides support at an elemental level of trying.

### **Contribution**

*I sat listening to the other team members discussing volunteering as contribution while I focused on contributions of members as essential to an understanding of contribution as a resource.*

*I witnessed contribution by members when they showed up to Wellspring and gave of their presence, joining in community, looking to share kindness a smile or a hug, or a place to belong again and to have structure and to sit with others. I saw in a tea group how much contribution was the essence of why the group existed. Some members at Wellspring wanted to volunteer after they had healed from their cancer struggles and give even more of themselves. I am one of these members.*

*This journey of contributing in a community seems second nature to anyone who shows up at Wellspring whether it be as a member, volunteer, staff, facilitator or donor. Contribution links all people present at Wellspring. (PG. PER researcher and Wellspring member)*

Contribution has its beginning in membership in a group that has deep meaning for you. Membership denotes that you belong to a group and therefore have responsibilities that provoke inner responses that cause individuals to become closer to one another and so to the group.

Wellspring members bring to the Tea Gathering Group the preparation of food, tea, a humorous story, themselves and contribution to clean up. Nothing however is as valuable as the voice they bring to contribute with. Without these member contributions there would simply be no Tea Group. Someone talks about this or that, they all appear to like each other's conversations (po.23.04.13). Members help brainstorm resource ideas for each other and are reminded that they have each other's phone numbers and help each other with tasks outside of the Wellspring community. (po.23.04.13)

Contribution is also evident within the workforce at Wellspring. With almost 200 volunteers Wellspring Calgary receives over 9,800 hours per year by volunteer's generous contributions. A large piece of Wellspring's workforce is made possible by the contributions of members, volunteers and many facilitators and donors. Also mentioned in the 2012 Annual Report is how Wellspring Calgary "freely offers space to many community groups who share our mutual vision of supporting those living with and beyond cancer" and "honoured to do this."

The Cancervive program at Wellspring allows for the development of contribution on a multifaceted level. Simply show up at Wellspring's doors to learn how to bike across Canada and in return help support someone struggling with cancer. The team approach of contribution allows the cyclist's struggles to parallel the struggle of the member with cancer. Each person supports the other through their different struggles and each make gains in self worth through contribution (fg.29.10.12).

Contribution also occurs when members become volunteers and supporters. "As I grew stronger, courses helped me learn how I, the caregiver, could help myself – and how I could start offering an empathetic ear to my family and others in my position ... I am proud and happy to now be a volunteer, supporting others on the cancer journey at Wellspring Calgary." (fg.29.10.12)

### **Analysis:**

The culture of contribution at Wellspring whether it be volunteering or other types of contribution make it possible for everything to be free for members. People want to contribute as part of coming to Wellspring because of the value of what they receive even though it is not expected. Contributing is also marks a shift in members as they are officially recognized for being part of peer support.

It's seen as a sign of health when a person has gained enough strength that their own resources won't be depleted by contributing. The ebb and flow of knowing when to let others give to you and when you have the resources to give to them is the matrix of healing. With this, healing through contribution improves self-worth and can be of great benefit to members. It is a privilege to be considered a helper.

The contribution of members giving back builds a sense of belonging. In the Qigong class members experience sharing energy and are reminded that by practicing healthy choices with other members is also key to your own health (po.25.04.13). Good health can be shared and member's health can improve when joining with other member's contributions.

In Qigong, I found a great way to ease back into exercising again, as well as to quiet my mind. There was something profound about practicing with a group of other cancer survivors, all of us doing all we can to get well, physically and spiritually, and all looking to find some peace in our lives amid the chaos a cancer journey can bring. I left these classes feeling reinvigorated and tension released. (Annual Report, 2012)

### **Relationship to Salutogenesis:**

Contribution gives meaning and provides purpose in life and is generally altruistic in nature. This helps to ground self worth and maintain coping against such stressors as isolation, lack of focus, lack of participation, lack of purpose, and lack of routine: "I felt reinvigorated being surrounded by others" (Annual Report, 2012).

### **The Journey**

Since this case study is the first to utilize patient engagement research, we have tried to record our experiences for those who follow. It was, above all, a chance to research together where everyone was an integral part of the process with much discussion, a little dissention, and a lot of excitement as the study progressed.

