Wellspring: An Intrinsic Case Study of Community-based Education

for Adults Living With Cancer

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Abstract

This paper presents education research as vital to addressing the issues faced by adults living with cancer. This qualitative study looked at philosophies of practice for cancer patient education. It was about understanding how values and beliefs shape the way program planners and managers operationalize their knowledge of adult education and how this has significant impact on meeting the needs of those touched by cancer. Improved technology has extended life expectancy, so that Canadians living with cancer, or even dying with cancer now spend less time in direct medical care. The notion of cancer as simply a medical concern is outdated. This study found that informational and support needs of adults living with cancer are often unmet, ignored or unknown.

This research investigated a community-based education initiative that is inviting, accessible, and promotes a sense of hope. More specifically, this case study uncovered factors contributing to the success of Wellspring, a grass-roots cancer patient support centre which has been recognized nationally for its ability to effectively meet the diverse non-medical supportive care needs of as many cancer patients and caregivers as possible. Therefore, Wellspring was selected as a case study. Educating people to take charge of their own lives and supporting them in making informed decisions about their lifestyle choices made Wellspring part of a social action movement that focused on improving social attitudes toward people living with cancer.

Results of this descriptive inquiry and philosophical inquiry evolved into data that was used to devise an organic model of community-based education that encompasses Adler's (1993) four dimensions of philosophy within a socio-cultural context.

Dedication

I dedicate this thesis to the loving memory of my mother

Rose Kelly Haughey

Acknowledgements

I want to thank Wellspring for supporting me

during my journey with cancer

This thesis moves beyond an academic achievement. It is a culmination of gratitude to all the people and experiences that have shaped my life, whereby enabling me to be alive, be well and be an advocate for people living with cancer. I have come to learn that healing, like learning is best achieved in a caring community.

I want to acknowledge and thank the Wellspring people who helped to contribute to this research:

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CHAPTER ONE: INTRODUCTION TO THE STUDY

People who have never had cancer can champion the cause and talk of what 'could be'. People who currently have cancer can champion the cause and talk of what 'should be'. People who have prevailed can champion the cause and tell what 'must be' (Girard, 2001, p. 137).

My Story

In the spring of 1982, my mother was diagnosed with cancer. I distinctly recall a conversation we had as she struggled with side effects to the treatments. She believed that everyday was valuable and posed that I would likely fight just as hard, if confronted with cancer. Of course, in my youth and good health I strongly denied that I would. Little did I know, twenty years later I too would be diagnosed with cancer. It was then that I understood what she was trying to teach me. Every day truly is important. By sharing my story, I trust that I too can educate others to understand the dynamics of living with a diagnosis of cancer.

Unlike my mother, I am a cancer survivor. My journey through this challenging time seemed so much kinder than my mother's. Many factors have contributed to my well-being. One of those factors was having the opportunity to receive the benefits of Wellspring, a community support and resource centre for people living with cancer. Initially, I joined the Sunnybrook and Women's Wellspring, Toronto, Canada, where I found information and support during treatments. Later, I joined Wellspring Niagara, St. Catharines, Canada where I participated in some of the programs and also trained to be a Wellspring Volunteer.

It is my experience that adults diagnosed with cancer rely on health care professionals for treatments, instructions, and information. However, cancer patients need more than factual information. The experience of having cancer is deeply personal and ultimately people are responsible for their own destiny. They need to gain a greater understanding of how to adjust to life changes imposed by cancer, so as to promote a sense of hope, a sense of peace, as well as a sense of personal growth and development. So often I think of my mother and I regret that she did not have the opportunity to benefit from a learning community like Wellspring. During her illness, 1982-1988, such a resource was non-existent.

My passion is to gain an understanding of how to make cancer patient education initiatives accessible and inviting. I believe that adults living with cancer, or even dying with cancer, need to learn skills to manage their own bodies and lives with dignity. My academic background includes a degree in Adult Education; therefore, I look to adult education theory and practice to understand how a community resource center organized at the grass-roots level, plays a vital role in addressing the concerns of people living with cancer. Reflecting this, my research draws on theories of adult education and the unique needs of people diagnosed with cancer.

I believe that Canadians committed to cancer research must also be committed to cancer patient education research. As science continually improves to bring about earlier diagnosis, earlier interventions, and longer life expectancy, the social implications for the meaning of cancer change. Philosophical questions that arise include:

- What does it mean to be human? Can we treat a "body bit" and ignore the person who must live with the consequences of cancer?

- Is expanding life expectancy a valuable goal if we ignore the quality of life?

- Can medical professionals treat symptoms of the person with cancer and ignore the implications to their families and other social relationships?

- Who decides the content of education for adults with cancer and how it is delivered?

- Who is financially responsible for education and support programs for people living with cancer?

- Can we provide information and support to those living with cancer and ignore social implications to the community?

- Can we continue with medical and scientific cancer research and ignore the changing informational and educational needs of those living with the illness?

Essentially these questions deal with the metaphysical and moral aspects of cancer patient education. These questions lead to determining important issues and categories of information to be explored. Therefore, Adler's (1993) four dimensions of philosophy; metaphysical, moral, objective and categorical, provide an effective framework for this study.

Beginning this research posed many emotional challenges in addition to the usual academic issues faced by graduate students. It had been less than two years since the completion of my own cancer treatments. I continued check-ups every six months, which was a constant reminder that I was still considered a cancer patient. The climax of my fears came about when I initiated a change of the oncologist and the location of my follow-up care. Repeatedly, I was asked where I would go "when" the cancer recurred. I was willing to accept "if" the cancer came back, but these people were saying "when".

This initiated feelings of urgency that leaked their way into my thesis work. I felt compelled to complete what I had started. I also came to realize that my voice concerning issues for cancer patients "is real". My credibility is mutually rooted in sound qualitative research methods along with the experience of having lived realities of a person diagnosed with cancer. I believe it is important for the reader to capture the emotions associated with issues surrounding cancer. Cancer patient education must move beyond the clinical approach and address the non-medical needs of individuals. Grappling emotionally and personally with the realities of cancer can lead to one's own fears of getting the illness. However, I believe that emotions must be seriously acknowledged in order that effective teaching and learning can emerge for adults living with cancer.

My health care professionals referred to the cancer as being "in remission". I argued that no, "it is gone". This use of words is troubling because the term "remission" suggests to me that the cancer has receded and it has the potential to return. Some months later, following more tests, I found a greater peace of mind when I was told, that yes, signs of the cancer are gone. Like most cancer survivors, I continually live with the possibility that it can return. This little nagging thought has found a home in my brain. Yet, it is this whole experience of my journey through cancer that causes me to demand changes in making cancer patient education initiatives more inviting, more hopeful, and more accessible.

Background of the Study

When a person is diagnosed with cancer it can be, and usually is devastating news. Initially it is necessary to help the newly diagnosed person adjust to becoming part

of a health care system and then to help the patient prepare for what might lie ahead. Educational needs typically change at different phases of the illness. The purpose of this study is not to give a clinical view, but rather to highlight considerations that are essential and unique to the planning and implementation of cancer patient education so as to ease people through these phases.

One woman, Anne Armstrong Gibson, had a vision to alleviate the sense of isolation experienced by so many cancer patients, like her. Anne worked with family, friends, some of the leading experts in the field of oncology, and supporters to establish Wellspring, a non-profit organization offering psychological, emotional, social, spiritual, and informational support to individuals and families living with cancer. In 1992 Wellspring opened its first centre in Toronto. Anne's vision for Wellspring was to create a Canada-wide network of community-based centres that would provide people with the tools they required to cope with cancer. Although Anne died in 1995, her vision still guides the organization toward achieving a network that will one day span across Canada.

In a recent media release, the Canadian Cancer Society reported that Canada is heading towards a cancer crisis (April 12, 2005). It is expected that over the next 30 years 5.7 million Canadians will develop cancer. Most adults living with cancer have inadequate access to education and non-medical support services (Hamilton Regional Cancer Centre, 2003). The prediction is that this situation will worsen with the number of new cancer cases increasing as the baby boom generation ages.

The Supportive Cancer Care Research Unit (SCCRU) of the Hamilton Regional Cancer Centre, Canada (2003) surveyed the supportive care needs of cancer patients across different communities in Ontario and concluded that a high proportion of patients

and their caregivers had their non-medical needs unmet despite receiving appropriate medical care. The final report recommended a need for more case managers. "...clients living with cancer have service and support needs that may be ongoing, fluctuating, and unique over time... To achieve these goals a specialized system-level case manager is required to facilitate and coordinate a 'seamless care experience' for clients and families living with cancer" (Hamilton Regional Cancer Centre, p. 149).

I argue it is more helpful to foster informal, caring, and accessible cancer patient support and education resource centers. Certainly, we could do with less reliance on "expert managers" and we could do with more community-based education programs which provide support to individuals in making decisions concerning their own coping strategies and recovery needs.

I am concerned that the recommendations in this report have clearly omitted a call for educational research. The four prerequisites identified in this report as necessary for supportive service include the following beliefs and commitments: (a) a belief in the benefits of systems of care rather than to single programs, (b) commitment to a comprehensive range of services, (c) a commitment to a model of supportive care that offers the greatest benefits to those who need ongoing support, and (d) a commitment to evidence-based decision making (Hamilton Regional Cancer Centre, p. 150).

This proposed strategy to help people living with cancer takes a "top down" approach, whereby decisions are made by healthcare and social agency administrators. I am proposing a more "bottom up" approach, also known as grass-roots approach, whereby people living with cancer decide their own needs in a knowledgeable way, and have access to education and support to do so.

Historically, community-based, non-profit organizations have been developed to address social and economic issues, such as adult literacy, unemployment, immigration, worker's rights, the environment, women's issues, homelessness, and family issues (Hemphill, 1996). However, cancer patient education has typically been part of the health care system. The non-medical aspects of cancer and what this means to educational needs for families living with cancer is not adequately addressed.

Statement of the Problem

Most adults living with cancer do not have adequate access to education and non-medical support services (Hamilton Regional Cancer Centre, 2003). It is necessary to find solutions that will shift the emphasis away from setting up costly professional service providers and move toward initiating accessible community-based education programs that offer ongoing, caring non-medical support to help adults make their own decisions concerning coping strategies, lifestyle choices and recovery needs.

The traditional role of health care professionals is changing. Today, many people are more self-directed to seek out information, coping skills, and alternative or complementary ways to manage the challenge of living with cancer. Cancer patients need help finding information and support to identify their own needs in an effort to give some kind of meaning to the changes in their life. Cancer patients who learn to take charge of their own bodies and lives have the potential for a much higher quality of life. In my experience cancer patient support and resource centres predominately staffed by volunteers, provide a viable option for helping to provide information and non-medical support services to cancer patients and their families during this time.

There is a gap in the literature concerning the grass-roots approach to cancer patient education. Individuals and groups who want to initiate community-based education and resource programs for people living with cancer will benefit from having a model to guide them in planning and implementing a successful program.

Purpose of this Study

The purpose of this qualitative research was to gain a greater understanding of community-based education initiatives that are inviting, accessible, and promote a sense of hope for people living with cancer. More specifically, the purpose of this case study was to uncover factors characteristic to the success of Wellspring, a grass-roots cancer patient information and support centre.

It will be helpful to other communities to have a deep and comprehensive understanding of how the successful Wellspring Model was planned and implemented as a unique approach for providing education and support to individuals and families touched by cancer. The heuristic characteristics of this case study can offer insight to others who apply similar concepts and strategies in their own communities. It was my expectation that theoretical statements would evolve concerning community-based education for adults living with cancer. I wanted to find out how and why Wellspring developed.

Questions Addressed

In *The Art of Case Study Research*, Stake (1995) suggests that the conceptual structure for case study research design: (a) begins with issues, (b) moves toward evolving issue questions which emerge from experience, early contact or relevant literature, (c) moves toward issue sub-questions which provide greater depth to the issue

question, and finally (d) poses topical information questions for description of the case. Because this was an intrinsic case study it is important to remember that "the case" was dominant. Therefore, I did not want the examination of the phenomenon expressed in the issue to become more important than examination of the case as a whole. Using this structural framework I organized questions around these themes (see Figure 1).

First, the issue statements were:

- People living with cancer need accessible programs that provide a caring environment to meet their informational and support needs.

- Canada needs more community-based education programs to support individuals living with cancer in making decisions concerning their own coping strategies and recovery needs.

Second, the issue question also known as my research question was:

- What guiding philosophies for education practice contribute to a successful model of community-based education for adults living with cancer? I use the Wellspring model as a case study.

I investigated the guiding philosophies that provide the foundation for all decisions, processes, and actions contributing to a successful community-based cancer patient resource centre. Philosophy is not a diagnosis. Rather, reflecting on beliefs, values and attitudes can help educators gain insight that informs practice in the everyday realities of life with adult learners (Tisdale and Taylor, 2000). All community and education programs begin with a set of beliefs and values which I call a guiding philosophy for practice.

ISSUE STATEMENTS

- People living with cancer need accessible programs that provide a caring environment to meet their informational and support needs.

- Canada needs more community-based education programs to support individuals living with cancer in making decisions concerning their own coping strategies and recovery needs.

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ISSUE QUESTION
Research Question

- What guiding philosophies for education practice contribute to a successful model of community based education for adults living with cancer?
  I use the Wellspring Model as a case study.

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ISSUE SUB-QUESTIONS: PHILOSOPHICAL INQUIRY
Emerging from Adler's (1993) Dimensions of Philosophy

1. What is real?
2. What is moral?
3. What ideas are important?
4. What are categories of important ideas?

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FOUR TOPICAL INFORMATION QUESTIONS:
DESCRIPTIVE INQUIRY
Description of the Case

(Anne's Story)   (Other People)   (What Happened)   (How Programs Chosen)
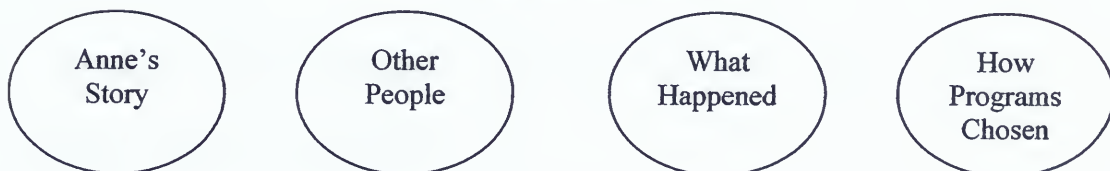
Figure 1. Conceptual structure for Wellspring case study research design

(Adapted from Stake, 1995)

Third, issue sub-questions were designed to discover the philosophies that form the basis of the Wellspring phenomenon. My four sub-questions were based on *The Four Dimensions of Philosophy* (Adler, 1993). Philosophical knowledge of the first order is knowledge about reality and philosophical knowledge of the second order is knowledge about knowledge itself (Adler, 1993, p. 13). Consequently, the four dimensions of philosophy are divided into philosophical knowledge and philosophical analysis. The first two sub-issue questions emerged from philosophical knowledge:

1. What is real? Describe realities of people living with cancer. Describe how Wellspring addressed these realities when originating programs.

2. What is moral? Prescribe what ideals we ought to seek when planning cancer patient education and support programs.

The third and fourth sub-issue questions emerged from philosophical analysis:

3. What ideas are important? Identify topics which typically stimulate great conversation. Are there common concerns shared by most adults living with cancer?

4. What are categories of important ideas? How does Wellspring organize these ideas or subject matters to develop programs and administrative structures necessary to the organization of meeting the needs of Wellspring members?

Finally, the topical information questions which seek deeper descriptive insight into the case being studied included:

1. Wellspring history begins with Anne's story. What can you tell me about Anne?

2. Who were some of the people who worked with Anne to initiate Wellspring? What were their contributions?

3. What happened? How did Wellspring evolve?

4. How did Wellspring choose what programs to offer?

These etic issue questions were brought to the study by me, the researcher. However, I was not limited to these alone. As concerns belonging to the people within the case emerged, the emic issues were addressed (Stake, 1995, p. 20).

Rationale of the Study

To justify why I conducted research on cancer patient education I need to explain: (a) why I am targeting the population living with cancer, and (b) why I chose Wellspring as a case study.

The population of people living with cancer is growing yearly. The Canadian Cancer Society (2004) reports that every week, on average 2,798 Canadians will be diagnosed with cancer. Based on current rates of incidence, it is estimated 38% of women and 43% of men living in Canada will develop cancer during their lifetime. As more people are diagnosed with cancer, the number of survivors also increases because of early detection and improved treatments. Therefore, the success rate for cancer survivors is improving every year. While I believe this is good news, I am concerned that this growing number of people touched by cancer has particular education needs that are unmet, are unknown, are overlooked, or are ignored. The Baby Boom population presents another growth factor. Baby Boomers (born between 1945 and 1965) are beginning to enter the age where they are likely subject to getting cancer (University of Texas, 2004).

I believe Wellspring is a model for cancer patient education. This grass-roots cancer patient support and resource centre evolved from the local needs and interests of the community. It is based on the goal of effectively meeting the diverse non-medical supportive care needs of as many cancer patients and caregivers as possible. The innovative approach to care of the whole person, which includes physical, psychological, social, and spiritual aspects, aims at improving quality of life. Service delivery is rooted in sound volunteer development and training partnerships with health care professionals.

At the time of this study, this model has been implemented in five Ontario centres (including Toronto, Halton-Peel, London, and Niagara), and adapted for use by other community groups. The Wellspring Model has been recognized by Health Canada, the Ontario Ministry of Health, and Cancer Care Ontario as an outstanding example of organizational excellence in community-based care (Wellspring, 2005).

Theoretical Framework for the Study

Adults differ from children in terms of their extensive life experiences, relationships, responsibilities, and their potential to make choices. Therefore, this study focused on the theory and practice of adult education.

I took a Freirean approach that education program content must evolve from dialogue with people living with cancer. I believe it is through dialogue and sharing of views that people interpret the meanings associated with having cancer and thus begin to envision new possibilities for delivering education and support programs. Freire's critical pedagogy is a way of thinking about negotiating and transforming the relationships among teaching, the production of knowledge, the institutional structures, and the social relations of the wider community (McLaren, 2003).

I also recognized the importance of philosophical lenses in shaping educational practice. Hence, to frame my research questions I used Adler's (1993) four dimensions of philosophy; metaphysical, moral, objective, and categorical. In addition, I used a cultural geography perspective to expose the biases that people bring to the learning environment. This perspective was useful in highlighting the role culture plays in defining the meaning of health and illness.

In summary, this qualitative study encompassed an eclectic theoretical framework which included: (a) adult education theory and practice, (b) Freire's critical theory (c) Adler's four dimensions of philosophy, and (d) a cultural geography perspective. I took a case study approach to guide this research in a descriptive and explanatory way.

Importance of the Study

This study is important because it provides a thick description of the process for creating and maintaining community-based cancer patient education programs. It exposes multiple realities experienced by people living with cancer. It describes the value of peer support as a trustworthy approach to alleviating cancer-related fears and helping people move forward in their recovery.

Readers will gain an understanding of how to organize cancer patient education and non-medical support initiatives that are inviting, accessible, and meet the needs of the local community.

Scope and Limitations of the Study

This was an intrinsic case study. As such, it was a study of the case as a whole and a search for patterns. It was not intended to study specific issues; therefore, I needed to set aside many evolving aspects of interest. For example, each of the themes and sub-

themes were worthy of their own in-depth discussion, yet this was not the purpose of this particular research. Intrinsic case study research and reporting are not simple and it was difficult to find a concise descriptive reporting style.

Guiding philosophies for education practice that contribute to a successful model of community-based education for adults living with cancer are to some extent part of a wider socio-cultural context. Therefore Wellspring must be understood within the scope of this dynamic process, rather than viewed as a static entity.

I am aware that my own biases were reflected in this study. It was my intention to be as open as possible about my views on education for people living with cancer. I believe it was essential to identify to the reader that I am a person who has experienced the journey of living with cancer. My views have evolved from my relationships with cancer; as a daughter who lost her mother to this illness, and as a person who was diagnosed with this illness. I have traveled through many medical, non-medical and alternative paths to my own recovery. While this does give me credibility, I also recognize that each person experiences cancer in a unique way. Therefore, to some extent this study was limited to my own understanding and expectations of what cancer is all about.

I stated Wellspring was successful because of its philosophy. Within the scope of this research, I was not able to compare with other successful community-based programs.

This study was limited to larger urban centres. The needs of smaller populated and rural communities present cultural differences that were not addressed. Further, the Wellspring programs are available at the Wellspring facilities or in other outreach

community centers with Wellspring facilitators. Housebound people living with cancer are less likely to benefit from this study.

It was my goal that there is enough in this research that could be transferable to other situations significant to the reader.

CHAPTER TWO: REVIEW OF THE LITERATURE

"Cancer is really about regaining your health ...you will go through treatment and that will deal with your physical issues. But it's finding the other pieces for the rest of your life that has to be there as well" (S. Sutcliffe, cited in Maddren, 2003).

When a person is diagnosed with cancer it can be, and usually is devastating news for the individual diagnosed as well as for those who care about the cancer patient. Initially it is necessary to help the newly diagnosed person adjust to becoming part of a health care system and then to help the patient, as well as loved ones, to prepare for what might lie ahead. Education and information needs typically change at different phases of the illness. The diagnosis of cancer is usually more than a crisis of the body. It often leads to a crisis of the mind and spirit and as such, it can be difficult to find the emotional, psychological and practical support so urgently needed. The purpose of this paper was not to give a clinical view, but rather to highlight considerations that are essential and unique to the planning and implementation of education for people living with cancer.

This review of the literature explored issues of concern for adult educators in putting together non-medical education and support programs for those living with cancer. While there is much literature on adult education as well as health education, I believe there is a gap in addressing the specific needs of those living with cancer.

Pierret (2003) reviewed the following publications on the illness experience written between 1975 and 2000: *Sociology of Health & Illness, Journal of Health & Social Behaviour,* and *Social Science & Medicine.* These publications showed that interest in studying the meanings and experience of illness has grown since the early

work of Strauss and Glasser in 1975. Initial studies of the illness experience explored the meanings that individuals gave to their encounter with illness. These studies often expressed notions of stigma, sense of shame and loss of self. During the 1960's and 1970's social scientists aimed to clarify and broaden conceptions of illness and the sick role. The 1980's studies on illness behaviour began to look at new variables, such as stress, coping, and life events with a focus on the quality of life (Pierret, 2003). When life is disrupted by illness, patients often begin a quest to redefine themselves and learn how to cope with the illness (Mathieson and Stam, 1995, as cited in Pierret, 2003).

A small number of articles have been devoted to self-help groups as resources for patients. Over time some self-help groups transformed into patients' associations. The transition from a self-help movement to an organization has enabled patients to act on medical research as well as open new ways to reach public acceptance for fighting against stigmatization of illness (Pierret, 2003). Certainly, this body of information gives a general sense of the illness experience, yet clearly points to the gap in educational research for addressing the non-medical informational and support needs of people living with cancer.

To theorize about cancer patient education requires one to examine existing practice critically or to have a vision. Yet, to think seriously about educational purpose without questioning established practice becomes a mindless effort. Purposeful thinking reflects on technique, content, and organization necessary to fulfill or alter the purpose of educational activities. All action is guided by some theory or some philosophy. In other words, we act for reasons (Elias and Merriam, 1984). All adult educators have a belief

about what they should be doing. In addition, all adult learners also have a belief about what educators should be doing (Tisdell and Taylor, 2000).

I explored these issues by discussing the following topics: philosophy and adult education, self-directed learning, emotional dimensions of learning, transformative learning, trust and caring in education practice, holistic view, cultural view, dialogue and consciousness raising.

Adults differ from children in terms of their extensive life experiences, relationships, responsibilities, and their potential to make choices (Barer-Stein & Draper, 1997, p. 87), therefore this literature review focused on the theory and practice of adult education.

Philosophy and Adult Education

The progressive adult education perspective is characterized by a holistic view of education that encompasses all aspects of living and learning. This perspective emphasizes the centrality of the learner's experience and practical problem solving methods. Progressives view adult education as an instrument of social development (Price, 2000). Community education movements have their origins in the ideas of early progressive educators. The movement had rural beginnings. Early urban communities sought to deal with problems of crime, unemployment, and delinquency. The original goal of community education was enhancement of the community through providing educational experiences for all people of all ages. One component of community education is programs designed to meet the needs and interests of adult members of the community. While community education has developed as a movement somewhat separate from adult education, the connections between the two are clear. Both are

interested in lifelong learning and in the continuing education of adults (Ellias and Merriman, 1984).

Planning programs for adult learners is more than following a series of steps. Rather, planning is a social activity in which people negotiate with each other in answering questions about the program. Planners need to co-construct programs with the interested participants. When planning adult education programs, the philosophies of the educators influence how programs are planned and carried out. The planners' philosophical perspectives significantly impact many of the decisions in the every day practice of planning programs – whether these are recognized and articulated or not (Hansman and Wilson Mott, 2000).

Philosophy has a very practical role to play in program management. Hiring appropriate staff is a critical part of building a successful program. Staff who understand and appreciate the philosophy of adult education understand that everyone is working together. A clearly articulated philosophy is helpful in finding funding sources and possible corporate sponsors who may be necessary for continuation of community-based education programs (Matuszowicz, 2000). A philosophical foundation of adult education provides a unified sense of purpose, a cohesive set of aims, and a coherent framework of beliefs. The philosopher is interested in general principles that apply to a large number of people. Principles are the foundations or basic structures by which phenomena and realities are understood. True professionals know what they are to do; they are also aware of the principles and reasons for so acting. Philosophy inspires one's activities and gives direction to education practice (Elias and Merriam, 1984).

Self-directed Learning

In *Planning Instruction for Adults*, Cranton (2000) gives a concise overview of theories of teaching and learning for adult education. The term andragogy, popularized by Malcolm Knowles (1978) is described as the art and science of helping adults learn. One of his basic assumptions is that people are interested in solving problems relevant to their own lives and only become ready to learn when they experience a need to learn. Though he advocates self-directed learning, he also poses that people move from dependency toward increasing self-directedness at different rates and in different stages of life. Cranton points out that Brookfield (1986) is skeptic about Knowles' andragogical model because he questions the problem-centred characteristic of the adult learner. He suggests that not everyone is as self-directed as we think they should be. He proposes that educators give people what they think they need, then also challenge the learner to go beyond expressed needs (Cranton, 2000).

When facilitating cancer patient education, it is valuable to reflect on the tensions and emotions of learning. In *The Skillful Teacher*, Brookfield (1990) claims that many people's prior educational socialization has a strong element of authority dependence which can predispose them to regress to childlike behaviour upon entering a formal educational setting. Therefore, people who are already anxious about the cancer diagnosis may not want self-directed learning and might actually yearn for some authority constraints.

Emotional Dimensions of Learning

Brookfield (1990) is critical about educational researchers giving little attention to the emotional dimensions of learning. He reports that a common emotional reaction by

learners is grieving for lost certainties. This is particularly significant where change is occurring. When people question the assumptions underlying habitually accepted ideas or actions, they end this process by discarding what was once familiar. Previously accepted common sense, conventional wisdoms can be seen as distorted and inadequate to account for a new reality. Brookfield refers to these critical episodes or educational experiences as "transformative". This process is often distressing.

When a life event or educational event causes people to question their own comfortable worldviews they may feel angry, resentful and sometimes very threatened. Educators may also feel very threatened when this occurs if they are not aware of the strong possibility that learners may be angry and resentful. Furthermore, psychological challenges of a cancer diagnosis include dealing with fear and all its emotional and social consequences. People often experience anger about having the disease, at not getting clear answers, as well as delays and obstacles in the health care system. The process of opening up to expressing all emotions, positive and negative, may lead to re-evaluating life values and the importance of certain goals. The Canadian Association of Psychosocial Oncology (CAPO) (2003) maintains "Feelings of guilt, depression, stress, and anxiety are emotions to contend with while trying to adjust to living with cancer". (pp. 18-19). Staff and peer support volunteers must be aware of these feelings, be prepared to expect them, and be able to help the individual deal with the emotions.

Brookfield (1990) believes that being aware of the possibility of anger will help educators avoid feelings of having failed in their educational efforts. Also this awareness will stop educators from rushing prematurely to quell these emotions. Brookfield views these "outbursts" as sometimes necessary to learning. It is his belief that to try to keep

classrooms and learning environments free from the messiness of emotions is to deny much of the power of teaching and learning. To know that the emotional nature of learning exists helps an educator come to view this as normal accompaniments to learning. We are more likely to let learners' displays of emotion run their natural course and then to analyze, and reflect upon, why it occurred.

Transformative Learning

In *Transformative Dimensions of Adult Learning*, Mezirow (1991) states that " it is not so much what happens to people, but how they interpret and explain what happens to them that determines their actions, their hopes, their contentment and emotional well-being" (p. xiii). His conviction is that meaning exists within our selves and that personal meanings attributed to our experience are acquired and validated through human interaction. In other words, what we make of this world is entirely a function of our past personal experiences. Information, ideas and contexts change. Therefore, our present interpretations of reality are always subject to revision or replacement. Mezirow explains meaning as an interpretation; so to make meaning is to interpret experience. Typically meaning is construed through cues, symbolic models, and language.

This discussion on meaning as interpretation is important because we have to understand our experiences in order to know how to act effectively. In transformative learning we reinterpret an experience, either old or new, and form a set of new expectations, thus giving a new meaning and perspective to that experience. Further, the search for meaning involves constructing an explanation of the circumstances that brought about a change that has already taken place.

Perspective transformation is a change in viewpoint. This often involves profound changes in self, changes with cognitive, emotional, somatic, and unconscious dimensions (Mezirow, 1991). Perspective transformation can lead to transformative learning. Some disorienting dilemma which is triggered by a life crisis causes doubting in which old meanings are perceived as inadequate and individuals need to change their frames of reference by critically reflecting on their assumptions and beliefs and consciously plan to redefine their world.

In the five stages of cancer, posed by CAPO (2003), there is disorientation at the diagnosis stage when a patient may be faced with the shock and sense of loss of control in preparing for what lies ahead. Throughout the treatment stage, adjustments to medical environments and procedures, changes in physical and emotional state, difficult social dimensions dealing with family and friends, financial concerns, and often issues of spiritual questioning all contribute to this disorienting process. Survivorship also presents a unique change in circumstance because "after treatment, individuals may feel 'dropped' from the system, ill-prepared for the transition between the intensity of care and treatment and the return to 'everyday' life" (CAPO, 2003, p. 21).

Trust and Caring in Education Practice

Transformative learning in practice has no single mode of teaching and learning. Imel (1998) advises educators not to see transformative learning as the only goal of adult education. However, when this is the goal, some suggestions for fostering learning environments can help it to occur. First, the educator's role is to establish an environment that builds trust and care. The educator's responsibility is to create a learning community where individuals come together to make meaning of their life

experience. Imel views the teacher as a member of that community who serves as a role model to demonstrate a willingness to learn and change by expanding and deepening understanding of the subject matter.

Secondly, the learner's role is to share the commitment for creating the learning environment. As part of a learning community, learners share the responsibility for constructing conditions under which transformative learning can occur. Learners must be willing to participate and to provide reflective feedback to the community members. Thirdly, Imel suggests that transformative learning has two layers: the rational, objective, cognitive side and the affective, subjective, intuitive side. Educators need to consider how they can help learners to connect the rational and affective by using feelings and emotions both in critical reflection and as a means of reflection. I believe this is where Imel falls short, because she does not offer strategies to meet this third suggestion.

Invitational education addresses the total learning environment. The focus is on the messages transmitted by people, places, policies, and processes. The educator assumes an inviting approach which is the basis for sustained action. By creating an environment supporting critical reflection and exploration of alternative perspectives, adult educators can lift barriers to learning and open the learner to a greater self-awareness and initiate change for personal development (Novak and Purkey, 2001).

Five assumptions at the heart of Invitational Education Theory point toward respect, trust, care, optimism, and intentionality. The terminology used by Imel (1998) in regards to establishing an environment that builds trust and care in education is similar to terminology used by Novak and Purkey (2001) to describe their theory of invitational

education. Thus, it would seem to me that there is a relationship between the two theories.

Brookfield (1990) also values the need to build trust between learners and educators. He states "In transformative learning events students often make explicit mention of how teacher's actions, and the trust these inspire or destroy, are crucial to learning" (p.163). Trust must be earned for fostering a trusting environment where a teacher has both credibility and authenticity; however, it is not quick and easy to do so. Taylor (1998) makes the assumption that the practice of transformative learning has been minimally investigated and poorly understood. His contribution to helping improve practice outlines essential conditions and techniques for fostering transformative teaching and learning, yet he argues that the most significant role of educators is to become transformative learners themselves, more so than employing various techniques and strategies.

When speaking of adult health education, Barer-Stein and Connolly (1997) use the term 'nurturing' instead of 'facilitating' the learning of adults. They feel this implies more. "The holistic nature of nurturing assumes that each person has the potential to learn and develop, and eventually shift towards independence from that nurturing... The holistic nature of nurturing mirrors well the holistic nature of learning" (pp. 89-90).

One way to make education more meaningful is by "making schools more home-like"(Noddings, cited in K. O'Toole, 1988). Noddings associates caring and trust with a moral education. A significant part of moral life is the relations with intimate others.

Aristotle wrote eloquently on friendship …as central in moral life….When we befriend others, we want good things for them not because those things may enhance our welfare, but because they are good for our friends (Noddings, 1995).

Organizations need to support a curriculum based on themes of trust and caring. "We should have learned by now that both children and adults can accomplish wonderful things in an atmosphere of love and trust" (Noddings, 1995).

Holistic View to Education

What is this view of educating the whole person? The name Holistic Education is built on the concept of "holism", derived from the word holos, meaning whole. Interestingly, the Holistic Education paradigm is derived in part from the field of Holistic Medicine, which focuses on the whole person; mind-body-spirit, well being and wellness. This medical approach appreciates the patient as a mental, emotional, social, spiritual, as well as physical being. Further, it respects the capacity for patients to heal themselves and regards them as active partners, rather than passive recipients of health care (Rinke, 1982, pg.13).

Nielson (2001) reminds us that a holistic view to education has a long tradition of profound thinkers and educators supporting its philosophical roots. He gives the example of Socrates and Plato, the forefathers of rational reasoning, so highly treasured in Western society, believed over 2000 years ago that teaching essentially is the art of "tending the soul and its vehicle" – the whole person (p. 5). Neilson also states: "There are today numerous voices calling for a secular education that caters for the whole person, irrespective of background and religious stance (Dalai Lama 1999; Glazer 1999; Miller 1999; Orr 1999; Palmer 1999; Gatto 1997; Neville 1989)" (Neilson, 2001, p.4).

The topic of spirituality in adult education is becoming more widely discussed in the literature. Secular spirituality is distinguished from religious spirituality. For example, Berry (1988) refers to public or secular spirituality as worked out in the everyday world of human existence and may or may not have a religious or institutional dimension. "This is a spirituality of living and being, which is broad enough to be inclusive of all practices and beliefs…. A public secular type of spirituality asks questions of meaning, purpose, and motivation" (English, 2001). The spiritual journey is not always easy. An ethic of care is essential to ensure that learners know they have choice and that educators will avail themselves to the learners. "As adult educators …we need to be willing companions through the ecstasy and grief that may arise as a result of learning for both are part of the educational journey that embraces the human spirit" (Lauzon, 2001).

Because this spiritual approach to teaching and learning can place great demands on an adult educator, there also needs to be an ethic for self care. It is essential to engage in activities that foster self care so that educators will be better prepared to care for others.

Cultural View

From a cultural geography perspective, the meaning of holistic extends to include the whole culture. In *The Cultural Geography of Health Care* Gesler (1991) argues that culture represents an entire way of life for a community; therefore all the elements of culture, including institutions, beliefs and rituals, are related so it is impossible to separate health care seeking behaviour from its cultural context. He encourages all those involved in health care delivery, including education, to pay more attention to cultural-

geographic factors because the best constructed theories and explanations may fail due to cross-cultural misunderstandings.

For many people, the provision of health care services deals primarily with physicians and hospitals. Gesler finds this to be an extremely narrow point of view which can be a barrier to understanding and to improving health care delivery. There are differing concepts about health and illness and cultural geography examines relationships among the components of each concept. Different people think about illness in very different ways. Ideas vary among medical systems and communities. To illustrate this point, Gesler uses three categories to classify principal medical systems: traditional non-professional medicine, traditional professional medicine, and biomedicine.

1. Traditional non-professional medicine – includes native doctors, shamans or traditional healers. For example; Native American medical practices with roots, herbs, leaves, charms and prayers.

2. Traditional professional medicine – has formal schools for training. Which include: a) Ayurvedic, b) Chinese Medicine,

   a) Ayurvedic – a holistic system of healing originating in India 3,000 to 5,000 years ago. It encompasses the study of diseases and remedies as well as the intellectual and spiritual health of the person. Ayurvedic medicine is currently practiced in India and in other communities around the world.

   b) Chinese Medicine – began 1,500 B.C. Practiced today in China and Chinese communities around the world

3. Biomedicine – a professional medical system influenced by Louis Pasteur's Germ Theory. It is also called modern, Western or cosmopolitan.

Biomedicine is the medical system most widespread today. It has made its way, to some degree, into every country in the world, yet it is a very important point to grasp here, that biomedicine is not the only professional medical system in existence today (Gesler, 1991, pp. 16-18). The approach to Eastern ways of thinking accepts that we have physical, emotional, intuitive, and spiritual capacities with which to perceive reality. Whereas Western training teaches us to look for the final analysis, the Eastern paths teach us to let go of that need and, instead to learn to rest in the observing part of the mind (Pond, 2003).

Furthermore, Gesler argues that "whether illness beliefs are scientifically sound or not, it is a fact that they affect the way illness is dealt with, to the extent that a strong belief in certain treatments or practitioners can even help bring about one's recovery. Gesler states that we know the mind and the body are linked in ways that we are just beginning to explore.

The Canadian Association of Psychosocial Oncology (CAPO) appears to support Gesler's outlook on improving health care delivery by recognizing that individuals may have differing approaches to their health care. The treatment stage of cancer is a time when patients look for education about treatment options and the use of alternative or complementary treatments (CAPO, 2003, p. 21).

A barrier to helpful cancer patient education is a disregard for viewpoints of the cancer patient. In *Learning to question: A pedagogy of liberation*, Freire (1989) states that any health education program should begin by finding out what knowledge of health the people already have. All medicine programs must remain close to the knowledge of the people to facilitate acceptance when ideas are coming from outside their own

experience. Freire points out that many educational plans have failed because they never took into account the 'men-in-a-situation' to whom the program was directed, but instead were designed according to the personal views of the educational planner's reality. "One cannot expect positive results from an educational action program which fails to respect the particular view of the world held by the members of that community. Such a program constitutes cultural invasion – good intentions not withstanding"(Freire, 1970, pp. 83-84).

Dialogue and Consciousness Raising

Education program content must evolve from dialogue with cancer patients. It is not the role of educators to speak to people about their own views, nor attempt to impose that view on them, but rather to dialogue with the patients about their view and share ideas. Freire (1970) cautions that education action which is not critically aware of this runs the risk of 'banking' or of preaching in the desert. The banking concept of education is a student/teacher relationship where the teacher narrates and the student listens. The student is a receptacle to be filled by the teacher. In libertarian education, both learner and teacher educate each other. Freire's approach to transformative learning replaces the banking education with problem posing methods. Learners are no longer docile listeners; instead they become critical co-investigators in dialogue with the educator. Herein lays a barrier to cancer patient education. Health care provider attitudes do not always agree with patient attitudes. Social change may be necessary for this to occur fully.

In *Pedagogy of the Oppressed*, Friere (1970) defines an act as oppressive only when it prevents people from being fully human. Living with an illness can be associated with changes in the physical body or life style adjustments which can lead to feelings of

lost power. Patients may call themselves ignorant and say that the 'doctor' is the one who has knowledge and to whom they should listen. It is possible the act of opposing the doctor provokes guilt feelings. "To alienate men from their own decision making is to change them into objects" (Freire, 1970, p.73).

Years before Paulo Friere's contributions to radical education theory, one of his predecessors was a Canadian, Father Moses Coady. In 1928 the University of St. Francis Xavier, Nova Scotia, under the leadership of Coady, developed an original community development program that combined the principles and practices of critical adult education. Coady, a charismatic leader with a clear vision argued that the essence of community development was that participants became masters of their own destiny. Adult educators, in his view, should be agents of reform for social change. Along with his cousin, Father Jimmy Tompkins, Coady worked in Antigonish, an impoverished fishing community in Nova Scotia. They used a practical and effective strategy of adult education and group action, which began with the immediate needs of the local people. (University of Toronto, retrieved, June 13, 2005).