As we sat in our internship classes we were struck by the reality that we were actually going to put what we were learning into practice: producing a publishable PACER report. As a group we felt we all now shared a passion for letting the patient's voice be heard, we chose research that we thought really meant something and really mattered. We leapt at the chance to do our

research in the topic of cancer. After all, we were different now; different in a feisty way. As we began to talk about what specific research we wanted to study we realized very quickly that our energy for this research was grounded in our shared experiences of Wellspring Calgary. That was it. The research would be on patient engagement at Wellspring. We thought we knew what we were about to take on but we had only our personal experience. How were we to use our experience but still move beyond it to talk to others in such a personally real topic?

Our team battled on the white board, on the chalk board, and on the flip chart paper racking our brains about specific questions we could ask patients/members at Wellspring. Would they be called patients or clients or members? We had to think differently and be observers of this process as well as of Wellspring. Since this kind of research had not yet been done with a community-based support centre, we had to look at that first. We would do a case study on a community-based support centre's members and their engagement in their own health. Our research topic was born. The key question we were looking to answer would have to wait for another day. That question eventually arose all on its own when we were looking at the kind of methodology we would employ. What is it that works for the members at Wellspring? How does Wellspring work for the member? And there it was, our question. What works at Wellspring and how?

When contemplating our personal achievements from doing this research project, first thoughts were about how much there was to discuss. Simply looking at the beginning of the process, going into the study whether as a member or a volunteer already at Wellspring, there was some certainty that we knew what the members were going to reveal. We were wrong. Secondly, researching an institution that was specifically a cancer resource centre could be thought of as easy... take the members who were already there, observe them attending the programs, discover how this attendance impacted on the member's wellness and ability to stay well, and report back on what was learned and that's it. Done... and also wrong. There was so much more rich data and integrating themes that emerged from this process. There were also hurdles to overcome. As research interns we watched each other's personal hurdles vanish. Confidence in writing, communicating, listening attentively, growth in self-esteem, working as a team and

adding new found skills into the research team, as well as reacquainting ourselves with lost skills were some of what we accomplished.

Other hurdles were regarding the research itself. Our first hurdle was actually engaging the members in our engagement research. As paradoxical at that seems, it was actually quite difficult to convince members who were in various stages of cancer recovery and not feeling strong that they would be ok sitting with our researchers for several hours discussing what they were busy living. We felt the members may have also had a bias against the concept of research, thinking it would be pages of questions and lots of pencil pushing! We had to do much explaining and much encouragement to reassure them that this was a new type of research was worth their time and effort.

We also discovered that Wellspring ran a very tight ship. The facilitators of the various programs were successful with what they accomplished because they felt each participant's pain and they delivered hope in huge doses. They accomplished that in a controlled environment where the participants felt safe and supported. Introducing researches into the room posed a challenge. Even though we were all Wellspring members, we were introducing something unpredictable into an environment where predictability was the norm and much time was spent again on reassurance and promises to not be intrusive. To gain the Board's approval to run this research we had to negotiate the time we were to be involved in programs, how we would present ourselves and how we would ensure that we met the ethical guidelines of Wellspring. Ethics took more than negotiation, no matter what reassurance was given, we knew we had to do more. This lead to the entire research internship class developing an "Aspirational Ethics" guideline specifically for community-based organizations. The benefit of an aspirational ethical guideline is that it unfolds based on the needs of the organization. This became the hallmark for the patient engagement research ethical guidelines when working with community-based organizations.

The reality was that being members actually created a conflict and did not ease us through the door in the way we had expected. Stepping out of our roles as members and volunteers seemed to confuse the population. Suddenly the person who had been at the front desk or taking a program or doing peer support was now putting on a totally new hat and conducting research in

the same institution. As a result we weren't in our familiar roles and felt out of place which impacted on the natural trust we all had within Wellspring.

As to the data collection itself, the field research method of participant observation and its data collection was expected to be fairly benign and almost seemed like something to be completed to adhere to the protocol of the research design. It seemed a bit voyeuristic and could be only a marginally productive exercise. To the contrary, this observational part of the research became hugely rich for the mining of data as well as providing themes that reappeared in focus group discussions. Observing the members interacting with the entire Wellspring environment exposed the deep connection they experienced. It can be likened to someone describing a piece of art in every detail. No matter your descriptive skills, you have to actually see the piece for yourself.