The Antigonish Movement was based on study circles in which people critically examined their problems and sought collective solutions. This formula of collective learning and economic self-reliance rapidly produced a noticeable impact. During the 1930s, 1,300 study clubs were formed in the Antigonish area reaching a total of 11,000 members (University of St. Francis Xavier, retrieved June 13, 2005). The Antigonish Movement addressed many of the themes that would reappear decades later in popular education; for example, the importance of self-confidence, self-reliance, and critical consciousness. (University of Toronto., retrieved, June 13, 2005). The community

education approach found at Wellspring resembles this Antigonish model of local study clubs or support groups.

Dialogue cannot be carried on in a climate of hopelessness. Through a human approach to cancer patient education, people become empowered to make choices. Freire is quite clear that "…without dialogue there is no communication and without communication there can be no true education" (1970, p. 81). Taylor (1993) recognizes the hallmarks of Freire's philosophy to be the notions of dialogue and conscientization. The process of raising consciousness is significant because it is not so much the actual learning that is helpful, but rather the transforming of the relationship between the world and reality. For changes to occur on any level, in particular between health care providers and patients, it becomes clear that a radical transformation of these relationship patterns is contingent upon the radical transformation of society at large.

Conclusion

In conclusion, I have identified theories and concepts for further educational research that certainly are important to the planning and implementation of education for adults diagnosed with cancer. I have also pointed out barriers that prohibit or challenge this view.

A helpful approach is to recognize that not everyone is self-directed and be prepared for people to move from dependency toward self-directedness at their own pace. Know the emotional dimensions of learning. The process of expressing emotions, both positive and negative, may help a person re-evaluate life values and the importance of certain goals.

It is helpful to establish an environment that builds trust and care. Continue to foster a trusting environment where the educator has both credibility and authenticity. Share the responsibility of creating the learning community. Connect the rational and affective by using feelings and emotions for critical and reflective learning. Create a learning environment that supports critical reflection and exploration of alternative perspectives. Remember that invitational education addresses the total learning environment by focusing on people, places, policies, programs, and processes.

Consider 'nurturing' instead of 'facilitating' the learning. Appreciate the person with cancer as a mental, emotional, social, spiritual, as well as physical being. Recognize that individuals may have differing approaches to their health care. Respect the particular view of the world held by each person. Ensure that all programs are suited to the knowledge base of the learners. Education program content must evolve from dialogue with cancer patients and must be personalized to meet the specific needs of those involved.

The fact that transformative learning in practice has no single mode of teaching and learning is both a bridge and a barrier. On one hand this gives the educator freedom to explore methods that can be flexible and ever-changing. On the other hand, without guidelines it can be a challenge to put into practice. Psychological challenges of a cancer diagnosis can be expressed in feelings of guilt, depression, stress, and anxiety. In addition, the person may be having physical discomforts associated with cancer treatments. This can be a barrier to effective communication and/or motivation. It is helpful to validate the experiences of the person with cancer. This can be facilitated through human interaction and communication.

Cross-cultural misunderstandings may cause failure in helping cancer patients. A narrow viewpoint concerning the provision of health care services sets up a barrier to improving health care delivery. It is important to comprehend that biomedicine is not the only viable professional medical system available. Another barrier to helpful cancer patient education is a disregard for the viewpoints of others. Many educational plans fail because they do not respect the views of the people for whom the program is intended. Healthcare providers who do not allow patients to question can set up barriers to self-directed healing. Patients who believe that only the doctor has the knowledge create their own barriers to self awareness. A climate of hopelessness fosters lack of motivation.

Adults diagnosed with cancer are faced with confronting a new reality which often necessitates a need to redefine a person's sense of self. To move toward a more human approach to helping people with cancer, radical changes need to be considered within the entire health care structure. The world has suddenly become smaller with respect to the exchange of information. Rapid modern medical advances are being met by the equally rapid proliferation of many ancient healing disciplines. Now the two worlds meld to create the birth of new, advanced hybrid health care techniques (Austin, 2004). Cancer patients who are learning to take charge of their own bodies, and their own lives have proven the potential for a much higher quality of life. The traditional role of health care professionals is changing as people seek out alternative or complementary ways to manage the challenge of having cancer.

Utilizing dialogue in local study groups and peer support groups has proven to be an effective strategy to raise self-confidence, self reliance and critical consciousness which can empower people to make choices based on their own needs.

Further educational research is needed to develop a model or approach to adult education that meets the diverse needs of adults living with cancer. To be under the umbrella of health education is too limiting, given these alternative options. In addition, other concerns, such as spiritual, cultural, financial, self-esteem, nutrition, relationships, and grieving, among other issues, go beyond the realm of healthcare. Therefore, research initiatives are needed to include an eclectic group of perspectives. There is still so much to be learned about the complex nature of cancer and its effects.

CHAPTER THREE : RESEARCH METHODS

Overall, the paramount objective of qualitative research is to understand the meaning of an experience. Qualitative researchers assume that there are multiple realities that are a function of personal interaction and perception. "Beliefs rather than facts form the basis of perception" (Merriman, 1988, pp. 16-17). This research uncovered beliefs that drove the actions of people; therefore this study was exploratory and inductive.

This study was about community-based education for adults diagnosed with cancer and for those who care for them. I examined the Wellspring cancer support and resource centre as a model for grass-roots, "bottom up" approach, whereby people living with cancer decide their own needs and they are provided access and support to do so.

Overview

Anne Armstrong Gibson, had a vision to alleviate the sense of isolation experienced by her and so many cancer patients. Anne worked with family, friends, some of the leading experts in the field of oncology, and supporters to establish Wellspring, a non-profit organization offering psychological, emotional, social, spiritual, and informational support to individuals and families living with cancer. In 1992 Wellspring opened its first centre in Toronto, Canada. Anne's vision was to create a Canada-wide network of community-based centres that would provide people with the tools they required to cope with cancer. Although Anne died in 1995, her vision continues to guide the organization toward achieving a network that will one day span across Canada (Wellspring, 2005).

This qualitative education research investigated the history of Wellspring and how it maintained its ongoing success in community-based education. In this chapter, I

outline the research methodology and methods that I used for this study. First, I describe

the research design and the position of the researcher. Then, I outline the philosophical

and theoretical framework used to shape the inquiry process. I include, data collection

techniques, and methods that I used to process and analyze the data. I discuss credibility

and trustworthiness of the research results, scope and limitations of the study, and ethical

considerations. Finally, I restate the problem and summarize the chapter.

Case Study Methodology

Qualitative case study is a research design in its own right. It is a means to

understanding, informing and improving education practice. This design is most

appropriate when description and explanation are sought. The qualitative mode of inquiry

into the single case captures the sequentiality of happenings in context and allows the

phenomenon to be studied systematically. I used Merriam's (1988) definition of case

study methodology; "A qualitative case study is an intensive, holistic description and

analysis of a single instance, phenomenon, or social unit" (p. 21).

Creswell (2005) describes a case study as a significant kind of ethnography that is

an in-depth exploration of a bounded system based on extensive data collection. The term

"bounded" means that the case is separated out for research in terms of time, place or

some physical boundaries. This case study was a bounded system which focused on the

historical development of the Wellspring phenomenon and the people associated with

Wellspring's beginning. The unique strength of the case study is its ability to deal with a

full variety of evidence – documents, artifacts, interviews, and observations.

This research is what Stake (1995) calls an intrinsic case study. Wellspring was

pre-selected for study because it has merit in and of itself. I had an interest to learn about

this particular case. Therefore the methods used depend on intrinsic interest in the case, rather than using this as an instrument to understand something else. I wanted to examine the phenomenon expressed rather than having specific issues becoming more important than examination of the case as a whole.

Case study methodology is not necessarily intended to produce generalizations. Yet, this case illustrated certain activities, problems, or responses that reoccur and thus can be capable of creating generalizations concerning community-based education for people living with cancer. For example, the realities of cancer can best be understood by those who have shared similar experiences, therefore, peer support can provide a unique way of helping people deal with so many of the issues associated with cancer.

More importantly, coming to know this particular case well can emphasize its uniqueness. I aimed to preserve the multiple realities, the different and even contradictory views of the Wellspring model.

Researcher Positioning

Qualitative research accepts differences in description and interpretation. Although phenomena need accurate description, interpretations of those phenomena are shaped by the mood, the experience and the intention of the researcher (Stake, 1995, p. 95). My positive experiences associated with Wellspring lead me to a position of advocacy for community-based education.

Research into the Wellspring model began with the story of one woman who saw a need for supporting and informing people living with cancer. Therefore, part of this study needed me to be a biographer who traced the chronology of Wellspring along with a life history of the late Anne Armstrong Gibson.

Most contemporary qualitative researchers accept that knowledge is constructed rather than discovered. This put me into the position of constructing a report based on what others told me and what I read. Although the reality I sought was a collective meaning, essentially as the researcher, I was the agent of this knowledge which was a product of my interpretation. The emphasis was on "thick description" of places, events, and people based on the emic interpretations of those being studied (Stake, 1995, p.102). Researchers make deliberate choices about the role preference that best support the researcher in contributing uniquely to the study of the case. I chose to expose my role as someone who is a cancer survivor and a member of Wellspring.

I positioned myself as an indigenous-insider (Acker, 2000). I am someone from the Wellspring community who is perceived as a legitimate member by others. I became a Wellspring member in the spring of 2002 shortly after being diagnosed with cancer. I participated in the Sunnybrook and Women's Wellspring, Toronto during my cancer treatments. Later, after relocating, I became a member of Wellspring Niagara, where I continued to participate in various programs and worked as a trained volunteer. As an insider, I have undergone similar experiences, possess a common history, and share knowledge that characterizes me as someone who has had cancer and someone who is a Wellspring member.

In my early search for documents and information about Wellspring, I found it helpful to begin all conversations with new contacts by giving a brief history of my experience with Wellspring. This indigenous-insider position gave me a sense of belonging which allowed me comfortable and easy access to information.

On the other hand, my researcher positioning tended to shift to somewhat of an external-insider when I explored the early history of Wellspring. The advisors and early organizers who assisted the founder, Anne Armstrong Gibson are not part of my own experience, yet I perceived myself as an insider who identified strongly with the research site as part of my adopted community.

Sherif (2001) emphasizes that the researcher, as producer and writer creates meaning and interpretation out of ongoing experience. The ethnographer's self affects every aspect of the research process from conception to final interpretation. Sometimes the boundaries between researchers and those being researched can become hazy. Yet, the strength of this research lies in my ability as an "insider" to offer new angles of vision and depths of understanding that would not be possible to an "outsider". I did not need to search for social acceptance into the Wellspring community. However, I was aware that I was consistently forced to make choices about identity as I moved back and forth between the role of participating member and the role of academic researcher.

My experiences conducting field research added a new dimension to my personal journey with cancer. I fluctuated between periods of high enthusiasm and times when I felt "cancered out". I fluctuated between wanting to be a forerunner in advocacy for cancer patient education and at times simply wanted to be nurtured. My understanding and sensitivities with respect to conducting ethnographic research with people who share a similar life challenge caused me to reflect on the unique and personal nature of conducting this case study.

Sources of Information and Site Selection

The information for this research came from nine interviews with people directly involved in some way with the conception and fruition of Wellspring. The voices and stories of eight of the original advisors and board members had been professionally recorded and published in public documents that were stored at the original site of the Wellspring at 81 Wellesley Street East, Toronto, Canada. In the *Sound Portraits* CD, Maddren (2003) spoke with seven of the key people involved with Anne Armstrong Gibson. I transcribed these interviews verbatim. In addition, Millar (1994) interviewed Armstrong Gibson in *Journeys – Anne Armstrong Gibson: Knowledge, the best medicine,* a documentary video interview. I viewed the video and made notes of significant quotes from Anne. This historical video was vital to the research because it documented Anne's perspective. Shortly after production of that video interview, Anne Armstrong Gibson died. I observed from the CD transcription notes that Maddren (2003) had also taken some of Anne's quotes from this video interview to include in her *Sound Portraits.* To confirm my interpretation of that data and to gain further insight, I interviewed, Marny Robinette, a long-time friend of Anne, who worked in a staff position since 1992 and still remained with Wellspring at the time of this interview, July 14, 2005.

Document research was significant to this study because of its historical nature. Two types of documents were used; those written and published by Wellspring and some written about Wellspring and published by others.

Research involved visiting three locations. The original Wellspring centre, known as The Coach House was where I was given historical documents, met staff and volunteers, and had a tour of the facilities. Visiting this location also provided me with an

experiential aspect to this research as it gave me a "feel" for the environment that was talked about in the historical documents and interviews. The Sunnybrook and Women's Wellspring, 2075 Bayview Avenue, Toronto is the site where I first attended Wellspring programs as a member. It is also where I interviewed Marny Robinette. Wellspring Niagara, 3250 Schmon Parkway, Thorold is where I volunteered and participated in programs as a member.

Philosophical and Theoretical Framework

Like most qualitative researchers, I set about conducting this study with a certain set of beliefs or assumptions that guided the inquiry process (Creswell, 1998). I took a critical theory view of community-based education. As such, I explored community-based education as an alternative approach to an institutional, bio-medical model of coping with cancer and moved toward a grass-roots network of individuals and groups living with cancer that came together to support and inform each other. I accomplished this through an intrinsic case study of a model that has been recognized by Health Canada, the Ontario Ministry of Health, and Cancer Care Ontario as an outstanding example of organizational excellence in community-based care (Wellspring, 2005).

The end goal for this study included transforming the traditional bio-medical view to helping people diagnosed with cancer into a more inclusive model which considers the non-medical needs of the person diagnosed with cancer, as well as tending to the needs of those who care for the cancer patient. Therefore, in this case study, the term "living with cancer" refers to the experience of having life touched by cancer, either as an individual diagnosed with the illness, or as an individual who lives with someone diagnosed.

I shed light on changing cultural responses to the diagnosis of cancer during the 1980's and early 1990's in Toronto, Canada. The evolution of Wellspring was in direct response to what was considered outdated social attitudes toward cancer as a disease and toward people living with this disease.

Unearthing the story of Anne Armstrong Gibson and the story of the founding of Wellspring gave insight into the changing attitudes toward people with cancer and to emerging education opportunities and supportive social structures initiated in Ontario, Canada in the 1990's. One woman had a vision for an innovative, creative, co-operative community effort, based on the needs of cancer patients and their loved ones. Her approach was designed to complement any medical treatments patients may be undergoing.

The question critical for insight into this case study was: who is Anne Armstrong Gibson? Using a constructivist approach to grounded theory, I extracted quotes from public documents and transcribed interviews to create a description of Anne's personality traits and how people responded to those traits. I also highlighted biographical data that was relevant to the founding of Wellspring.

Philosophy as a mode of inquiry

The method of philosophy as a distinct mode of inquiry enables it to answer questions that cannot be answered by any other methods of human inquiry. There are purely philosophical questions that are, to whatever extent, answerable by philosophy alone (Adler, 1993). Philosophy is a domain of knowledge concerned with realities of the world and of human interactions with the world. As such, it is also associated with

historical research. For this reason, an historical investigation into Wellspring as an intrinsic case study was a practical approach.

Reality is knowable by the human mind. Reality is the truth we have in our minds. In other words, there is a correspondence between our minds and what we perceive as real. Therefore, this study included questions about the material and immaterial realities.

Philosophy plays a pivotal role in education research. Like science, philosophy can have its own mode of inquiry. Its separate sphere of inquiry, identified by Adler (1993) includes four dimensions; metaphysical, moral, objective, and categorical. Hence, this study used Adler's four dimensions of philosophy to focus research questions into four themes that represent the intellectual work of this case study.

Approval and Access Considerations

This study took an historical perspective on the evolution of Wellspring. This decision initiated the need to investigate the original Wellspring centre, known as The Coach House, located in downtown Toronto, Canada. Much of the original documents are archived here, including Wellspring newsletters, video tapes and brochures. The front-desk volunteer at The Coach House Wellspring connected me with Helen Brent, Manger, Outreach and Program Policy at Wellspring,. Helen asked me to submit details of my proposed research prior to my visit so that she could direct me to helpful resources. We arranged our first meeting to be at The Coach House in June, 2005. I was given a tour of The Coach House and The Odette House. I was given an assortment of public documents, including a video recording, a Compact Disc with recorded interviews of the founding members of Wellspring, a DVD with a brief history of Wellspring, and The

Wellspring 10th Anniversary Newsletter (2002), which gave an overview of the first ten years of Wellspring's existence.

Volunteers and staff at Sunnybrook and Women's Wellspring welcomed me into the facility when I visited the site to conduct the interview with Marny Robinette, manager of the centre. Prior to the interview I submitted to Marny a brief overview of the proposed research and a copy of the interview guiding questions (see Appendix C). This seemed to meet her approval because we set a date for the interview. Overall, the kind support and enthusiasm expressed by Wellspring staff and volunteers to help me access resources and to share time talking with me about this research encouraged me to continue.

Data Collection Procedures

I took the systematic approach to case study research influenced by Robert Stake. I developed a data-gathering plan which included: defining the boundaries of the case to be an investigation of the first Wellspring centre, a list of research questions, identification of data sources, intended reporting documents, and allocation of timelines (Stake, 1995). A matrix of tasks to be accomplished displayed the progress of the study. This was modifiable to allow tasks to be added and deleted over the course of the study.

The data storage system included a researcher log to record ongoing personal reflections on the literature as well as thoughts on progress of the research. A researcher field notes journal was used to record descriptions and observations of participant observation and interviews. Files were set up to identify literature themes, documents, issues, and persons interviewed. Reference material was number coded for easier retrieval. Data management is the term used by Huberman and Miles, (1998) to refer to

the operations needed for a systematic, coherent process of data collection, storage and retrieval. Careful planning of data management aims at high quality, accessible data, documentation of the analysis that have been carried out and retention of data and associated analysis after the study is complete. While this proved to be somewhat time consuming at the beginning, I found it was time well spent, as I was able to readily retrieve information as needed.

Triangulation

Triangulation is directed at judging accuracy of specific data items. (Lincoln and Guba, 1985). Data collection in this study was triangulated by:

1. Public Documents – Two types of documents were used; some documents written and published by Wellspring and some written about Wellspring and published by others. Newsletters, flyers, brochures, and other secondary documents provided a history of Wellspring.

2. Field Notes Journal – Descriptive participant observation field notes maintained in a journal of my own experiences during more than 25 visits to Wellspring. For respectful consideration to participants, no identifying data of any members or volunteers was recorded. Simply my own experiences were noted.

3. Interviews – I set up a semi-structured interview with one Wellspring manager who worked as a staff member since 1992, just prior to the opening of the centre. All other interviews with Anne Armstrong Gibson and advising colleagues had already been conducted and recorded by other researchers. Hence, my only task was to transcribe these audio taped

interviews (Maddren, 2003, Millar, 1994) for later coding and analysis..

The purpose of these interviews was:

- To get a variety of perspectives on how Wellspring was conceived, initiated and developed.

- To determine how ongoing success was monitored and maintained.

- To discuss how programs were selected, initiated, and evaluated.

- To uncover what philosophies are the driving force behind the decisions made by Wellspring organizers.

There are multiple realities based on the perceptions of people who were involved, in some way, with the founding of Wellspring. My goal was to find the emerging themes that could shed light on philosophies that shaped the Wellspring model. Therefore, I used a variety of data sources. I practiced methodological triangulation (Stake, 1995) by preceding interviews with a review of historical records found in public documents, such as Wellspring newsletters, flyers, brochures, and visual productions. While many qualitative researchers argue that triangulation is really a search for additional interpretations more than the confirmation of a single meaning (Stake, 1995), I contend triangulation is useful for credibility and trustworthiness of the data. For example, in this case study, the interview with Marny Robinette brought to life and confirmed data that was pre-recorded. In addition, my previous document research enabled me to probe Robinette for more depth and clarity of information.

Story Telling

Story telling is seen as one of the fundamental ways in which people organize their understanding of the world. Narratives told by individuals or groups under

ethnographic study give the researcher access to tellers' understandings of the meanings of key events in their lives and communities. Therefore, soliciting stories about the beginning of Wellspring gave me insight into significant ideas and events that lead to the opening of the first Wellspring in 1992. The term "narrative" covers a range of types of talk and text. Essentially, the term refers to structures of knowledge and storied ways of knowing (Cortazzi, 2001).