The common threads we discovered seemed easily identifiable. The intense loyalty the members had to the various programs seemed to change how they acted and interacted with the world in and outside of Wellspring. There is a connectedness here that goes very far beyond just being a part of something innovative. It is actually owning your place; receiving a healing goodness and then giving it back. Because the tools offered are healing to the heart, mind and body they are readily transferable to all life situations. The members respond to the value Wellspring puts on their attendance and when this compromised population feels valued they reciprocate with personal growth and a flood of enthusiasm.

### **Summary**

In the face of catastrophic disequilibrium of cancer, the disruption of a sense of coherence and the ebbing away of major generalized resistance resources, Wellspring finds ways to introduce unique resources to rebuild resilience and a new sense of coherence.

In carrying out this study, we also asked how our findings may relate to Wellspring Calgary's mission and mandate.

In regards to the mission, "Wellspring Calgary is a warm and welcoming community that provides a comprehensive range of support, resources and programs for anyone living with



cancer and the people who care about them, so they can improve the quality of their lives,” we found the statement to be the case.

In regards to their mandate, “to support the development, implementation, monitoring and evaluation processes involved in research at Wellspring to ensure that programs and services correspond to Wellspring’s mission,” we note that this study, in collaboration with Wellspring, was conducted as part of their continual monitoring and evaluation of their services. We discussed our provisional findings with Wellspring staff during our final REFLECT focus group. We discussed possible gaps in programming which has already been listened to. The result? New programs have been implemented and added to the Wellspring schedule for Fall 2013.

It all sounds so simple and straightforward, but our iterative analysis process has been arduous, piece by piece we have found that there is logic to what happens at Wellspring and how it works.

We acknowledge that our work has focused on a community-based wellness centre and does not in any way diminish the work within a healthcare setting to treat the biological disease. It is, however, our conclusion that the improvements in outlook, self-esteem and engagement with one’s own health brought about by the ability to attend a facility such as the Wellspring, facilitate a better quality of life and outlook to cancer treatment.

### **Outcomes**

As already mentioned above, the suggestion of several new programs such as a “Men’s Program” and also a “Family Information Program” has been put forth to Wellspring. Plans to develop these programs are now in place.

Those working in health care will find value in the understanding of the determination to be well that we discovered in our research participants. People really do become experts in their cancer and themselves. To deny that or dishonor that by declining to give them a voice in their care is a betrayal to all of us.

The Wellspring style of care delivery is worthy of being studied and replicated in other institutions. We have also come to affirm the value of engagement as a tool to conduct the

research. This translates to the entire system and the value of a research-informed patient voice. Many of our findings can be taken up by the health care system to enhance patients engaging in their own health.

These interpretations in a report and in journal publications such as *Psycho-Oncology* will benefit other “Wellspring- like” groups, for instance, the Tom Baker Cancer Centre in Calgary, The Cross Cancer Institute in Edmonton, and Alberta Health Services’ Cancer SCN. Likewise, local community health centres and other cancer centres will benefit from the interpretations of this patient engagement research on a salutogenic environment for cancer patients. Other groups to gain from the outcomes of this research are oncologists, patient education specialists, family doctors and the Primary Care Networks to which they belong, through accessing information from their medical websites. In addition to these groups, we hope that ultimately benefiting are cancer patients themselves, who will also benefit by gaining knowledge of accessible programs, enjoy better health and wellness spaces and facilities, who will have access to publications of this research in various types of media (e.g., the *LEAP* magazine and social websites).

### **Future Research**

This research has laid out the foundations for future PACER research. One research project potential is using the Sense of Coherence Short Scale as an interpretive tool to gauge patient’s gains before and after utilizing programs in a salutogenic environment. The Healing Journey Program at Wellspring, which has five program levels, would be a good choice for this.

Further research questions to be explored would be:

- What are the barriers to people engaging in their health?
- What are the demographic and cultural differences influencing engagement?
- How important is the concept of sanctuary as part of one’s psycho-social health?
- Can salutogenic approaches be utilized and adopted by business (e.g., HR, Employee Assistance Programs)?