Like many researchers, I relied on interviews as a means to gather stories. While some of these interviews were formally tape recorded other, less formal story-tellings emerged from spontaneous conversations with Wellspring members. I used narratives in this qualitative research to optimize the opportunity of the reader to gain an experiential understanding of the case (Stake, 1995). The narrative is crucially shaped by the questions asked; therefore, the stories were, in fact, jointly constructed in interviews.

Sometimes a researcher can obtain narratives by telling a story first (Cortazzi, 2001). I found this to be a helpful strategy. When talking to informants I took time to get acquainted and shared a little of my own history with cancer as well as my experiences at a Wellspring. I believe that my insider-status was helpful in giving me acceptance for access to people and information. For example, when I made an on-site visit to Wellspring Odette House and The Coach House, downtown Toronto, I found the staff and volunteers very open. Helen Brent, Manager, Outreach and Program Policy kindly offered me many documents to help me with my research and I was given a tour of the facilities as we shared stories about Wellspring. One thing that did surprise me was my emotional response to conducting this research. I felt a little teary-eyed to recount bits of

my story and to find myself in the presence of the original Wellspring facility with some of the original staff and volunteers.

As Oakley points out, "in interviewing there is no intimacy without reciprocity" (cited in Fontana and Frey, 2000, p. 658). I attempted to do away with the traditional hierarchical situation in interviewing. I took a more feminist approach and showed my human side, answered questions and expressed feelings. I do not believe that I could ignore neither my gender nor my own relationship with cancer as these are important elements that filter my perception of knowledge. I agree with Fontana and Frey (2000) that this approach provided a greater spectrum of responses and greater insight into the lives of the respondents being interviewed.

Initially my research plan was to formally interview people involved in the founding of Wellspring. However, early into the document research, I discovered that in fact, other investigators had already interviewed most of those individuals. I transcribed, coded, and analyzed these interviews. In addition, I viewed the documentary video (Millar, 1994) and made notes of significant quotes from Anne. I observed from the CD transcription notes that Maddren (2003) had also taken some of Anne's quotes from this video interview to include in her *Sound Portraits*.

To further triangulate the data, I interviewed, Marny Robinette, a long-time friend of Anne, and staff person at Wellspring since 1992. This 90 minute interview was audio tape recorded and later transcribed verbatim by me for analysis. I invited active involvement of the participant in the research process by requesting member checking, which is directed at judgment of overall credibility (Lincoln and Guba, 1985). Because the interview was conducted out-of town from my home base, I first e-mailed a short

synopsis within a week of the interview. Then I couriered two copies of the typed transcript of the interview, plus a synopsis of my interpretation of the interview, to read and approve for accuracy. The interviewee was invited to add anything that may have been missed that was felt important, as well as to delete what the participant may not want recorded. I included a self-addressed, prepaid courier envelope for the participant to return the transcription and analysis to me, signed with her approval. I respectfully made any edits suggested by the participant. She signed the transcription notes and returned them to me within ten days of receiving them.

Historical and Cultural Geography Considerations

Story interpretation and analysis of both oral and written narrative can be culturally based. Familiarity with the situation, the cultural values and beliefs of the time and the social and political context of the story contributed to shaping how the story was told and received. Therefore, recording the story of this case study needed to be told within a socio-cultural context. The historical background of Wellspring must be understood within the context of having cancer during the 1980's and early 1990's in Toronto, Canada.

In 1980 Canadian icon Terry Fox initiated a dramatic turn-around in community attitudes toward cancer when he ran his Marathon of Hope. He provoked a public awareness of a disease that had long been silently hidden. His meeting with Prime Minister Pierre Trudeau and his highly publicized entry into the city of Toronto helped him reach his goal of a Canadian commitment to cancer research by raising millions of dollars. He also contributed to changing ways of thinking about cancer from a state of hopelessness to one of hope. After his death, The Terry Fox Foundation continued to

raise funds to find a cure. Certainly, over the next decade scientific and medical advances began to improve the outcomes for people diagnosed with cancer. Yet, cancer patients found other aspects of living with this illness were still being ignored. (MacQueen, 2005). Anne Armstrong Gibson responded to this gap in the support needs for people living with cancer. Today, Wellspring is recognized provincially and nationally as a model for community-based programs (Wellspring, 2005).

Collecting the Data

Using constructivist grounded theory methods; I systematically began collecting the data by searching public documents (see Appendix A). Most documents used were from the Toronto Wellspring, known as The Coach House. Some of the newsletters used were mailed to my home because I am a Wellspring member. Brochures were picked up by me while visiting the site. Other documents, including newsletters, video recording, Compact Disc sound recording, and DVD were given to me by the Outreach and Program Policy Manager at The Coach House in June, 2005.

A field notes journal was used to record my observations and reflections. This evolved into an eclectic assortment of concrete observations about physical surroundings, notes on my own experiences at Wellspring and some reflection on relevant readings. Observations and field notes were recorded on the left-hand column of the journal page while the right hand side was used to add reflective thoughts and further questions.

Eight of the nine interviews were collected from other sources that had been pre-recorded. One interview was personally planned and conducted by me.

I wanted to inquire into what guiding philosophies formed the foundation of Wellspring to contribute to its success. Therefore, I stayed focused on the four

dimensions of philosophy; metaphysical, moral, objective and categorical, as identified

by Adler (1993) to organize the emerging data. These dimensions were identified in two

ways. First, I surveyed the data, including public documents, interview transcripts, and

field notes journal. I used colour coding to highlight chunks of text showing the four

dimensions as four dominant themes and established axial coding, a strategy where sub

themes were systematically developed and linked with each of the four dimensions

(Strauss & Corbin, 1998). This selective coding was a process of integrating and refining

sub-themes of data. Yellow represented metaphysical data, pink represented moral data,

green represented objective data, and blue represented categorical data.

Metaphysical themes were coded to create sub-themes. I looked for reoccurring

ideas and assigned number codes to each variation or view of reality. The moral

dimension studied the ideals of what we ought to seek. In other words, what is right and

what is good. I examined the data and number coded ethical issues to create sub-themes

about moral philosophical concerns.

The objective dimension of philosophy refers to objects of thought that have

intentional existence. These are regarded as objects of philosophical analysis (Adler,

1993). Words convey objects of thought. I number coded words that represented sub-

themes or topics of conversation that were reoccurring. Each topic represented where

great conversation occurred. This is important because it identified issues and topics of

common concern.

The categorical dimension of philosophy is concerned with various categories of

subject matter (Adler, 1993). This dimension required a third step in coding the data.

Great topics of concern which evolved from the objective dimension were organized into

a table which illustrated how the sub themes evolved into programs for participants at Wellspring.

Data Analysis

This was an intrinsic case study. My primary task was to come to understand the case. I needed to examine relationships, to probe issues, and to collect categorical data, but essentially, those ends are subordinate to understanding the case. The search for meaning is often a search for patterns (Stake, 1995).

I looked to constructivist grounded theory methods to systematically collect and analyze data. "Constructivists assume the relativism of multiple social realities; recognize the mutual creation of knowledge by the viewer and the viewed, and aim toward interpretive understanding of subjects' meanings" (Charmaz, 2000, p. 510). This approach to grounded theory methods is a more open-ended practice that stresses emergent, constructivist elements. Charmaz reminds us that data are narrative constructions of experience; they are not the original experience.

First, I gathered data from multiple sources, including observations, conversations, interviews, biographies, public records, Wellspring organizational reports and newsletters, as well as my field notes journal. All information was recorded in a left-hand column on the page, leaving the right-hand column open for memo writing. Recording brief notes beside the data helped to spark my thinking in a reflective way that lead to further emergent questions, and aided in linking the literature to observations. Early memo writing also kept me focused on my analysis and helped me to grapple with ideas about the data as it emerged. It was also a way to refine emerging categories and to

define the relationships among the various categories. This gave me a sense of control and a sense of confidence in my ability to analyze the plethora of data.

All data was coded into preliminary themes based on Adler's (1993) four dimensions of philosophy and later into emerging themes. I took a comparative look at the themes from the literature review and the themes that evolved from the fieldwork data and interviews. I identified themes that were not expected during the study; for example, governance structure and budgetary considerations. I also looked for major and minor themes, as well as any unexpected themes that arose from the coding.

The constructivist approach assumes that what people take as real, as objective knowledge and truth, is based upon their perspective. My intention was to find multiple realities based on multiple perspectives. From these different views, I looked for themes that illustrated philosophies that drive the Wellspring model. Using constructivist grounded theory methods allowed me to place emphasis on meaning without assuming the existence of a uni-dimensional external reality. This approach to qualitative research analysis recognized the interactive nature of both data collection and analysis as it fosters the development of qualitative traditions out of the study of experience from the standpoint of those who live it (Charmaz, 2000).

Limitations of Method

Qualitative case study is very personal research. The way the case and the researcher interact is presumed unique and not necessarily reproducible for other cases and researchers. The quality and utility of the research is not based on its reproducibility, but rather on value of the meaning generated by the researcher or the reader. Thus a personal valuing of the work is expected (Stake, 1995). A case study presents many

opportunities to make it both intrinsic and instrumental and to make it serve many audiences. My descriptions, interpretations and analysis represent my interest in Wellspring as a model of community-based education for people living with cancer. There are many stories to tell and there are others to tell the rest of the other stories!

I am aware of my own bias for a holistic approach to cancer patient education. In choosing Wellspring as my case for illustrating community-based education for people living with cancer, I demonstrated what I found most useful, rather than what might be most typical for cancer patient education programs.

I needed to rely on second hand information for historical data collection, as Anne Armstrong Gibson, the founder of the Wellspring concept has since died of cancer. I interviewed one person who worked with Anne on the original proposal. The other eight interviews were conducted and recorded by other researchers; therefore I did not have control over the questions asked. I also relied on public documents to give further insight. Using other people's interpretations of the Wellspring story may provide conflicting views.

I had to accept the limitations of using the closed group of Wellspring supporters in providing me with information. I did not locate people who may have disagreed with what was being said. I was also limited in that most of the nine interviews were conducted by other researchers; therefore I was less able to shape the direction of the questioning.

Case studies are generally not known by their problems. Although problems and problem solving exists, the essence of the case is not its problem. The essence of the case is the case itself. Intrinsic case study research and reporting are not simple. "The

traditional research report of statement of the problem, review of the literature, design, data gathering, analysis, and conclusions, is particularly ill-fitting for a case study report" (Stake, 1995, p.128). The case was neither a problem nor a hypothesis. Therefore case study reporting is limited in finding a reporting style that is adequately descriptive, yet able to serve the writer's reflective interpretation without undue bias.

Ethical Considerations

Because of the sensitive nature of the cancer population, I did not involve in anyway individuals who were Wellspring members participating in the cancer education programs that I observed. Notes from my reflective journal recorded my own experience and thoughts and did not intrude on the confidentiality of any person that I encountered.

The people that I chose for an interview were organizers and administrators who had first hand knowledge of the history of the development of the existing cancer education centre. Eight of the nine interviews were recorded on public documents. I asked permission to have an interview with Sunnybrook and Women's Wellspring manager. I informed her that she could terminate participation or decide not to answer any questions during the interview. Informed consent is the most central of ethical principles (Howe and Moses, 1999). I gave a verbal and written explanation of the interview process (see Appendix B). The participant signed that she read, and understood the purpose of the research and the rights and expectations of the participant (see Appendix D).

Privacy is the second central principle in the traditional ethical treatment of social research participants (Howe and Moses, 1999). Participating informants were asked if

they would prefer to keep their identity confidential. Marny Robinette opted to use her own identity (Personal communication, July 25, 2005).

When looking for public documents written or published by Wellspring, I asked permission to conduct my search at the Wellspring site. Further, I asked permission to use specific information in my reporting. Plagiarism was avoided by fully citing any data compiled by another author.

Noddings (1995) regards caring as the ethical universal. She applies the ethics of care specifically to educational research. She believes that "the relationship between researchers and participants ought to exemplify caring, particularly trust and mutual respect" (cited in Howe and Moses, 1999, p. 34). I respected and honoured this universal ethic by presenting myself as someone who truly cares about the work that Wellspring does. I believe that my insider status allowed me to be authentic in my caring, trust, and respect for Wellspring and the people who share the vision of Wellspring. Further, I agree with Noddings' belief that research ought to be based on its potential to contribute to caring communities.

Summary of the Chapter

This chapter conceptualized the structure for the research design of this intrinsic case study. While the case itself remains dominant, in terms of thick description and interpretation, the research question emerged as a means to create a bounded system with a clear focus. The research question, also known as the issue question was: What guiding philosophies for education practice contribute to a successful model of community-based education for adults living with cancer? I used the Wellspring model as a case study.

Inquiring into these guiding philosophies was a collaborative act. I believe that this case study research involved the enthusiasm and co-operation of informants and participants to assist me along the way. Ultimately, I found the most significant instrument was me, the researcher. Identifying researcher positioning was pivotal in conducting the research and in the eventual analysis and reporting. My insider status afforded me a privilege that made this particular case study unique. Obtaining approval and access to information was more easily facilitated by my own involvement in Wellspring.

I used a variety of research methods and tools. Data collection was triangulated by public documents, field notes, and interviews. Using narratives was the best way to gain an experiential understanding of the case; therefore, oral interviews and stories in text were significant to this case study. The search for meaning is often a search for patterns. I used memo writing and coding applied to participant observation field notes, to documents, and to interview transcriptions in order to track patterns that lead me to finding the guiding philosophies for the renowned success of the Wellspring model. I used constructivist grounded theory methods because this allowed me to recognize the interactive nature of both data collection and analysis as it studies experience from the standpoint of those who live it.

The separate sphere of philosophical inquiry, identified by Adler (1993) included four dimensions; metaphysical, moral, objective, and categorical. Hence, this study used Adler's four dimensions of philosophy to focus issue sub-questions into four themes that represent the intellectual work of this case study.

The greatest limitation to this study was the bias and experiences that I, the researcher brought to the research. On the other hand, the very personal nature of qualitative case study contributed to the uniqueness and authenticity of the research. Ethical considerations were of utmost importance to this case study.

It is important for the reader to keep in mind that the ultimate purpose of this qualitative research was to gain insight into the philosophies that guide Wellspring in decisions, processes, and actions. This in turn offered an understanding of how to make community-based cancer patient education initiatives that are inviting and accessible, so as to promote a sense of hope, as well as personal growth and development for people living with cancer.

CHAPTER FOUR: FINDINGS

It's a place. It's a drop in centre where people can congregate. It's outside of an institution. You don't smell the antiseptic. It's not the light green walls. It's warm. It's done like a home....It's very cozy and nice.

(A.Armstrong Gibson, 1994, cited in Maddren, 2003)

This chapter reports findings that emerged from this case study research design (Stake 1995). This was an intrinsic case study therefore "the case" was dominant. Examination of the case as a whole was more important than the examination of any particular phenomenon expressed in the issue.

This qualitative research was concerned with programs that respond to the unique needs of adults living with cancer. Wellspring was selected as an innovative model of community-based education that successfully used a grass-roots approach to initiate a network of cancer patient support and resource centres across Canada. At the writing of this paper, five Ontario centers were established including the Greater Toronto Area, Halton-Peel, Niagara, and London. In addition, two more were in the process of opening; in Calgary, Alberta and in Halifax, Nova Scotia. A cancer diagnosis can have a ripple effect, whereby those who care for the patient also have concerns. Therefore the findings of this research addressed adults diagnosed with cancer *and* those who care for them.

The issue question, also known as my research question was:

- What guiding philosophies for education practice contribute to a successful model of community based education for adults living with cancer? I used the Wellspring model as a case study.

Overview of the Findings

Data was collected from public documents, interviews with nine people who were involved in the founding of Wellspring and the researcher's field notes journal. The findings of this research had two components: (a) descriptive inquiry results and (b) philosophical inquiry results. Division in the data evolved because information from this case study first supplied the researcher with a thick description of the case, including historical data on the Wellspring organization and biographical data on those involved. Secondly, the philosophical inquiry results moved the researcher to a more reflective level of recognizing the multiple realities of people living with cancer as well as recognizing the multiple realities in the planning and founding of Wellspring. In addition the philosophical inquiry lead the researcher to finding moral and categorical themes that contributed to a teaching and learning design that influenced programming at Wellspring.

Descriptive Inquiry

This case study was viewed within a geographical, cultural, and historical context. It began with a look at the social structure and attitudes toward adults diagnosed with cancer in Toronto, Canada during the 1980's and early 1990's. A description of Wellspring emerged from coding and analysis of public documents and nine interview transcriptions. Using constructivist grounded theory strategies, I number coded reoccurring themes. Public document coding resulted in locating 13 themes. Interview transcription coding was more detailed and resulted in locating 21 themes. By collapsing the themes from both sources, seven major themes emerged: (a) clear vision and articulated mandate, (b) teamwork and connections, (c) trust and caring,   (d) dialogue, (e) self-directed learning, (f) budgetary considerations, and (g) governance

structure. Data emerging from these perspectives were used to construct answers to the following four topical information questions used in this descriptive inquiry:

1. Wellspring history begins with the story of one woman. Who is this woman named Anne Armstrong Gibson?

2. Who were some of the people working with Anne to initiate Wellspring? What were their contributions?

3. How did the Wellspring organization evolve?

4. How did Wellspring choose what programs to offer?

Philosophical Inquiry

Subsequently, this study used philosophy as a mode of inquiry to discover those dimensions of Wellspring that cannot be answered by simple descriptive methods, or any other methods of inquiry. Philosophical knowledge is defined as knowledge about reality and philosophical analysis is defined as knowledge about knowledge itself (Adler, 1993). Philosophical findings identified the beliefs and values that guided Wellspring.

Results emerging from this research were organized within the theoretical framework of Adler's (1993) four dimensions of philosophy: metaphysical, moral, objective and categorical. All data from documents, interview transcripts, and field notes journal were colour-coded to highlight text that represented these four dimensions. A system of assigning yellow, pink, green and blue to indicate metaphysical, moral, objective and categorical respectively, provided a clear visual strategy to organize the data. Using this grounded theory approach, I constructed answers to the following four questions used in the philosophical inquiry. The first two sub-issue questions are concerned with philosophical knowledge:

1. What is real? What are the realities of people living with cancer? How have these realities been addressed by Wellspring?

2. What is moral? Prescribe what ideals we ought to seek when planning education and support programs for people living with cancer.

The third and fourth sub-issue questions are concerned with philosophical analysis:

3. What ideas are important? Identify topics which typically stimulate great conversation and represent common concerns shared by most adults living with cancer.

4. What are categories of important ideas? How did Wellspring organize these ideas or subject matters to develop programs?

Connecting the Findings

Finally, I searched for meaning by searching for patterns (Stake, 1995). I used constructivist grounded theory methods, a more open-ended practice that stresses emergent, constructivist elements to systematically analyze descriptive inquiry findings and philosophical inquiry findings in order to observe connections between the two sets of findings (Charmaz, 2000). The descriptive findings informed me "what" Wellspring was all about and the philosophical findings informed me "why" they did what they did. This led me to answers for the research question: What guiding philosophies for educational practice contribute to a successful model of community-based education for adults living with cancer? (See Figure 1).

Descriptive Inquiry Results

A thick description of the Wellspring model must be understood within a geographical, cultural and historical context. The descriptive inquiry results are discussed under the following headings:

- Historical and Cultural Geography Context

- Socio-cultural Context

- The Changing Canadian Cultural Landscape

- Anne Armstrong Gibson - Profile of a Visionary

- Anne's Vision

- Other Contributors to the Wellspring Model

Historical and Cultural Geography Context

The emerging Wellspring center in 1991, initiated in Toronto, Canada by Anne Armstrong Gibson was in direct response to the dissatisfaction with cancer patient care. Not long after being diagnosed in 1988 Anne realized cancer had changed her life. This problem was not easily resolved. She didn't have command of enough support to put her disease into perspective where she could deal with it. Anne was not looking for crisis intervention. She wanted to learn how to be a stronger person to deal with cancer. She didn't know where to learn those skills. "Despite her repeated attempts to find comfort, information and support for herself and her family, little was forthcoming" (Wellspring, 2002).

Along with all the other fears about treatment, survival, and the future of her family, Anne experienced an overwhelming sense of isolation. "She quickly realized that this was an all-too-common experience among cancer patients, and became determined to

fill the void" (Wellspring, 2005). She found the medical system to be inadequate to deal with the emotional needs of cancer patients. Although physically ill, Anne was inspired to create Wellspring, a new approach to cancer care.