We propose:

- Future collaborative research between Wellspring and the wider provincial health service (particularly the Tom Baker Cancer Centre) could be very beneficial to the patient experience.
- Incorporation of theories on salutogenic environments and the GRRs uncovered at Wellspring Calgary should be taken into account and brought to bear when building new health and wellness facilities in both the public and private sector.
- That some of the salutogenic elements in play at Wellspring could be adapted to fit current AHS facilities and incorporated into their roadmaps for a better patient engagement process.

That is to say, all these potential research ideas above will help to identify improved patient engagement in health with a greater salutogenic focus. This research and future research is beneficial for the patient and a part of a greater public service.

## References

- Alberta Health Services. (2012). *Strategic Clinical Networks. A Primer & Working Document* (Aug 7, 2012-V5). Retrieved from the Alberta Health Services website  
<http://www.albertahealthservices.ca/Strategic%20Clinical%20Networks/ahs-scn-primer.pdf>
- Alberta Health Services. (2011). Strategic Clinical Networks (SCNs) FAQs website:  
<http://www.albertahealthservices.ca/Strategic%20Clinical%20Networks/ahs-scn-faqs.pdf>
- Alberta Health Services Channel. (2011). *Patients become 'significant new voice in health planning.'*  
[http://www.youtube.com/watch?v=qc4ifE9JRPw&list=PL44F829E72A47383B&index=1&feature=plpp\\_video](http://www.youtube.com/watch?v=qc4ifE9JRPw&list=PL44F829E72A47383B&index=1&feature=plpp_video).
- Alberta Innovates Health Solutions. (n. d.). ARECCI Ethics Decision-Support Tools for Projects. Retrieved from Alberta Innovates Health Solutions website  
<http://www.aihealthsolutions.ca/arecci/areccitools.php>
- Antonovsky, A. (1985). *Health, Stress and Coping: New Perspectives on Mental Health and Physical Well-Being*. San Francisco: Josey-Bass.
- Antonovsky, A. (1987). *Unravelling the Mystery of Health: How People Manage Stress and Stay Well*. San Francisco: Josey-Bass.
- Antonovsky, A. (1990). *Studying health vs. studying disease. Lecture at the Congress for Clinical Psychology and Psychotherapy*. Berlin, 19 February 1990.
- Antonovsky, A. (1993). The structure and properties of the Sense of Coherence Scale. *Social Science Medicine*, 36(6), 725-723.
- Berg, B. L. (1989). *Qualitative Research Methods for the Social Sciences*. Toronto: Allyn and Bacon.
- Bogdan, R. & Taylor S. J. (1975). *Introduction to Qualitative Research Methods*. New York: John Wiley & Sons.

- Canadian Foundation for Healthcare Improvement. (n.d.). *About Us*. Retrieved from Canadian Foundation for Healthcare Improvement website: <http://www.cfhi-fcass.ca/AboutUs.aspx>
- Detmer, D.E. & Singleton, P.D. (2004). *TIP-2: The Informed Patient. An EU Framework for Action, August 2004*. University of Cambridge Press.
- Dilani, A. (2009). Psychosocially supportive DESIGN: a Salutogenic approach to the design of the physical environment. 1<sup>st</sup> International Conference on Sustainable Healthy Buildings, Seoul, Korea, 6 February 2009.
- Dooley, L. M. (2002). *Advances in developing human resources*. Thousand Oaks, CA: Sage.
- Epp, J. (1986). Achieving health for all. *Health Promotion International* 1(4), 419-28.
- Erring, J. (2004). What is a case study and what is it good for? *American Political Science Review*, 98(2), 341-354.
- Gerring, J. (2004). What is a case study and what is it used for? *American Political Science Review*, 98(2).
- Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Brunswick (U.S.A.): Aldine Transaction, A Division of Transaction Publishers.
- Glesne, C. & Peshkin, A. (1992). *Becoming Qualitative Researchers*. White Plains NY: Longman.
- Hirvonen, J., Blom, M., Tuominen, U., Seitsalo, S., Lehto, M., Paavolainen, P., Hietaniemi, K., Rissanen, P., & Sintonen, H. (2006). Health-related quality of life in patients waiting for major joint replacement. A comparison between patients and population controls. *Health Quality of Life Outcomes*, 4(3).
- International Alliance of Patients' Organizations (IAPO). (n.d.). *About IAPO*. Retrieved from IAPO website: <http://www.patientsorganizations.org/showarticle.pl?id=7&n=101>
- Kirk, J. & Miller, M. L. (1986). *Reliability and Validity in Qualitative Research*. Newbury Park: Sage.

- Koch, R. (1884). *2 Die Aetiologie der Tuberkulose*. Mittheilungen aus dem Kaiserlichen Gesundheitsamt, 1–88.
- Koch, R. (1893). Ueber den augenblicklichen Stand der bakteriologischen Choleradiagnose. *J. Hyg. Inf.* 14: 319–33. doi:10.1007/BF02284324.
- Kushner, C. (1996). Consumers and health policy: Confessions of a guarded optimist. *International Journal of Quality in Health Care* 8(5), 479-84.
- Labonte, R. (1992). *Community health responses to health inequalities*. North York: North York: Community Health Promotion Research Unit.
- Laverack, G. and R. Labonte. (2000). A planning framework for community empowerment goals within health promotion. *Health Policy and Planning* 15(3), 255-62.
- Lilley, S. (1993). *Making it work! Community participation in health planning in Nova Scotia*. Discussion paper for the Strengthening Health Partnership of Nova Scotia. Nova Scotia: Dalhousie University.
- Lincoln, Y. S. & Guba, E. G. (1986). But is it Rigorous? Trustworthiness and Authenticity in Naturalistic Evaluation. In D. D. Williams (Ed.), *Naturalistic Evaluation* (p. 73–84). San Francisco: Josey-Bass.
- Lindström, B. & Eriksson, M. (2010). *The Hitchhiker's Guide to Salutogenesis*. Folkhälsan Health Promotion Research Report.
- R. Macadam, R., Drinan, J., Inall, N., & McKenzie, B. (2004). *The task of capacity building: A report for the Rural Industries Research and Development Corporation*. Australia: Rural Industries Research and Development Corporation
- Marlett, N. & Emes, C. (2010). *Grey Matters: A guide to collaborative research for Seniors*. Calgary: University of Calgary Press.
- Mason, M. (2010). Sample size and saturation in PhD. Studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3), Art. 8.
- Mayer, C-H. & Krause, C. (2011). *The meaning of Sense of Coherence in transcultural management*. Germany: Waxmann.

- Mayer, C-H. & Krause, C. (2012). *Exploring Mental Health: Theoretical and Empirical Discourses on Salutogenesis*. Germany: Pabst Science Publishers.
- McCarley, P. (2009). Patient empowerment and motivational interviewing. *Nephrology Nursing Journal*, 36(4).
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *A Cancer Journal for Clinicians*, 61(1), 50-62. doi:10.3322/caac.20093.
- Milberg, A. & Strang, P. (2007). What to do when 'there is nothing more to do'? A study within a salutogenic framework of family members' experience of palliative home care staff. *Psycho-Oncology*, 16(8), 741-51.
- Ontario Ministry of Health. (1993). *A Healthier Ontario: Progress in the 90s*. Toronto: Ontario Ministry of Health.
- Ontario Ministry of Health. (1989). *Deciding the future of our health care: An overview of areas for public discussion*. Toronto: Queen's Printer for Ontario.
- Ontario Ministry of Health and Long-Term Care. (2002). *Community Health Centres*. Toronto: Ontario Ministry of Health.
- Pasteur, L. (1878). On the extension of the germ theory to the etiology of certain common diseases. *Comptes rendus, de l'Academie des Sciences*. XC. Ernst, H.C. (trans). p. 1033-44. <http://ebooks.adelaide.edu.au/p/pasteur/louis/exgerm/complete.html>
- Patients Matter Project. (2011). *Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis Care in Alberta*. Retrieved from Patients Matter Project website <http://bit.ly/PatientsMatter>
- Patton, M. O. (1990). *Qualitative Evaluation and Research Methods*. Newbury park: Sage.
- Pivik, J. R. (1997). *Facilitating collaborative research: Strategies from the perspective of health researchers*. Ottawa, Canada: University of Ottawa.