She wanted to use Wellspring as a resource for patients, so that people wouldn't have to be afraid when they came here that somebody was going to come and say, 'Mrs. Smith, it's your turn to come to chemo now'. So, they weren't going to have anticipatory nausea or anything. It was to be just a low key, beautiful kind of place. (Vachon, cited in Maddren, 2003)

Helen Brent suggested that this was not necessarily a new view. "I don't believe Anne had a new approach to cancer care. I believe she was rare in being able to voice her ideas in a way that resulted in action" (personal communication, June 3, 2005).

Anne took a holistic view toward cancer. Along with her medical and non-medical advisors, she recognized multiple factors play a part in people becoming ill, staying ill and recovering. For this case study a holistic way is defined as addressing physical, psychological, social, and spiritual aspects of health. This idea was not unique in the world. However, it truly was cutting edge for Toronto, and maybe for Canada (Lowy cited in Maddren, 2003).

In the 1980's and early 1990's physicians and hospitals had been aware of the need to provide psycho-social support services for cancer patients. Yet, despite the scientific grounding to substantiate this view, there continued to be a gap in the service delivery. Volunteers who had influence in the community were prepared to help Anne fill this gap.

Today there are many counseling services available in hospitals. However, at that time it was rare (Maddren, 2003). Education and psycho-social support for cancer patients and their families was part of the vision Anne had for Wellspring.

And in a hospital setting, yes, you can see a psychiatrist. Or yes, you could be referred to a patient and family counseling or social welfare. That wasn't quite what Anne was looking for. It's crisis intervention. This is 'How do I put this disease into perspective to deal with it? Where do I get the intelligence? Where do I learn those skills?'" (Sutcliffe, cited in Maddren, 2004).

For most people, if they have not known someone with cancer, then they do not know about living with this disease. Those who helped Anne with this idea, all agreed about providing a service that had not been previously provided in any organized systematic fashion in Toronto (Maddren, 2003).

Socio-cultural Context

By 1990, Canadian viewpoints about medicine were beginning to change from very acute care hospital-based health care to recognizing there was a wider relationship with the community in which people lived. Because of technical and medical advancements in healthcare a cancer diagnosis was becoming more, and more a chronic disease, and less likely viewed as a life threatening illness that is confined to a hospital-based model of care.

For most cancer patients, the larger part of their life is actually spent outside the hospital and not under the influence of direct medical care. Community and in particular community-based education began to be valued aspects within the concept of health and wellness. Sutcliffe explained that "people living with a disease began to realize they

cannot be life dependent on how the hospital or physicians shape their lives and more determined in how you take control of your life, be it short, or be it long" (Sutcliffe, cited in Maddren, 2003).

Community-based education became a way of taking charge of one's own health, of people learning from each other, and of cancer patients making decisions about setting a course of action that was right for them.

The trouble is that many, many patients have never had the opportunity, or been given the opportunity to participate in decisions about their own care...And now we know from research that those patients who do participate in decisions do much better. And they do much better in terms of symptom control, and there's some evidence that they may do better in terms of longevity.

(Laidlaw, cited in Maddren, 2003)

Further, Sutcliffe described this changing paradigm as less focused on physical aspects of health "...you will go through treatment and that will deal with your physical issues. But it's finding the other pieces for the rest of your life that has to be there as well" (Sutcliffe cited in Maddren, 2003).

Wellspring is noted for promoting a shift in thinking about cancer in terms of regaining health, rather than simply focusing on illness. "... Not just your physical health, bur your spiritual health, your mental health, your well being. It's all those things".(Sutcliffe, cited in Maddren, 2003). Wellspring was designed to be "a space where people regardless of their backgrounds, could share their questions, answers and stories" (Wellspring, 2002, p.7). Marny Robinette, the first program co-ordinator described this as a major innovation in the early 1990's. At that time, this type of support

was nonexistent in Canada. Wellspring was on the fringe, but also on the leading edge of what was to come (Lowy, cited in Maddren, 2003, Robinette, cited in Wellspring, 2002).

The Changing Canadian Cultural Landscape

Canada's health system faces two major problems in cancer care "… overworked health professionals and increasing focus on technical aspects of care. It means that humane aspects of care get shorter shrift" (Laidlaw, cited in Maddren, 2003). Jack Laidlaw predicted that in the future there will be even more need for teaching health professionals the skills to cope with these changes, and to also provide cancer patient education and support. In other words, there will be even more need for Wellspring.

> …you can teach health professionals communication skills to enable them to provide a degree of humane care in a remarkable short period of time…But that's with people with high school education or better, whose first language is English. But Canada doesn't consist of people like that. The Caucasians who speak English in Canada are probably less than 50% now. And we are dealing with people who have cultural, religious, language differences. We are dealing with low literacy, people in low income…And that is why Wellspring has to, in my view, pursue *that* journey as well. (Laidlaw, cited in Maddren, 2003).

One example of cultural challenges is the social stigma that many Chinese people face because talking about cancer is considered taboo. "This is compounded by the cultural and language barriers that prevent them from gathering information, learning how to cope and ultimately healing" (Wellspring, 2005). Wellspring helped by offering Chinese people support and information in their own languages.

Anne Armstrong Gibson: Profile of a Visionary

To understand Wellspring it is helpful to develop a profile of the founder. Anne Armstrong Gibson was the driving force behind the conception and fruition of Wellspring. Her characteristics, values, and beliefs influenced it's direction. "It was Anne's brainchild. It was her idea. As a cancer patient, she felt the need" (M. Robinette Narrative, July 14, 2005).

Interviews with individuals who were involved in the founding of Wellspring formed a rich basis for the findings in this study. In the *Sound Portraits* CD, Maddren (2003) spoke with seven people who helped Anne. I transcribed these interviews and used actual quotes in the findings and analysis to give a detailed description. In addition, Millar (1994) interviewed Anne in *Journeys – Anne Armstrong Gibson: Knowledge, the best medicine,* a documentary video interview. I viewed the video and made notes of quotations from Anne. By comparing transcription notes, I observed that Maddren (2003) had also taken some of Anne's quotes from Millar's video interview (1994) to include in her *Sound Portraits.* This recording of Anne's own story provided authentic historical and biographical accounts from the perspective of Anne Armstrong Gibson.

To further triangulate the data, I interviewed, Marny Robinette, a long-time friend of Anne, who worked in a staff position since 1992 and still remains with Wellspring today, as the manager of Sunnybrook and Women's Wellspring, Toronto (M. Robinette Narrative, July 14, 2005).

Anne's Characteristics

Anne was an attractive, vivacious, intelligent, well connected person in society (Maddren, 2003). She was a wife, a mother of six step children and two young sons, aged

5 and 8. She was as a brilliant lawyer with a thriving law practice. (McDowell, 2002, Tjerkstra, 2004). Anne was a stubborn person with clear ideas of what she wanted and believed that if she wanted to get it, then it must be gettable (Sutcliffe, cited in Maddren, 2003). "As an experienced attorney, Anne was used to receiving answers to her questions, and she quickly became concerned that so many of her cancer-related questions would remain unanswered…The fact that the medical system had no provision for this was unacceptable to her" (Wellspring, 2002, p. 1).

Narratives from interviews and public documents helped to create a portrait of Anne Armstrong Gibson. She was a formidable woman. She wouldn't listen to opposition for very long and nobody could say no to Anne. She was considered an immovable force (M. Robinette, Narrative, July 14, 2005, Lackenbauer, Laidlaw,. Lowy, Vachon, cited in Maddren, 2003).

She was a person of large vision, incredibly persuasive, charming and able to sell her ideas to people. She had a very clear idea of where she wanted to be. She was undoubtedly the driving force behind Wellspring (Campion, Lowy, Sutcliffe, cited in Maddren, 2003). "Anne could take charge of virtually everything in her life, but a disease was not something in which she had any familiarity" (Sutcliffe, cited in Maddren, 2003). Wellspring so embraced Anne's ambition that she was almost distracted from her own personal needs. (Campion, Sutcliffe, cited in Maddren, 2003). "Anne's illness created in her an unrelenting sense of urgency and had she lived, it is possible that she would have pushed to grow the organization further and faster than we have done" (McDowell, 2002).

"Anne had a religious sensibility and … realized that there was a whole other dimension there that needed to be embraced" (Stoute, cited in Maddren, 2003). She was not a contemplative person and her response to the effects of cancer was not to ever rest. "The more stressed she was, the more pain she was in, the more she pushed herself in terms of, what in fact was Wellspring" (Campion, cited in Maddren, 2003). Anne revealed "My hope is that we can be there for people. I think that cancer patients need this kind of support" (A. Armstrong Gibson, Narrative, cited in Millar, 1994).

This character study of the founder proved to be important in terms of finding leadership traits. "That's right. And she was a force. And so, I think when Lynda, our CEO is approached by people in other communities wanting to start a Wellspring – we really look for one of those people in the community" (M. Robinette, Narrative, July 14, 2005).

Anne's Story: Realities of Living with Cancer

Anne was diagnosed with cancer in December, 1988. She described herself as being terrified of chemotherapy as she became violently ill to the side effects. Her skin was burned from the radiation and she recalled herself being in excruciating pain and badly burned. What kept her hanging on? She knew that if she died she would not see her two boys, aged 5 and 8 grow up. Anne's life was further complicated when her husband, Douglas suffered a stroke and died. This left Anne feeling that she had no option; she must stay alive for her boys! Anne's children were very angry at the illness. In her videotaped interview she gave her sons' view that their mother missed their concerts and activities. The boys asked why she went through the pain of treatments.

She replied that she was trying to stay alive for them. It gave her a better statistical chance (Millar, 1994).

When discouraged with her medical care, Anne replaced her oncologist with Dr. Simon Sutcliffe. "I made up my mind that this is too serious a thing. You have to have a degree of comfort and confidence in your doctor" (A. Armstrong Gibson , Narrative, 1994, cited in Maddren, 2003). Anne found the medical system inadequate to deal with the emotional needs of cancer patients. She took a cancer coping skills course run by Dr. Alastair Cunningham. This later inspired her to call together a team of professionals to help her plan a centre that provided support to cancer patients. Her belief was that "knowledge is the best medicine" (A. Armstrong Gibson, cited in Millar, 1994).

What motivated Anne?

1. If she died she would not see her sons grow up (Millar, 1994).

2. She wanted to provide hope to every cancer patient that would follow her (Millar, 1994).

3. The energy channeled into Wellspring helped to distract Anne from her personal problems associated with cancer (Campion, Sutcliffe, cited in Maddren, 2003, Wellspring, 2002, pg. 1).

Anne's Vision

Anne dreamed of the day when supportive care would be available free of charge in a cozy, warm environment. "Anne's vision was Wellspring" (Wellspring, 2002, p.1).

I want Wellspring to continue to be the refuge that it is. I feel as though we've got this little gem. This little jewel that's worked out so well. And my hope is

that we can be there for more people. (A. Armstrong Gibson, Narrative, 1994,

cited in Maddren, 2003)

Other Contributors to the Wellspring Model

It was essential to identify contributions of people who supported the Wellspring

concept because ideas evolving from dialogue among Anne Armstrong Gibson and her

advisors lay the foundation for the philosophical direction of the Wellspring Model. The

public documents and those interviewed identified the early advisors. I scanned text in

the documents and transcription notes for key descriptors of these contributors, coded the

data and thus, created mini profiles of each individual (see Table 1). This table illustrates

the value of utilizing the expertise of a team approach. The diversity of these early

advisors committed to Wellspring provided a strong support system with sound

professional and personal advice to bring to fruition an innovative idea in cancer patient

care.

Philosophical Inquiry Results

The purpose of the philosophical inquiry was to come to some understanding of

the beliefs and values that form the foundation of the Wellspring Model for cancer patient

education. The philosophical inquiry results are discussed under the following headings:

- Philosophical Findings

- Four Dimensions of Philosophy

- Curriculum Philosophy

- Progressive Philosophy

- Radical Philosophy

- Wellspring Philosophy: Emerging Themes

Table 1
Contributors to the Founding of Wellspring

Contributor	Background	Interests	Contributions
Anne Armstrong Gibson	-Diagnosed with cancer, 1988. -Mother, wife, lawyer -Well connected society person -Dissatisfied with system of cancer care - rallied people to help with her make changes	-To create cozy home-like centre that would provide the support, coping skills, and education and required by people living with cancer.	-The founder of Wellspring -The driving force behind Wellspring -Her vision continues to guide the Wellspring community
Joanna Campion	-Long-time friend of Anne	-Spiritual dimension -Involved in the Anglican Church -Helping Anne	-Founding board member -Support to Anne
Dr. Alastair Cunningham	-Scientist at Ontario Cancer Institute -Immunology research scientist /psychologist	-Psycho-behavioural domain. - main professional interest was to	-Founding board member -Clinical co-director of Wellspring

Contributor	Background	Interests	Contributions
	at Princess Margaret Hospital -Cancer survivor -Ran coping with cancer programs and support groups	understand how the mind may affect the body and influence health -Self help strategies	-He introduced scientific methodology and rigor of thought (Maddren, 2003).
Gordon Lackenbauer	-Deputy Chair of the BMO Nesbit Burns -Lost his sister and father to cancer -His brother was a cancer survivor	-Financial domain -Peer support groups for family and those who care for the cancer patient	-Founding board member -Financial advice - fundraising -He and his wife helped to arrange cocktail parties to raise awareness and money
Dr. Jack Laidlaw	-Consultant with Cancer Care Ontario -worked closely with Princess Margaret Hospital, Toronto	-Patient education -Considered it vital to foster warm and effective communication	-Founding board member -Part of the first program committee -Acted as co-chair

Contributor	Background	Interests	Contributions
	-medical doctor with extensive background in patient education -Cancer survivor	between patients and health professionals (Maddren, 2003). -Patient peer support groups	for about 10 years
Dr. Fred Lowy	-Director for the Centre for Bio-ethics -Past Dean of Medicine at U of T	-Moral dimension - Ethical implications of decisions in healthcare -Technical, biological, psycho-social aspects of health care	-Founding board member
Rev. Douglas Stoute	-Anglican priest -Rector of St. Clements Anglican Church	-Spiritual dimension of healing -Role of faith in healing	-Founding board member -Spiritual advice - Anne believed that any social

Contributor	Background	Interests	Contributions
			organization had to have a priest on it. (Maddren, 2003)
Dr. Simon Sutcliffe	- Anne's oncologist	-Enjoyed working with cancer patients "… do something to make some one's life a little better"(S. Sutcliffe, cited in Maddren, 2003).	-Founding board member -Assisted Anne is researching a model for Wellspring -Board member -Co-chaired the first program committee
Dr. Mary Vachon	-Counselor/therapist -Personal friendship with Anne	Psycho-social dimension of illness	-Clinical co-director of Wellspring - Anne paid first two years of the stipend to make sure that people would have counseling Maddren, 2003).

Philosophical findings

Philosophy is a branch of knowledge that is concerned with the reality of the world and the reality of human interactions with the world. Perceptions of reality can take on new meanings as life circumstances unfold. As such, a study of changing realities is also associated with historical research. For example, when Wellspring launched in 1991 it changed socio-cultural perceptions about what would be helpful to those living with cancer. "People who didn't have cancer weren't as interested in the idea of supportive care, but with the Wellspring center opening and attracting so many people, the climate began to change" (J. McDonnell, cited in Wellspring, 2002).

Four Dimensions of Philosophy

The findings in this study included the human world in *every* aspect. It looked at metaphysical questions concerning material and immaterial realities. Metaphysics is the traditional name for descriptive philosophical knowledge. Early into the coding of the data I found that reality and truth is expressed in a variety of forms.

Metaphysical Dimension

Investigation into the metaphysical dimension emerged into three modes of existence which addressed these multiple forms of reality:

- Material existence – the world of things that can be seen or touched.

- Immaterial existence – the world that can not been seen or touched. For example: spiritual entities, God, angels, human intellect, feelings and emotions.

- Intentional existence – entities that once were, no longer exist. For example: signify objects of thought, memory (Adler, 1993).

Coding the data for themes about perceptions of reality became more complex than I first anticipated. Two sets of realities began to emerge. The realities faced by the Wellspring organization over its history of becoming an entity had its own organizational existence which was different from the realities of people participating at Wellspring. For example; "…reporting structures changed a bit. I suppose to the outsider it hasn't changed. You know, those are just things that internally you are aware of" (M. Robinette, Narrative, July 14, 2005).

Certainly, some would argue that what cannot be measurable does not exist in reality. Yet, this research clearly demonstrated that reality for people living with cancer is not always material. The experiences of Anne Armstrong Gibson illustrated the physical, emotional and social realities of living with cancer. Although this description was about Anne's story, it was also representative of what was real for many people touched by cancer.

Sometimes it is hard to express perceptions of reality that are not visible. For example, I observed in a Wellspring Qi Gong class that a spontaneous discussion arose about lack of sensation that cancer survivors feel at surgical sites. The variations in returned sensation varied from two years to more than four years. In my field notes journal I wrote:

These are the things that are so helpful to talk about. Medical people don't seem to address these variations in recovery times or even address the notion of what recovery really means. Peer support and peer sharing of information gives not only a place to voice concerns, but also a place to get helpful information to help adjust to the many changes after having cancer. (Field Notes Journal, February 9, 2005)

One of the realities of volunteering at Wellspring is that not all members survive. "I was on peer support today. A conversation with another volunteer helped me to realize how difficult it can be when a member we have come to know dies" (Field Notes Journal, April 23, 2005). The results of the metaphysical inquiry showed that immaterial reality, that is reality that cannot be seen or touched, tends to be a greater part of the cancer experience for all concerned; patient and caregivers.

Moral Dimension

Moral philosophy sets out the ideals we ought to seek in framing and operating our institutions. This moral dimension studied the ideals of what we ought to seek. In other words, what is right and what is good. This research highlighted ethical issues faced by Wellspring, as well as some of the ethical decisions made by the Western biomedical practitioners at the time Wellspring was evolving in the late 1980's and early 1990's. Using grounded theory methods I examined the documents and colour coded ethical issues to create dominant themes about moral philosophical concerns.

The results of this moral inquiry showed two aspects to the moral dimension: (a) the Wellspring lens, and (b) the dominant culture lens. Wellspring had a static moral lens that remained consistent in its mission to provide support in a home-like environment to care for the psycho-social needs of all people touched by cancer. The moral lens of the dominant culture proved to be more dynamic. Practices in cancer care changed in response to the socio-cultural expectations of the time and to some extent to the pressures imposed by the social action initiatives of Wellspring in the attempt to reform support for cancer patients and those who care for them. For example, medicine was changing from

acute care, hospital based approach to knowing "there is a relationship with the community here, and the community has a place" (S. Sutcliffe, cited in Maddren, 2003).

Therefore these findings would imply that an important aspect to successful grass-roots community-based education is that program planners and managers be consistent with the moral stance of the organization. These findings also imply that attitudes of the dominant culture can be changed. For example, practitioners who used the existing biomedical model for cancer patient care began to acknowledge the value of involving the wider community to address the psycho-social aspects of living with cancer.

Objective Dimension

The objective dimension of philosophy refers to objects of thought that are found as frequent topics in dialogue. (Adler, 1993). Hence, I collected and analyzed topics of conversation that were reoccurring. I found two sub-groups within this dimension. One was great topics for Wellspring, the organization, and another was great topics for members who participated at Wellspring.

Categorical Dimension

The objective dimension of philosophy lays the foundation for the categorical dimension of philosophy, which is concerned with various categories of subject matter (Adler, 1993). This categorical dimension was important in analyzing how Wellspring organized great topics of concern into curriculum (see Table 2). In other words, Wellspring curriculum emerged from the topics and concerns of the membership. This is also known as a grass-roots approach to curriculum development.

The list of Wellspring programs and services was constructed from emerging categories of recurring topics found in the transcription notes and the public documents.

Table 2

Categorical Dimension: Emerging Programs and Services at Wellspring

Category	Emerging Programs	Brief Description
Group Support	• Cancer patients with any diagnosis • People caring for cancer patients • 'I'm Too Young' People aged 18-30 who have cancer • Children's support Group • Children and parents coping with cancer • Metastatic Cancer Patients • Lymphoma patients • Laryngectomy patients and their families • Women with breast cancer • Gynaecologic cancer patients • Ovarian cancer patients	• Designed to meet the particular needs of patients and their caregivers (families and friends) • Participants explore their feelings, express reactions to the diagnosis of cancer, discuss current problems, and share information and coping strategies • Designed to offer support and practical suggestions in a safe, confidential environment. • All programs are professionally facilitated

Category	Emerging Programs	Brief Description
Group Support *(cont'd)*	• Lung cancer patients • Patient Connection • Caregiver Connection • Lesbians and Partners Cancer Support Group	
Individual Support	• Peer support • Chinese Peer Support over the phone • Professional counseling services	• For patients and caregivers • Support, information, and coping tips • Offered on a drop-in basis • Provided by trained volunteers who are cancer survivors and people who have cared for cancer patients • In some cases, people coping with cancer may

Category	Emerging Programs	Brief Description
Individual Support (cont'd)		seek professional counseling services • Available on a limited basis • Referral from Wellspring volunteers and staff
	• Well-being support	• Reiki • Healing Touch • Therapeutic Touch • These are gentle, soothing approaches that promote well-being and relaxation • Body energy work • Facilitated by qualified, experienced professionals
Coping Skills	• Yoga • Tai Chi • Qi Gong • Meditation • Guided Imagery	• Gentle stretching, rhythmic breathing, meditation exercises, body postures and guided relaxation programs

Category	Emerging Programs	Brief Description
Coping Skills (cont'd)	• Relaxation and Visualization • Look Good Feel Better	• Promotes personal healing and relaxation • Facilitated by qualified, experienced professionals
Expressive Programs	• Art Therapy • Journaling • Music Therapy • Quilting	• Provide an opportunity to express one's feelings and issues in a creative manner • No prior art, journaling, or musical experience is necessary for participation • Facilitated by qualified, • experienced professionals
Discussion Series Presentations and Workshops	• Financial concerns • Emotional concerns • Post Treatment topics • Drumming • Support for Personal Support Workers caring for Aboriginal cancer patients at home	• Series of interactive presentations • A range of topics of interest to cancer patients and their loved ones • Facilitated by experts

Category	Emerging Programs	Brief Description
Spiritual Growth	• Joining Together in Spiritual Growth	• Non-denominational • Addresses a variety of spiritual questions related to the cancer experience
Bereavement	• Bereavement Support Group	• For people who have lost a family member or close friend to cancer • Facilitated by qualified, professional
Caregiver	• Caregiver Connection	• A program in which family members and friends of cancer patients can share information and coping strategies • Facilitated by qualified, experienced professionals

Category	Emerging Programs	Brief Description
Professional Caregiver	• Care for the Professional Caregiver	• Support and information program for healthcare professionals
Lending Library	• Books • Printed materials • Audiovisual materials	• Subjects related to cancer
Services	• Transportation • Childcare • Chinese Cancer Resources	• Referral to services in the region
Volunteer Training		• Training and orientation for all volunteer positions

Public documents included the following reference materials: Living with cancer: Where do I start? Brochure (undated), Wellspring (2004), Wellspring (2005), Wellspring Brochure (2003), Wellspring Brochure (September, 2004) (October, 2004).

Great topics of concern for the Wellspring organization evolved into categories of subject matter that contributed to the emerging administrative structure and organization values.

Curriculum Philosophy

Planning curriculum for adult learners is more than following a series of steps. Rather, planning is a social activity in which people negotiate with each other in answering questions about the program.

In March, 1990 Anne, her husband Douglas, and Dr. Sutcliffe went to California to visit the Wellness Foundation. They observed it to be more like a drop-in center where people were having tea and chatting. The trio found goodness there, yet it was lacking in structure. Anne believed in structured planning. "She was looking for a system of education and transfer and application that ought to be here, which she didn't see" (S. Sutcliffe, cited in Maddren, 2003).

Anne viewed this California Wellness Foundation to be a good start, but it would not help her. Anne's reaction to this visit was to start something like that in Toronto, although more structured. She concluded that they needed to find friends supportive to the cause and incorporate them into a working group to get this concept underway. She wanted a place for people who didn't necessarily have her resources. "Where they can come and talk with peer support volunteers because she had found Lisa [her bone marrow transplant buddy] very helpful to her at that point" (M. Vachon cited in Maddren, 2003).

"When you think about it, a year and a half later Wellspring was a legal entity. Six months after that, it was up and running" (Campion citied in Maddren, 2003). Early on Wellspring established itself as a democratic place where the ideas of all involved were considered.

> From the very beginning, the patients, so called members had as much to say about what went on at Wellspring as anyone else … on the program committee. That was terribly important for Anne. If health professionals alone had been running the thing – it wouldn't have worked nearly as well. (Laidlaw, cited in Maddren, 2003).

Therefore, the values and beliefs of the founder, Anne Armstrong Gibson and her advisors shaped Wellspring. Today these philosophical views continue to remain solid cornerstones for the Wellspring Model. "A major focus of this work is … to ensure that we are meeting the diverse needs of people living in the communities we serve" (Brown, cited in Wellspring, 2005, pg. 1).

This study also highlighted a progressive adult education perspective which is characterized by a holistic view of education that encompasses many aspects of living and learning.

> She wanted to help cancer patients cope with their disease. And their families as well… she thought of psychological coping, coping in their social life with their family and friends and their work. She was thinking about spiritual help. And she was thinking of course about informational help about their disease. (Laidlaw, cited in Maddren, 2003).

Clearly, this case study demonstrated that teaching and learning at Wellspring are collaborative social activities designed to create and maintain community-based education to help people receive the tools they need to cope with cancer.

Progressive Philosophy

The progressive view of adult education aims for both personal development and social progress to create a more desirable society. The basic democratic values promote teachers and learners collaborating as partners in the teaching and learning process (Darkenwald & Merriam, 1982). I found that although the primary concern was to help individuals to cope with cancer, there was recognition that many of their problems were generated by the social milieu in which they lived. In other words, the interests, the needs, the problems, and the expectations of cancer patients were products of their environment. Therefore, along with helping people acquire the tools for physical, psychological, and social survival, Wellspring also helped the community to provide more humane cancer care. "When Anne talked about part of our mandate is being education, I believe she thought that as educating health care professionals as to the reality of the cancer journey" (M. Robinette, Narrative, July 14, 2005).

Mary Vachon's experience in psychosocial counseling helped to shape what programs would be offered and Alastair Cunningham provided a strong scientific direction in planning. Cunningham's past studies verified "emotional support, counseling and coping skills can improve the quality of life of cancer patients (Cunningham, 1992, pg. 54). My initial finding was that much of Cunningham's writings in his *Healing Journey Program* (Cunningham, 1992) appeared to be a major influence on the beginning of the Wellspring Model. However, my interview with Robinette suggested that the

programming was more organic, in that programs, including meditation, yoga, and t'ai chi evolved from the interests of members and professional leaders offering their services.

> …we started a little more strongly support group focused. We've diverged a little bit from that… because society has gone in that direction. Cancer patients find help, peace, comfort and healing in those directions. So, I think that's how we've responded. (M. Robinette, Narrative, July 14, 2005).

Some of the leaders from Cunningham's coping with cancer program provided that leadership at Wellspring, But, "…some of the things were a little more haphazard" (ibid). For example, one day a yoga instructor who had studied the mind-body connection came in to Wellspring and volunteered his time. The advisory committee agreed to try it out and eventually that became an integral part of the programming. "Yoga is now the most popular thing that we offer at this building" (ibid). Another example is a therapeutic touch practitioner who came in one day and offered to practice at Wellspring. "That's become a big program…Some people who aren't group people wish to come in on an individual basis... There is something for them" (ibid).

Program director, Mavis Himes used a system of interviewing members to ask for their perceptions of what the center should be. "Based on the interviews and guidance of professionals and advisors on the Program Committee, we decided to offer a broad menu that touched on the psychosocial support, coping mechanisms and informational dimensions that people highlighted" (Himes, cited in Wellspring, 2002, pg.7).

Marny Robinette managed programs when The Coach House opened in 1992 and eight years later agreed to open and manage Wellspring at Sunnybrook and Women's

Hospital where she remained at the time of our interview. "Anne would probably be totally thrilled with what's happening at Wellspring. … And I think it was her wish, and certainly those of us who worked here, that the programs develop in response to the needs of the members" (Robinette, Narrative, July 14, 2005).

Radical Philosophy

In *Education for Critical Consciousness*, Freire (1973) contended there is a relationship between education and culture. His radical view placed great importance on the role of education bringing about social change (Darkenwald & Merriam, 1982, pg. 64). While in practice, few educators advocate social transformation as the aim of adult education, Wellspring brought about radical social change through education. Wellspring revolutionized socio-cultural responses to the diverse needs of people diagnosed with cancer, and to the needs of those who care for them. "This was a major innovation in the early 1990's…a center that provided a range of programs never before offered. At that time this type of support was nonexistent in Canada" (M. Robinette, cited in Wellspring, 2002). In addition, Wellspring raised community consciousness about cancer. "Wellspring's greatest contribution is the awareness that those services brought with them – that cancer could be talked about, and that there were strategies to help people navigate through this terrible thing" (M. Himes, cited in Wellspring, 2002, p .5).

Wellspring Philosophy: Emerging Themes

In looking at the objective dimension from the perspective of Wellspring, the organization, I searched for examples of the great topics that represent the values and beliefs of Wellspring. I scanned the data to find examples of the organization values and beliefs. I used numeric coding and memoing to identify the top reoccurring themes to be

the following: (a) clear vision and articulated mandate, (b) teamwork and connections, (c) trust and caring, (d) dialogue, (e) self-directed learning, (f) budgetary considerations, and (g) governance structure.

Clear Vision and Articulated Mandate

Wellspring specifically caters to cancer patients and those who care for them. This was a very personal thing for Anne because she was also a cancer patient. Her vision began with what she felt she needed and wanted for herself, for her family, and for her friends. This evolved into the concept of Wellspring "to provide emotional support and information to anyone with cancer and to their caregivers in a warm, welcoming home-like setting" (M. Robinette, Narrative, July 14, 2005). Her clear vision articulated the need for a sense of place, a sense of purpose and peer support.

Sense of Place

Wellspring centers are non-institutional, non-residential, warm and supportive (http://www.wellspring.ca/about , pg.1, retrieved May 5, 2005, Millar, 1994,). When Anne suggested finding space in the Princess Margaret Hospital, Sutcliffe strongly argued against this. First, hospitals are very controlling environments. Once you put something into a hospital you loose control. The control is with the hospital system, and the system will tell you how it will function for you. Secondly, "if you want it to be a community, then put it into the community and don't stick it into a teaching hospital" (Sutcliffe, cited in Maddren, 2003).

Sutcliffe was adamant against using Princess Margaret Hospital because of the likelihood Wellspring would be tossed out. Hospitals are always pushed for space. He assumed that "…when pushed for space, the softest, easiest thing goes out" (S. Sutcliffe,

cited in Maddren, 2003). Sutcliffe and Anne agreed that they must make the center very unlike a hospital. They looked for a house environment that was warm and welcoming without any connotations of illness, doctor-patient, or hospital-like aspects to it.

Sense of Purpose

I scanned public documents and interview transcripts for statements of purpose and recurring themes to construct a list of goals for Wellspring. Goals emerging represented the purpose of Wellspring. This grounded theory method stressed emergent, constructivist elements (Charmaz, 2000).

The list of goals identified included the following:

- "To provide support to patients and their families because it's a time of crisis" (A.Gibson, 1994, cited in Maddren, 2003).

- To care for the whole person with the aim of improving the quality of life

- To be innovative and responsive in meeting the emotional, social, psychological, and informational needs of people living with cancer and those who care for them

- To provide programs and services free of charge, in a cozy, warm environment to anyone coping with cancer.

- To create a Canada-wide network of community-based centers that provide people with the tools they require for coping with cancer.

- To complement any medical treatments patients may be undergoing

- To make available resources and information to health care providers because education aimed at health-care professionals is important to make changes to the medical system and health care system.

- To be rooted in collaboration between health care professionals and specially-trained peer support volunteers

- To have strong ties to the community, reflected in volunteer development and training, relationships with area health care professionals, fundraising and partnerships

- To be there for more people because cancer patients need this kind of support.

In summary, the sense of purpose is to provide education, friendship, and non-medical support for people living with cancer. In her interview with Lauren Millar Anne clearly stated her belief that "Knowledge is the best medicine" (cited in Millar, 1994). Anne realized that Wellspring takes a lot of teamwork and a lot of effort by a lot of people to provide cost-effective care outside an institution. In her own words Anne described the purpose of Wellspring, "I want Wellspring to continue to be a refuge. We fill a void" (cited in Millar, 1994).

Peer Support

Wellspring is a peer support organization. "That's what we do" (M. Robinette, Narrative, July 14, 2005). Anne had many friends, but the people she related to most strongly were the people she met in clinic. That was peer support – so that was the concept that she found it on. Peer support was critical to Anne.

> One of the things that I think is really important you see – you get role models. You see people who have gone through the disease and are coping as they are going through the treatment and are coping on the other side. And I think it is very important for patients to see that. (A. Armstrong Gibson, 1994, cited in Maddren, 2003)

Teamwork and Connections

Many people collaborated to bring Wellspring from conception to fruition. Anne wanted the credibility of having health care leaders on side, as well as people who were connected to the business establishments. She trusted that if they could assemble the right people, then collectively they could work out how to put it all together. "Everybody had a reason. She picked people very, very cleverly" (M.Robinette, Narrative, July 14, 2005). "She had great knack for identifying key people who could make it happen. And she was really expert at getting them to come on side" (J. Campion, cited in Maddren, 2003).

Anne created an eclectic group of advisors who were knowledgeable, influential in the community, and dedicated to the cause (see Table 1). A variety of expertise was essential to meet the multi-dimensional aspects of building an innovative center with programs never before offered in the city of Toronto. (Maddren, 2003).

These people had different approaches and they didn't always work well together. Sometimes mediation had to happen. The common denominator was that they were friends of Anne and they were committed to Wellspring. Those connections are part of the history and Wellspring is still very connected to Anne (M. Robinette, Narrative, July 14, 2005).

Teamwork was essential among the advisory board members and various committee members in developing programs. The people who came together to help create Wellspring had a unique team experience.

It was really such a joy for me because I find I don't just enjoy working with members of my own union. To be able to work with people who have very

diverse backgrounds and professions and interests toward a common goal. That's a real joy. And that's what happened in Wellspring (G.Lackenbauer, cited in Maddren, 2003).

Positive efforts were made to connect well with health care professionals. Professional speakers brought in to educate patients served the dual purpose of providing quality information to Wellspring members and exposing professionals to the realities faced by people living with cancer. As a result, medical professionals began to recognize and value the psycho-social aspects of healing. Today, Wellspring works closely with the established medical community. Sunnybrook Regional Cancer Centre and Princess Margaret Hospital endorse Wellspring programs and collaborate with them in a variety of ways (Tjerkstra, 2004). Many referrals come from these cancer centres.

Community liaisons can be cost-effective ways to provide Wellspring outreach programs. For example, efforts have been initiated with the Hospice Association of Ontario to get a Trillium grant to provide Wellspring programs throughout the hospice facility network. Furthermore, Wellspring will supply appropriate leadership to other organizations or communities that can provide that warm, welcome and home-like setting.

Teamwork was critical to the success of Wellspring. Robinette found the opportunity that Wellspring provided for people to connect in a profound way, to be especially moving. "Many, many people have become friends because they come together at such a difficult time"(M. Robinette, Narrative, July 14, 2005). "It takes a lot of teamwork, a lot of effort by a lot of people if you can make the trip a little bit easier for the people that come after you..." (A. Armstrong Gibson, 1994, cited in Maddren, 2003).

Trust and Caring

The educator's role is to establish an environment that builds trust and care (Imel, 1998, Noddings, 1995). Marny Robinette highlighted for me that trust and caring in education practice is of utmost importance as a value contributing to the success of Wellspring. "People would come through the front door and say, I love the energy here" (M. Robinette, Narrative, July 14, 2005). This was consistent with my observations of Wellspring Niagara "Upon entering, the atmosphere was inviting and easy to feel like escaping from the *real world*" (P. McGill, Field Notes Journal, Sept. 15, 2004).

Invitational education addresses the total learning environment and focuses on the messages transmitted by people, places, policies, and processes (Novak and Purkey, 2001). A home-like setting is important. Robinette clearly stated that was the core value. That was why people love Wellspring. "Part of this is because the facilities are physically small. It's small, it is so intimate that Wellspring can have an impact" (M. Robinette, Narrative, July 14, 2005). I too experienced that sense of small intimacy. For example,

> This is my second class for QiGong. There are six students today. One of the first things we noticed was a rearranging of the furniture. One lady said she didn't like that because the familiar was more comfortable for her" (P. McGill File Notes Journal, Nov. 3, 2004).

While I found the homey décor welcoming, I also noticed that many entries in the Field Notes Journal refer to the feeling of escape to a place of safety. For example,

> I am still intrigued by the colour scheme of yellow with blue accents. Everything has been donated to the center and yet, everything flows so nicely. The large paintings hanging throughout give character and the soft colours appear to add to

the sense of escape that the centre offers. Wellspring has the atmosphere of a clubhouse rather than a clinic. (P. McGill, Field Notes Journal, Oct 4, 2004).

The programs at Wellspring can affect the quality of life. During my volunteer shifts I was able to observe some indications of this "…I observed the people from the Bereavement Group leave Wellspring with cheerful goodnights to me. I am surprised, but pleased to see how a bereavement group can seem so hopeful" (P. McGill, Field Notes Journal, May 17, 2005).

The Metropolitan Church of Toronto Lesbians and Partners Cancer Support group collaborated with Wellspring to offer a support group at Odette House. After the first meeting of fourteen women, one member said that she had never seen a group bond so quickly. "The original group welcomed the newcomers with open arms, and any fears the new women experienced were soon erased as they talked to each other, discussed their individual experiences and where they were on their journey" (J. Alexander, cited in Wellspring, 2005, p. 5).

In 1991 Lieutenant Governor Hilary Weston recognized the achievements of caring Wellspring volunteers. One volunteer explained "We need people willing to care for others – people who know what they're going through. I could relate to people who were newly diagnosed" (M. Purves, cited in Wellspring, 2002, pg. 2). Keith, another volunteer said "I am strengthened from the courage, the laughter, the depth of feelings freely expressed all around me" (K. Telfer, cited in Wellspring, 2002, p. 2). Helen Brent has been working at Wellspring since 1992. She felt that "the biggest challenge will be to maintain the atmosphere as we grow" (H. Brent, cited in Wellspring, 2002, p. 5).

Caring for Health Care Professionals

Wellspring provides professional development programs similar to those that are offered to patients and caregivers. A program called *Care for the Professional Caregiver* is for health care professionals to examine what their work is, and deal with the various trauma and stresses of their work. It is a way to foster personal care skills. Consequently, health care personnel can deliver their care to patients in a better way.

Wellspring planners found this program works best if the workers get out of the workplace in some kind of relaxing environment with group leaders who are not related to their job. In this way, they can talk about their stresses and it is not viewed as a work bashing opportunity. "It's just a way to develop good personal care skills" (Robinette, Narrative, July 14, 2005).

Challenges to a Model of Caring

There are some challenges to this invitational model. In particular, "Getting the word out about what the programs were and how to access them. Bringing people in" (M. Robinette, Narrative, July 14, 2005). Not everyone is looking for this kind of support. Perhaps, people do not understand exactly what Wellspring offers. As a result, Wellspring serves a limited number of people. Many young people, many men, and some ethnic minorities do not feel comfortable coming in the Wellspring buildings. Also transportation and parking issues can appear uninviting at some of the five centers. "And the really discouraging thing about this center [Sunnybrook and Women's] has become the parking because the hospital needs the money from parking. We don't get any concession, and so, people find that difficult" (Robinette, Narrative, July 14, 2005).

Dialogue and Consciousness Raising

Freire (1970) was quite clear that "…without dialogue there is no communication and without communication there can be no true education" (p.81). The programs Anne Armstrong Gibson wanted emerged from her own needs as a cancer patient. There was a lot of discussion in those first few weeks and months about how the programs would be delivered. Initially there was talk of streaming by having all members begin with a support group and then move into elective programs. However, through discussions with the early advisors, it was determined that they would not impose any structure and everybody lived with those decisions (M. Robinette, Narrataive, July 14, 2005).