- Pivik, J. R. and L. Weaver. (1997). *Facilitating community participation in health care planning: Recommendations from consumers and health professionals*. Kingston, Ontario: Health Information Partnership.
- Pivik, J. R. (2002). Practical strategies for facilitating meaningful citizen involvement in health planning. *Commission on Future of Health Care in Canada*. Romanow Commission on the Future of Health Care in Canada, Discussion Paper #23. Ottawa: National Library of Canada.
- Program of Patient Engagement in Health Research (PPEHR) as part of the Institute for Public Health, Department of Community Health Sciences, Faculty of Medicine. Founding Meeting, April 19, 2013
- Rogers, C. (1951). *Client-centered therapy*. Cambridge Massachusetts: The Riverside Press.
- Rogers, C. (1957). The necessary and sufficient conditions of therapeutic personality change, *Journal of Consulting Psychology*, 21(2): 95-103.
- Rosenthal, C. (2000). Caring for Myself to the End: A Sacred Enterprise. *Generations*, 23(4), 25-26.
- Sarton, M. (1994). *On Coming into Eighty: New Poems*. New York: W.W. Norton.
- Saunders, C., & Girgis, A. (2010). Status, challenges and facilitators of consumer involvement in Australian health and medical research. *Health Research Policy and Systems*, 8(34).
- Stang, I., & Mittelmark, M. B. (2009). Learning as an empowerment process in breast cancer self help groups. *Journal of clinical nursing*, 18(14), 2049-57.
- Stucky, H. & Nobel, J. (2010). The connection between art, healing and public health. Framing Health Matters. *American Journal of Public Health*, 100(2), 254-63.
- Taylor, D & Bury, M (2007). Chronic illness, expert patients and care transition. *Sociology of Health & Illness*, 29(1), 27-45.
- Ulrich, R.S. (2006). Evidence-based Healthcare Architecture. *The Lancet*, 36, 538-9.



- Ussher, J., Kirsten, L., Butyow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine* 62(10), 2565–76.
- van der Molen, B. (2005). Living with cancer – education programs for patients. *Progress in Palliative Care*, 13(4) 203-08.
- Visram, N., Roberts, A., Seebohm, P. (2012). – 16 – 3- 139). The role of self-help groups in promoting well-being: experiences from a cancer group. *Mental Health and Social Inclusion*, 16(3), 139-46.
- Waller, H. (1986). *Gesundheitswissenschaft: Eine Einführung in Grundlagen und Praxis*. Cited in *Salutogenesis and Shamanism*. Master's Thesis by Barbara Bush, 2006. Retrieved from <http://www.salutogenesis-shamanism.com/2.php#2.1>
- Wellspring Calgary. (n.d.). Wellspring Calgary website: <http://www.wellspringcalgary.com/mission.asp>
- Wellspring National. (n.d.). Wellspring National website: <http://www.wellspring.ca/>.
- Worden, I. (2013). The Path to Increased Patient Engagement Lies in the Definition. Retrieved from Better Patient Engagement website: <http://www.betterpatientengagement.com/2013/03/03>
- Yin, R. (1984). *Case study research: designs and methods (1st ed.)*. Beverly Hills, CA: Sage.
- Yin, R. (2009, p 2-4). *Case Study Research, Design and Methods (4th ed.)*. Beverly Hills, CA: Sage.
- World Health Organization. (1978). *Traditional Medicine: Proposed Programme Budget for the financial period 1981*. Geneva, Switzerland: World Health Organization.
- World Health Organization. (1988). *Guidelines for rapid appraisal to assess community needs*. Geneva: WHO/SHS/NHP.
- World Health Organization. (1978). *Primary Health Care: Report of the International Conference on Primary Health Care, Alma-Ata, USSR, 1978*. Geneva, Switzerland: World Health Organization.