Programs developed in response to the needs expressed by the members. "From the very beginning, the patients, so called members, had as much to say about what went on at Wellspring as anyone else" (J. Laidlaw, cited in Maddren, 2003). Wellspring always encouraged people to give feedback. When cancer patients talked about certain programs as being helpful, then those would be the directions to which Wellspring responded. Wellspring began more support-group focused, but over time diverged to offer more individual-based programs. Robinette described the evolution of programming as "organic". It has grown as people's awareness of new modalities has grown and that seems to be the direction where people find help. For example, yoga, meditation, mindfulness-based stress reduction, Reiki and Therapeutic Touch.

Dialogue with different populations resulted in the creation of innovative programming to meet the unique needs of different communities. For example, the following groups have had their needs addressed: (a) the Aboriginal community received help in education and support, (b) a Chinese speaking peer support phone line was

developed, (c) women of Muslim background met for training so that they can help people in their community with cancer, (d) the lesbian and gay community have an outreach program, (e) continued dialogue with the Hospice Association is hoping to lead to more outreach programs throughout the hospice network (f) a group of people with metastatic cancer asked for a workshop to talk about wills, estates, and issues that they are approaching in a different way from other Wellspring members, (g) ongoing dialogue with health care professionals is intended to bridge the gap between patients and caregivers to create a more sensitive approach to healing. When a person approaches Wellspring with a new program proposal, it is assessed, and discussed to see if it is appropriate for the Wellspring mandate.

Sometimes an individual living with the stresses of cancer simply needs to talk. Dialogue can help people feel a lot better. Wellspring values the opportunity for people to talk freely in a safe environment. Robinette recalled one member who came into the center with devastating news about his cancer treatments. When he left he felt much better. While he wasn't actually physically better, he was able to unload in a safe place.

Self-directed Learning

The term andragogy is described as the art and science of helping adults learn (Cranton, 2000). One basic assumption is that people are interested in solving problems relevant to their own lives and only become ready to learn when they experience a need to learn.

This study found that participation in Wellspring typically began with motivation originating from a personal drive. For example, Anne Armstrong Gibson, faced with cancer, felt a need to learn coping strategies to deal with this illness. As a very pro-active

kind of person, Anne responded to her diagnosis by rallying others to help her solve the problems associated with living with cancer. That self-directed motivation was essential to the founding of Wellspring. Organizers came to realize that it is difficult to start a place like Wellspring without people truly committed and passionate about it. So, when people in other communities want to start a center, Wellspring looks for one of those highly motivated, self-directed people in that community (M. Robinette, Narrative, July 14, 2005).

Contrary to the belief that only those who have no coping skills tend to seek out support groups, the reverse is actually true. Robinette pointed out that many people who come to use Wellspring are the most highly coping people. They want to be able to cope and continue to do it and learn something from this experience. Because people are struggling they are motivated to want support at this difficult time (M. Robinette, Narrative, July 14, 2005). For example, one of the programs I participated in was a support group for people who had been diagnosed with the same cancer as me. In my reflections I wrote "I'm not really sure why I'm here. I'm simply trying to improve the quality of my life" (P. McGill, Field Notes Journal, May, 18, 2005).

Research gives much credibility to describing the benefits of support groups. However, it has also shown that very few cancer patients attend support groups, with some estimates as low as 10 percent. Researchers conclude that many people are unclear as to what support groups had to offer. (C. Edmonds, cited in Wellspring, 2004, pp. 1-2). This study showed that a challenge for Wellspring was to provide clearer understanding of support groups. How do you reach people to motivate them to explore benefits from a support group? This is an ongoing issue for Wellspring.

Formal support groups may not be right for everyone. All Wellspring programs and services had some element of support available. It is up to members to be self-directed to find the program that would best suit their needs.

Programming at Wellspring was also driven by meeting the learning needs of the community. For example, the Aboriginal community asked for outreach programs because they had huge health issues. There was a lack of understanding, so people in that community died at a greater rate because they tended not to get medical help. They put it off, and put it off until it was too late. Wellspring was asked to help in education and support (M. Robinette, Narrative, July 14, 2005).

A special program for cancer patients aged 18 to 30 emerged because those young people "…were often heard to say they wished there was something for people their age" (M. Himes, cited in Wellspring, 2002, pg. 6).

Self-directed Volunteers

Today, in 2005, there are approximately 500 volunteers working at the five centers in Ontario. Three varieties of backgrounds motivate volunteerism: (a) One group is people who used the programs when they were undergoing cancer treatment. They found quality in what they received here and want to be involved. (b) Another group is people who might have known about Wellspring, but didn't feel the need to come because they had family and friend support. Now they want to give back in some way. (c)The third group is people, like Anne, who did not get the support they expected and wanted and so don't want that to happen to somebody else.

The common motivation for all volunteers was that they've learned a lot through their experience and want to help others. At Wellspring people learn different kinds of

strategies and tools and maybe a different kinds of healing. Not everybody survives cancer. But many people don't survive - in a healed way.

Volunteers perform a variety of tasks (see Table 3). Volunteer training is a major part of education programming at Wellspring. The use of volunteerism contributes to the non-institutional environment. Members who are ready to move forward in their recovery, and are able to supply many of the Wellspring services, can become role models for those who are in the early stages of the diagnosis. It is hopeful to meet survivors!

Budgetary Considerations

Wellspring has no core funding of any type. It is a non-profit, charitable organization that depends entirely on donations for its daily operations and programs. "One thing about Wellspring, we are a very cost effective way of delivering care outside of an institution, which is a very expensive, dollar for dollar way of caring" (A. Armstrong Gibson, 1994, cited in Maddren, 2003).

The very early efforts grappled with how to fund Wellspring and where to get the commitments. Lackenbauer described how they used Anne's social connections. Interested people gathered together at a small cocktail party to hear about the concept and to discuss how they might move it forward. And then it was decided to do it on a much larger scale. By inviting the Prime Minister's wife, Mila Mulrooney as a drawing card, they were able to attract about 100 people. "And that was the early stages of getting real commitment and real involvement and we started to raise money from there" (G. Lackenbauer, cited in Maddren, 2003).

Table 3

Tasks Performed by Volunteers

Wellspring recruits and provides training of volunteers for the following tasks:

Task	Brief Description
Peer support	Cancer survivors or caregivers meet one-on-one with members to provide compassionate listening, information, and understanding. They also introduce new members to Wellspring's other programs and assist with enrollment
Front Desk	Volunteers provide reception duties. They contribute to a warm, welcoming atmosphere by greeting visitors.
Support Group Co-Facilitators	Whenever possible, professional group leaders are accompanied by support group co-facilitators. These volunteers are people who have participated in a support group as a member and who are now interested in helping others cope with their disease.
Transportation	Volunteer drivers bring members to and from their appointments at Wellspring Halton –Peel (Wellspring, 2005)
Childcare	Volunteers help provide childcare for members who are attending programs at Wellspring Halton-Peel (Wellspring, 2005).
Events and Outreach	Volunteers assist with events and other types of outreach activities.
Other Areas	Wellspring Volunteers also help with a variety of other duties, including library maintenance, mailing information to members, gardening, fund-raising, and committee work.

Although much advice was taken in the early days, there were always budgetary considerations in determining what programs would be added. It was hard work bringing in the funds needed to provide Wellspring services. At one point the newly formed board moved to abandon the project because of lack of ongoing funds. Although Anne was having chemotherapy and very ill at home in bed she called a meeting "And it was there that night that she not only said 'this is going to go ahead' but 'I am personally putting up the money to hire an executive assistant.' I think that was the turning point of Wellspring" (D. Stoute, cited in Maddren, 2003). Stoute recalled that Wellspring was very much a 'shoestring operation' and he was not sure where Anne was going to get the money. But she got it.

In the second year there was not enough money for an executive director. (M. Robinette, Narrative, July 14, 2005). "After Wellspring had been going for a year or so, the financial support was tough to get. Very tough." (J. Laidlaw, cited in Maddren, 2003).

The Membership Fees Question

At one point Anne proposed that Wellspring begin to charge those who came for help. However, members of the advisory board were concerned "that if we charged then that would mean that certain people wouldn't have access to what was very much needed….But any way, we band together, and Anne backed down"(J. Laidlaw, cited in Maddren, 2003). "And that was a decision of the organization…all said 'no we shouldn't be charging. There shouldn't be any utilization fee or any cost associated with the infrastructure…So it was really, where can you go to find the money? So, it was tapping foundations and people" (S. Sutcliffe, cited in Maddren, 2003).

Henderson Hoedown

One board member, Mark Henderson, helped to solve the problem when his family organized a fundraising party called *The Henderson Hoedown.*

"The goal for the first Henderson Hoedown for Wellspring in 1993 was to raise $10,000 – money desperately needed to help Wellspring survive. In one evening, Mark, his wife, and two daughters, and 400 of their friends got together to dance, celebrate and raise $146,000 thereby allowing Wellspring to continue it's mandate to help those in need" (E. Thurlow, Narrative, July 25, 2005).

Although Henderson died shortly after that, the funds raised in his honour kept Wellspring going and it has been solid ever since. "Mark Henderson left us a very strong legacy…Three other hoe-downs followed and the last one raised almost half a million dollars" (M.Robinette, Narrative, July 14, 2005).

Outreach Programs

The more expensive dedicated Wellspring facility requires the cost to hire staff, pay electrical bills, phone bills and all those things. Therefore, sharing facilities for outreach programs became a more cost effective way to provide organized support programs to cancer patients in a broader geographic range. Doan House Hospice in New Market became an outreach facility for Wellspring members who were previously traveling to Sunnybrook and Women's Wellspring from communities north of Toronto, such as Richmond Hill, Thornhill, Markham, Stouville and New Market. Arrangements were made for Wellspring programs, such as Yoga, and Relaxation and Visualization to be offered weekly to cancer patients and their care givers at the New Market hospice site.

" If another organization or community can provide that warm, welcome and home-like setting, and Wellspring can provide the group leadership, or the funding to provide the appropriate leadership, then that's O.K." (M. Robitaille, Narrative, July 14, 2005).

Workshops

The more recent trend toward using workshops instead of full programs does not require a huge budget and was a way to test interest in new programs. For example, the group leader for the drumming workshop is only paid for that one day.

Budgetary Challenges

Getting the word out is one of the biggest challenges. It is difficult promoting Wellspring and what they offer. Robinette is concerned that somebody could have benefited and was not told about Wellspring. It is sad when people didn't know and could have used it. Marketing is hard when you have a small budget or no budget to put up billboards, make videos, and all those kind of things. Wellspring is working hard to do that in a way that doesn't cost money. "We now have a communications committee of the board headed up by a CBC on-camera person, and they've been doing a great job" (M. Robinette, Narrative, July 14, 2005). Wellspring values donor contributions by spending the money on actual programs rather than advertising dollars. Ongoing financial restraints continue to be a big challenge for Wellspring.

Governance Structure

Much of the discussion in the interview transcription notes and less, so in the public documents emphasized the role of the governance structure. Over time there was a lot of governance work, mostly relating to reporting structures. Robinette clarified the position of Anne Armstrong Gibson.

Anne was the founder....because I knew Anne so well, and I think Anne would want to be referred to as *The Founder*....I have heard others here, call themselves co-founders, and I don't personally think that that's my memory of it" (M. Robinette, Narrative, July 14, 2005). A board of directors and advisors worked with Anne. The programming people were working with the programs.

You know, all these people support the concept and certainly supported Anne....Yeah, it's a fine line between the board. The board is totally aware of what programs are offered and why. But there is a distinction. And the board has become more and more about fundraising, and less, and less about programming (ibid).

Over time governance has changed the structure and its functions in an effort to best adjust to changing needs of the Wellspring community.

Chapter Summary

In this chapter I used a case study research design adapted from Stake (1995). Inquiring into philosophies that guided Wellspring allowed investigation to focus on the case as a whole, rather than individual phenomenon. Research question findings emerged from an exposé of the case which was shaped by four topical information questions and four philosophical issue sub-questions (see Figure 1).

Data findings and analysis revealed two sets of results. The descriptive inquiry provided a thick description of the case. A detailed exposé of the historical and socio-cultural context bound this study within a geographical time and place. It also provided some biographical insight into leadership qualities that contributed to success in creating the first Wellspring centre. Further, it described the growth process of the organization.

Philosophical inquiry provided insight into perceived realities for those living with cancer and perceived realities for Wellspring organizers. The moral dimension helped to identify what was perceived to be right and good when making decisions.

The objective dimension identified topics of conservation that reoccurred. I found this evolved into two sub-sets of topics. One set for those living with cancer and another set of topics for organizers of Wellspring. The categorical dimension grouped topics of conversation into categories of themes. The categorical dimension relating to people living with cancer emerged into programs and services at Wellspring whereas the categorical dimension relating to the organization of Wellspring evolved into guiding philosophies for practice. Essentially, the descriptive findings informed "what" Wellspring is all about and the philosophical findings informed "why" participants of Wellspring did what they did.

CHAPTER FIVE: SUMMARY AND IMPLICATIONS

"Everything and anything is easier if not done alone" (Girard, 2001. p. 134).

This qualitative research explored community-based education for adults living with cancer. The growing number of people in Canada who are touched by cancer has particular education needs that are often unknown, overlooked, or ignored. This case study exposed the many aspects of living with cancer that must embrace more than physical attention provided by a technical-medical model of health care.

Wellspring is a grass-roots cancer patient support centre that evolved from the local needs and interests of people living with cancer in Toronto, Canada in the 1980's and 90's. The innovative approach to care of the whole person aimed at improving the quality of life. Educating people to take charge of their own life and supporting them in making informed decisions about their lifestyle choices made Wellspring part of a social action movement that was geared to improving social attitudes about people living with cancer. Service delivery was rooted in sound volunteer development and training partnerships with health care professionals. Wellspring has been recognized by Health Canada, the Ontario Ministry of Health, and Cancer Care Ontario as an outstanding example of organizational excellence in community-based care.

My research question was:

- What guiding philosophies for education practice contribute to a successful model of community-based education for adults living with cancer? I used the Wellspring Model as a case study.

Summary of the Study

This was an intrinsic case study of Wellspring, a community-based education centre which provides a holistic approach to informational and support needs for cancer patients and for those who care for them. Chapter One predicted Canada is heading toward a cancer crisis and provided an overview of the issue of cancer patient education and the need for educational research. Chapter Two was a review of the literature that explored several issues of concern for adult educators and adult learners in putting together non-medical education and support programs for people living with cancer. Chapter Three conceptualized the structure for this qualitative research design. I pre-selected Wellspring for an intrinsic case study because it has merit in and of itself. It was my intention to examine the case as a whole rather than using it as an instrument to understand something else. Chapter Four provided an overview and summary of the descriptive inquiry findings and the philosophical inquiry findings.

Chapter Five is the final chapter. It is here that I discuss my interpretations of the findings. Based on the results of this study I designed a community-based education model of Wellspring to illustrate how the four dimensions of philosophy intersect and influence each other within the framework of a socio-cultural context. I also explore possible philosophies that guided Wellspring to its national recognition of success.

Discussion

Initial studies of the illness experience explored the meanings that individuals gave to their encounter with illness. These studies often expressed notions of stigma, sense of shame and loss of self. During the 1960's and 1970's social scientists aimed to clarify and broaden conceptions of illness and the sick role. The 1980's studies on illness

behaviour began to look at new variables, such as stress, coping, and life events with a

focus on the quality of life (Pierret, 2003). When life is disrupted by illness, patients

often begin a quest to redefine themselves and learn how to cope with the illness

(Mathieson and Stam, 1995, as cited in Pierret, 2003).

The story of Wellspring began in late 1988 with the story of Anne Armstrong

Gibson, a woman who was used to being in charge of her life and had a very successful

career in law, a young family, and her vivacious personality attracted a large circle of

friends. When her life was disrupted with cancer, at the age of 40, she was dissatisfied

with the care she received as a cancer patient and dissatisfied with the unmet needs of

those who cared for her. She began a quest to learn how to cope with this illness, not

only for her, but also for all those who would be diagnosed with cancer after her.

Helping people to learn is what adult educators do. In this intrinsic case study the

examination of Wellspring, as whole, was more important than examination of any

particular phenomenon expressed in the case. Therefore, it was reasonable to search for

the philosophies that guided all the education practices rather than focus on any particular

teaching and learning strategies. What is Wellspring? How does is help people learn, and

what does it teach?

Sense of Place

Wellspring is a place. "It's a drop-in centre where people can congregate. It's

outside of an institution....It's warm. It's done like a home" (Anne Armstrong Gibson,

1994, cited in Maddren, 2003). It is a place where education, friendship and non-medical

support for people living with cancer became a reality. Wellspring is a place where

people can come for practical information and demystify all the complicated medical

information (Tjerkstra, 2004). A home-like setting is very important to Wellspring "That is why people love Wellspring. So, that's the core value" (M. Robinette, Narrative, July 14, 2005).

Other education theorists (Brookfield, 1980; Hutchison, 2004; Imel, 1998; Noddings , Novak and Purkey, 2001) also support this notion of a warm, inviting environment. Noddings claimed that one way to make education more meaningful is "making schools more home-like" (Noddings, cited in K. O'Toole, 1988).

While Wellspring is not considered a school, in the traditional sense, it is a place where people faced with a disorienting life challenge go to learn. It is an education facility where people learn how to cope with the experience of having cancer. The practice of invitational education aims to invite everyone into the facility. "Places are the sights, the sounds, the smells, the tangible totality our senses receive....Inviting educational leaders are aware of the powerful messages that are conveyed by the landscape and upkeep" (Novak, 2002).

The term "place" is typically filled with emotion. It can be understood as an individually constructed reality and also understood as a socially constructed reality. The boundaries that define places and the purpose of those spaces are often shared and understood by a community of people. The concept of place is a way of expressing the emotive relationship of person to environment, which in turn gives a place a unique identity. Places that are culturally meaningful and emotionally resonate, focus not only on the physical space, but also on the psychological character. Hutchison (2004) argues that "in educational writings, the larger patterns of geography and ideology that connect a broad view of place to the history and philosophy of education tend to remain

unacknowledged" (p. 16). In this study, Sutcliffe very clearly articulated the importance of "where" Wellspring needed to be. He was adamantly against housing Wellspring in Princess Margaret Hospital.

> So I prevailed. And we said we must find something in the community and we must make it very unlike a hospital....This should be like a house. It should be warm and welcoming. It shouldn't have any connotations of hospitals, illness, doctor-patient, any of those sorts of aspects to it. (Sutcliffe, cited in Maddren, 2003)

Participant observation at Wellspring Niagara conferred with this importance Wellspring gave to a welcoming place.

> Upon entering, the atmosphere was inviting and easy to feel like escaping from the "real world". The yellow walls are relaxing and a wonderful collection of artwork on the walls has all been donated. The large activity room is painted with a serene mural. The blues of the sky and water, the greens of the grasses and the birds in the air give the feel of a little retreat. The library is small but very well organized. A small meeting room has couches, chairs – a very cozy and welcoming room. The kitchen has snacks – juice, cookies, tea for people to help themselves (P. McGill, Field Notes Journal, September 15, 2004).

Quality of Life

Wellspring is a concept about moving away from a sense of hopelessness and helplessness to finding choices and ways of dealing with a life touched by cancer. Sutcliffe believed that "It is unreasonable to think that we are going to be immortal and that you can remove all causes of death" (cited in Maddren, 2003). Wellspring is not so

much about improving the longevity of life, it is more about providing "an innovative and creative approach to the overall care of the whole person, with the aim of improving quality of life" (Wellspring, 2005). Imel (1998) suggested that the educator's role is to establish an environment that builds trust and care in order to create a place where people can come together and make meaning of their life experience. One day while participating in a program a member shared her perspective "Wellspring has opened up so many doors. Cancer has been a blessing in disguise" (P. McGill, Field Notes Journal, December 1, 2004).

Barer-Stein and Connolly (1997) described the educator's role is to nurture, with the intention of transforming perspectives. Wellspring seeks to change attitudes from a focus on illness to a focus on wellness. I believe this implies a shift in focus from living long to a focus on living well. The definition of "normal" changes when a person is diagnosed with cancer. Part of the role of the nurturing educator is to help those living with cancer, or even dying with cancer, to find a "new normal" that will provide a sense of dignity, of hope and of quality of life. Community-based education (CBE) methods are gaining recognition as important in health education because these types of issues are best dealt with outside a health care institutional setting. Most health professions practice efforts to cure individuals in a way that only represents a small part of the whole person and a small part of the prevailing community health problems.