## Appendices

### Appendix A. SET Focus Group Guide

10 a.m.	Introductions Purpose of focus group Explanation of the process
10:30 a.m.	Exploring _____ Guiding questions: <ul style="list-style-type: none"><li>• Tell us about your experience at the Wellspring (prompts: when did it start; how has it impacted you)</li><li>• What _____?</li><li>• Tell us about _____</li></ul>
Noon	Lunch
1 p.m.	Presentation of flip chart information
1:30 p.m.	Discussion of flip chart information: explore, define, refine
2 p.m.	Wrap up and evaluation of the session <ul style="list-style-type: none"><li>• How did this session go for you?</li><li>• What worked best?</li><li>• How could it be improved in the future?</li><li>• Was this worthwhile?</li></ul>

## Appendix B. COLLECT Focus Group Agenda

### A CASE STUDY OF PATIENT ENGAGEMENT

Wellspring Calgary: What Works and How?

May 8, 2013 1pm – 4pm

Wellspring Calgary – Great Room

#### 1. Welcome and Thank you

##### Purpose and Process

##### Rules, Refreshments and Location of washrooms

##### Introductions

##### Sharing and Engaging: (1.5 hr)

- Group format with Members and PERs mixed together in a Sharing Circle (15 participants)
- Each participant introduces themselves and talks about “How they came to be at Wellspring”, “Something you’ve noticed at Wellspring that made a difference to you”, “How Wellspring has helped your health”. Other participants can interject as we go around the circle.
- PERs will interject some of what they have observed so far at Wellspring that also connected to their own experience as a member of Wellspring; eg. Rebuilding, Try on a new life, A sanctuary, Humour, Sharing energy, Contributing, Practicing saying Cancer, Sharing etc.

#### 2. Break (15 min)

#### 3. Summarizing (30 min)

- What you found, by participating at Wellspring, to be helpful for your own engagement in your health; adding further ideas; have you missed anything?

#### 4. Other (15 min)

- Any message you would like to pass on to the AHS/Cancer Control Plan from a patient perspective?
- Interest in Narrative Interviews for further discussion on this topic?
- What have you learned today, appreciated, or would like to follow up on?

#### 5. Evaluation

## Appendix C. REFLECT Focus Group Guide

10 a.m.	Introductions Purpose of focus group Explanation of the process
10:30 a.m.	Presentation of research findings: commonalities and differences
11 a.m.	Guiding questions: <ul style="list-style-type: none"><li>• How do these findings fit with your experience at Wellspring Calgary?</li><li>• How might these findings be used?</li><li>• What other observations and thoughts do you have?</li><li>• What future research can you suggest?</li></ul>
Noon	Lunch
1 p.m.	Presentation of flip chart information
1:30 p.m.	Discussion of flip chart information: categorizing and prioritizing
2 p.m.	Wrap up and evaluation of the session <ul style="list-style-type: none"><li>• How did this session go for you?</li><li>• What worked best?</li><li>• How could it be improved in the future?</li><li>• Was this worthwhile?</li></ul>

## Appendix D. Recruitment Invitation

Primary Project Letterhead

Date:

Dear Friend,

I have been participating in a University of Calgary course on *Patient Engagement Research*, where I have been learning to design, carry out, and publish peer research. My research group in this course is proposing to research the experience of the Calgary, Wellspring. The research question guiding this study is: *What works at Wellspring Calgary and how?*

I know that you have experience with Wellspring Calgary, and invite you to participate in our research.

If you decide to participate in this study, you will be asked to participate in two focus groups together with other participants, one in the beginning and the second by the end of the project. Alternatively, you will be asked to give an interview to one of the patient engagement researchers. The interview will last up to one hour and be an open conversation, where you will be asked questions about your experiences with osteoarthritis pain. The interviews will be audio taped and then recorded in computer files. The information collected will be used by the investigators for analysis. Your time commitment for the focus group will be approximately four hours each time you participate in a focus group. Alternatively, your time commitment for the interview will be approximately one hour.

Please consider this invitation to participate. If you are interested, contact me at \_\_\_\_\_

Sincerely,

\_\_\_\_\_

Ethics ID Number: E-25194

This study has been approved by the Conjoint Health Research Ethics Board

## Appendix E. Recruitment Poster

Join a research study  
that will take place in the \_\_\_\_\_

Through focus groups and interviews  
this study explores the experience of.

This study is conducted  
by Patient Engagement Researchers –  
*trained researchers with patient experience*

Contact \_\_\_\_\_

Ethics ID Number: E-25194

This study has been approved by the Conjoint Health Research Ethics Board