Community-based education is a way of achieving educational relevance to the community needs and as such serves to implement a community-oriented program. It consists of learning activities that utilize members of the community, representatives of other sectors, educators and learners who are all actively involved throughout the

educational experience. Community-based education refers to any set of learning activities that take place in a community environment. The curriculum is responsive to the changing needs of the community as the priorities shift. In this way community-based education keeps the curriculum updated. However, this also poses problems in putting together a national education program because communities can be quite distinct and although they may share general goals, the community, regional, and institutional factors all shape the CBE program and give it its identity. (Magzoub and Schmidt, 2000). I predict this will pose a problem for Wellspring to become a Canada-wide network of community-based support centres for individuals and families living with cancer. Helen Brent, who has been working at Wellspring since 1992 expressed concern "the big challenge will be to maintain the atmosphere as we grow" (Wellspring, 2002, p. 5).

Socio-cultural Perspective

The community-based educator has the role of responding to socio-cultural needs of the community. As such, this often leads to an activist role in facilitating social reform. For example, the adult literacy movements in South America, and in the community of Antigonish, Canada, demonstrated the importance of raising self-confidence, self-reliance, and critical consciousness in transforming individual lives as well as in transforming the social structure of the community to improve the quality of life for those living there (University of Toronto., retrieved, June 13, 2005, University of St. Francis Xavier, retrieved June 13 2005, Freire, 1970, 1971, 1973, 1985). Therefore, I found a relationship between the moral values of the dominant culture and the moral values of the community-based education organization.

In the case of Wellspring, the holistic moral lens which looked at all aspects of cancer reacted to the dominant culture's traditional-biomedical lens, which predominantly treated the physical and technical aspects of cancer. The socio-cultural context of the meanings of health and illness needed to change in order for changes to occur at the community level. This in turn, resulted in changes to health care and education practices that moved toward attention to the psycho-social aspects of cancer care. Furthermore, community attitudes about people living with cancer began to change. It became more acceptable to talk about the illness. Wellspring became involved with awareness and fundraising campaigns that raised social consciousness about the issues associated with living with cancer.

Adult Education Philosophy

Radical adult education philosophy is rooted in various radical movements that help learners to have the ability to make social condition changes in their lives. By using dialogue and problem posing methods adult educators help learners to use knowledge that will enable them to transform the social world (Elias & Merriam, 1984). This would include adult educators, such as Freire, Coady and Tomkins. Because Anne Armstrong Gibson took an active stance against the status quo in cancer care, she too contributed to radical adult education in health and wellness. Following her investigation of the Wellness Centre in California she said "I will start something like that in Toronto....And when you think about it that was a year and a half later Wellspring was a legal entity. Six months after that it was up and running" (Campion, cited in Maddren, 2003).

Community education movements are used as a teaching and learning method for proponents of progressive adult education philosophy. The goal is to develop and apply

practical knowledge and skills for life in a progressive democratic society. Progressive adult educators include J. Dewey, Lindeman, and Knowles. Here the greatest influence is found in the learner centred approach that views teaching and learning as a partnership between educators and learners (Elias & Merriam, 1984). Wellspring offers practical coping strategies for adults living with cancer. Programs result from dialogue with members. The program committee work was "a mixture of health professionals and patients…From the very beginning the patients, so-called members had as much to say about what went on as anyone else" (J. Laidlaw, cited in Maddren, 2003). "If we had a little bit of something in a program and they loved that – we would know that from evaluations. We've evaluated programs, really from the beginning" (M. Robinette, Narrative, July 14, 2005).

Humanistic adult education philosophy is about development of people who are open to change and continued learning. Self actualization is a goal. It aims to develop all potentials of the whole person and the learning process involves the emotional, psychological and intellectual. Adults take responsibility for their own actions and learning is highly personal. This leaner-centred approach uses group dynamics, sensitivity workshops, encounter groups and self-directed learning. The humanistic approach is related to existentialism and can be traced back to Confucius and Greco-Roman thinkers. Contemporary humanist adult educators include Maslow, Carl Rogers, and Knowles (Elias & Merriam, 1984). The humanistic approach to helping people living with cancer is a guiding philosophy for Wellspring. "Wellspring is a peer support organization. That's what we do" (M. Robinette, Narrative, July 14, 2005).

And we have peer support where other cancer patients have gone through the experience.…And one of the things that I think is really important is you get role models. You see people who have gone through the disease and are coping as they are going through the treatment and are coping on the other side. And I think it is very important for patients to see that. (A. Armstrong Gibson, 1994, cited in Maddren, 2003).

Lackenbauer advocated peer support. "You can go into a support group with people who have had it before or are currently dealing with it …it's so much easier to say what's really on your mind and what your fears really are" (cited in Maddren, 2003).

In summary, I found that Wellspring has an adult education philosophy that incorporated the views from radical, progressive, and humanistic perspectives.

Implications for Education Philosophy

When I looked at the seven themes that emerged from the data: clear vision and articulated mandate, teamwork and connections, trust and caring, dialogue, self-directed learning, budgetary considerations, and governance structure, I was able to collapse all themes into one – trust and caring. It was my conclusion that the philosophy that guided Wellspring to be a successful model for community-based education was based on this holistic commitment to care of the whole person. All organizational decisions were based on what would provide a caring, trusting environment to support people living with cancer.

Philosophy as a mode of inquiry includes four dimensions of philosophy; metaphysical, moral, objective, and categorical (Adler, 1993). In this research I used these four dimensions of philosophy to frame the intellectual work of the case study. I

have synthesized all the data and devised a model of community-based teaching and learning that illustrated these four dimensions within a socio-cultural context (see Figure 2).

Implications for Theory

I used the four dimensions of philosophy (Adler, 1993) to create a community-based education model for Wellspring (see Figure 2). I found the moral dimension to be the dominant feature for Wellspring. I identified two moral perspectives; the Wellspring moral lens and the dominant culture moral lens. The dominant culture moral lens represents the values and beliefs of the larger community which must be understood within the boundaries of a socio-cultural context. In this model the socio-cultural context of the larger community influences the moral practices of that community. What is perceived as right and wrong provides a way to see the world and shapes the sense of what is real. For example, when Anne Armstrong Gibson was diagnosed with cancer, the medical community and the dominant culture at large, neglected to value the psycho-social aspects of cancer. Therefore, the reality for Anne became one of feeling isolated, afraid, and excruciating pain.

The Wellspring moral lens represents the reaction to the dominant culture view. Anne Armstrong Gibson envisioned a place where people could find the support they needed – body, mind, and spirit. Dissatisfaction with existing traditional technical-medical practices in cancer care led Anne and her team to challenge the values and beliefs of the larger community by creating an innovative cancer support centre that was new to Toronto, and possibly unique to Canada. This represented a sub-community with
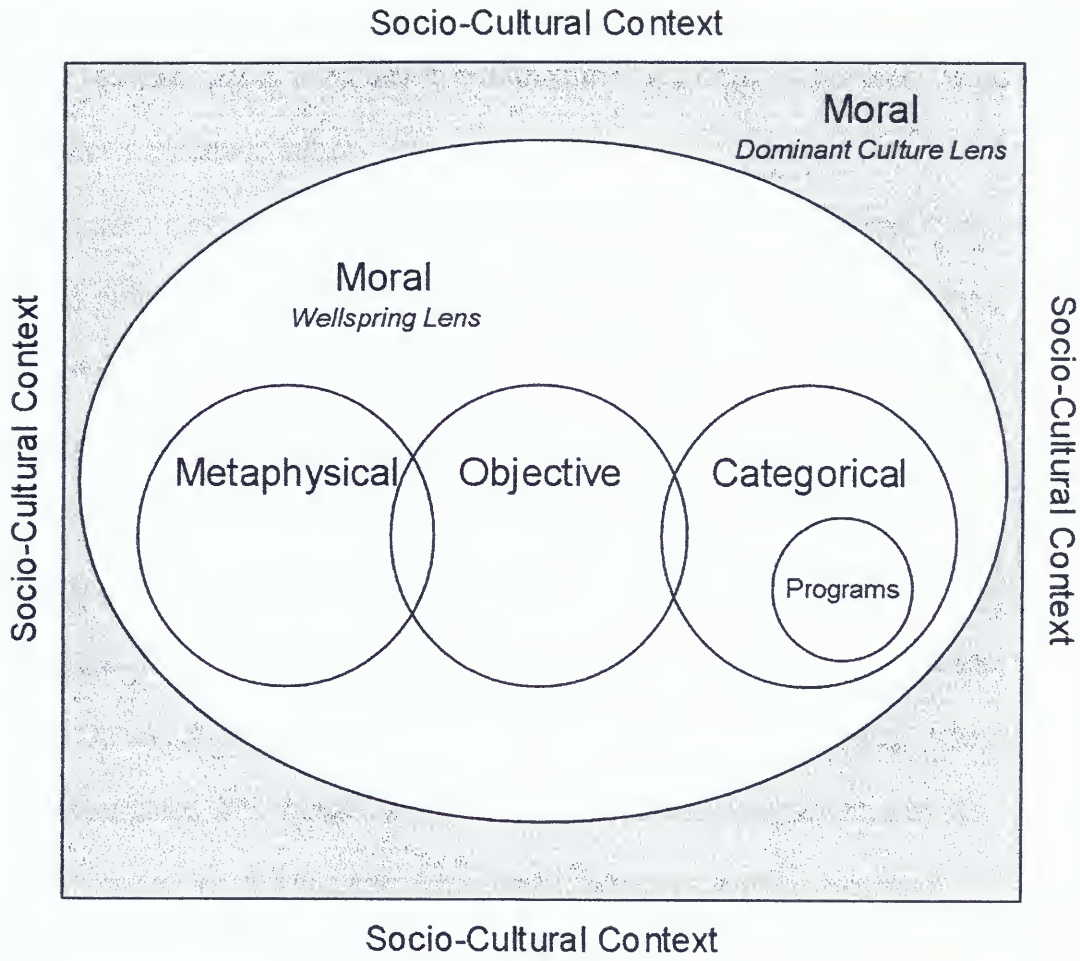
124

Figure 1. Wellspring: Four Guiding Dimensions of Philosophy

its own set of values and beliefs about what is right and good for people living with cancer.

Wellspring held a consistent belief that people diagnosed with cancer needed emotional and social support to develop coping skills that would enhance the quality of life. What is cancer? Cancer is really about regaining your health. "Not just your physical health, but your spiritual health, your mental health, your well being. It's all those things" (S. Sutcliffe, cited in Maddren, 2003).

A strong static moral stance on the part of Wellspring helped to influence changes to the moral lens of the dominant culture. Canadian society, and particular regions that house a Wellspring centre, began to shift beliefs and values about what it means to live with cancer. More humanistic attitudes emerged and the cancer care system became more sensitive to the psychological, emotional, spiritual and informational needs of cancer patients and those who care for them. For example, the Hamilton Regional Cancer Centre conducted a study of the supportive care needs of cancer patients across different communities in Ontario (2003). While it can be troubling that this survey reported a high proportion of patients and their caregivers had their non-medical needs unmet, I do feel hopeful that that cancer care providers are beginning to invest time and money into making assessments and improvements in this area.

The objective dimension of the philosophical inquiry looked for reoccurring topics of interest which emerged from the metaphysical and the moral dimensions. These reoccurring topics were organized into categories which became the basis for curriculum at Wellspring (see Table 2).

Because of the intersecting relationships of all four dimensions of the philosophical inquiry, there was a domino effect, in that when there was a change in one dimension, a responsive change occurred in the other three. Therefore, I describe the program planning at Wellspring as "organic". It constantly shifted and changed to meet the changing needs of the community it served. While at the same time, it maintained a static, unchanging set of beliefs and values that were set out at the founding of Wellspring in 1992.

Implications for Practice

The implications for practice discussed below are essential components of community-based education for adults living with cancer.

A Visionary

The vision of Anne Armstrong Gibson continued to guide the moral direction of Wellspring; hence, all programming was guided by this vision of maintaining a home-like, inviting environment to offer psychological, emotional, social, spiritual, and informational support to all people living with cancer. This case study demonstrated the importance of having a clear vision and mandate for education practice. The visionary, Anne Armstrong Gibson and her team of supporters were unwavering in their commitment to this vision. Furthermore, a charismatic leader with a clear vision, strong leadership skills and a diverse team of advisors committed to the cause was essential to take Wellspring from an idea to a reality.

Adaptable to Change

This innovative approach to community-based education had built in flexibility that allowed maintaining its mandate and yet being able to respond to the changing needs

of its members. For example, when the number of people in outreach areas grew, Wellspring initiated a working relationship with the Hospice Association, whereby Wellspring professional staff and volunteers would facilitate Wellspring programs off-site, provided the facility had a home-like environment. Ability to adapt to changing circumstance allowed Wellspring to continue to be viable and valuable over time.

Peer Support

This model illustrated that the moral dimension, what is right and good, was the dominant dimension that influenced the perception of reality, the topics of great concern and how these topics were organized into curriculum of Wellspring. Wellspring was founded on the moral position that cancer care systems needed to change their approach to a more holistic, caring paradigm. The use of peer support is at the heart of this paradigm. "It was Anne's idea, as much as anyone's to do a lot of it through peer support, where groups of patients ... would come together and help each other. The patients who had had the disease for a longer period of time would help those who were newly diagnosed" (J. Laidlaw, cited in Maddren, 2003). Peer support can provide a unique way of helping people deal with so many of the issues associated with cancer. "I don't think you could ever appreciate what it is like if you're not actually dealing with it" (G. Lackenbauer, cited in Maddren, 2003). The realities of having cancer can best be understood by those who have also been faced with living with this disease. People who have shared a similar experience share a similar reality that can only be understood by having been touched by cancer on a personal level. Health care professionals, case managers and administrative personal who have not entered that intimate journey with cancer cannot truly guide teaching and learning in a meaningful way. Herein lies the

strength of the Wellspring Model. "The emotional sustenance provided by this kind of peer support is consistently spoken of as being much more important than any information-exchange function the network might have" (Brookfield,1990, p.55).

Grass-roots Approach

Another strength of Wellspring was its grass-roots approach whereby programming initiatives were prompted by the people who needed and wanted the programs. A high regard for quality assurance helped to maintain this commitment to constant feedback from Wellspring members who continued to shape the direction of Wellspring. Community-based education programs are typically associated with some social issue.

Implications for Further Research

This case study exposed a wide number of aspects and issues associated with philosophy of education, community-based education, adult education theory and practice, and with cancer patient education. Because this was an intrinsic case study I was concerned with looking at Wellspring as a whole phenomenon and did not address individual issues that evolved from the data. This study was intended as a starting point in education research for addressing the needs of adults living with cancer. As such, it has provided a rich menu of topics for further research.

I believe further study into Adler's four dimensions of philosophy as they relate to teaching and learning will provide a much deeper understanding of education philosophy that goes beyond the philosophies of adult education outlined by others (Cranton, 2000, Elias, 1995; Elias and Merriman,1984; Poonwassie, 2001).

It is difficult to find a metaphor for Wellspring. It has been described as a place, a concept, a refuge, a jewel, an idea, an approach to dealing with the reality of coping with cancer. It is an education facility, an organization, a belief, a model, a philosophy. Wellspring is all of these things. I propose further research into the use of metaphors for Wellspring. I believe that one way to respond to the ongoing challenge to meet budgetary concerns for community-based education is by tapping into funding sources that are supportive to the cause. An exploration of metaphors could become a way of assisting in "the marketing" of Wellspring.

Wellspring's success has been grounded in a strong governance structure. Further research into educational leadership and administration at Wellspring has the potential to be a model reflective of invitational education leadership (Novak, 2002).

Wellspring operates on voluntarism. Further study of volunteer training and the use of volunteers for community-based education would give insight to an area often ignored in the literature. Wellspring demonstrates volunteerism is a viable strategy for adult education for people living with cancer.

In this case study sense of place emerged an unexpected theme. Hutchison (2004) offered an historical perspective into how curriculum is shaped by sense of place. Invitational education theory also looked at how place can be used to make teaching and learning an inviting experience (Novak and Purkey, 2001). Wellspring is unique in that everything is donated to the centre. I believe this is an interesting aspect to sense of place when the physical surroundings have been created by the community members.

There is so much more about cancer education that needs to be explored. I am concerned that cancer education issues have been dominated by the health care

professions and are not properly represented in the literature for education research. Adult educators have a vital role to play in contributing to improvements to the quality of life for people living with cancer.

Final Word

The purpose of this paper was to gain an understanding of community-based education initiatives that are inviting and accessible, so as to promote a sense of hope for people living with cancer. Through this research I have learned that finding "a sense of hope" is what education is all about.

The Supportive Cancer Care Research Unit (SCCRU) of the Hamilton Regional Cancer Centre reported that cancer patients across Ontario have their supportive care needs unmet despite receiving appropriate medical care and thus recommended more professional case managers to facilitate and coordinate cancer care for clients and families living with cancer (2003). While this professional approach may appear to be a sound solution, research gives much credibility to describing the benefits of cancer patient education and support groups as viable alternatives for helping to meet supportive care needs.

Wellspring is a place where education, friendship and non-medical support for people living with cancer became a reality. Wellspring is a place where people can find practical information and demystify complicated medical information. This study showed that community-based education programs, such as Wellspring, provide caring and accessible support and education. Helping people living with cancer in making decisions concerning their own coping strategies and recovery needs can lead to improved quality of life for cancer patients, for families and friends, and for the

community at large.   Anne Armstrong Gibson needs to be remembered as a remarkable Canadian who helped to bring hope to so many people living, or even dying with cancer. Although Anne died, her message of hopefulness lives on for all those associated with Wellspring.

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Appendix A

Wellspring Public Documents Selected for Coding

Title	*Source*	*Reference*
About Wellspring	Website	http://www.wellspring.ca
Journeys - Anne Armstrong Gibson: Knowledge, the best medicine	Documentary Video	Access Network, Saskatchewan Communication Network (SCN), and Knowledge Network (Co-producers) and Millar, L. (Host/Writer) (1994) Canada: TV Ontario.
Living with cancer: Where do I start?	Brochure	Wellspring
The Wellspring News: Greater Toronto and Halton-Peel Edition. Volume 8.1	Newsletter	Wellspring (Spring, 2002)
The Wellspring News: Greater Toronto and Halton-Peel Edition.	Newsletter	Wellspring (Winter, 2004)
The Wellspring News: Greater Toronto and Halton-Peel Edition	Newsletter	Wellspring (Spring, 2005)
Wellspring	DVD	Wellspring Cancer Support Network. Tjerkstra, M., (Script, Narration, and Production Advisor) (2004) Mississauga, Canada: American Productions
Wellspring: Celebrating the tenth anniversary of Wellspring	Compact Disc Recording	Maddren, J. (Interviewer/Producer). (2003). Toronto, Canada: Soundportraits memories on CD.
The Healing Journey	Book	Cunningham, A (1992). Toronto, Canada: Key Porter Books Ltd.

Appendix B

Letter of Information

Title of Study - <u>**Wellspring: A Case Study of Community-based Education**</u>

<u>**For Adults Living With Cancer**</u>

Dear Participant,

I am a graduate student at Brock University. I invite you to participate in this research study – "Wellspring: A Case Study of Community-based Education For Adults Living With Cancer". I am interested in community education and support for people living with cancer.

The purpose of this research is to learn the history of Wellspring and to uncover factors characteristic to its renowned success in meeting diverse non-medical support and information needs of cancer patients and care givers.

I first became familiar with Wellspring during my own recovery in 2002. Today, I am in a Master of Education program and I would like to learn more about the Wellspring story in order that other communities have a deep understanding of how the co-founders of Wellspring planned and implemented such a unique and successful model for helping people touched by cancer.

<u>My research question is:</u> What guiding philosophies contribute to a successful model of community-based education for adults living with cancer?

The expected duration of your participation in this study is approximately 45-60 minutes for one audio-taped interview. I will schedule the interview at a time and a place convenient for you.

The procedure to be followed includes an individual semi-structured interview, which will be conducted, tape-recorded, transcribed and analyzed by me, the researcher. Following the interview, you will receive a copy of the interview transcript plus a synopsis of my interpretations. You will be encouraged to comment, correct or clarify any information on the transcript, sign it and then return it to me within 10 days. If you would like a copy of your transcript for your records, a copy will be provided.

There are no risks associated with this research. You may benefit by having an opportunity to formulate and express your ideas and feelings about your experiences. A summary of the results will be made available to you, the participant. There will be no payment for your participation.

You will be asked if you would like to select a pseudonym to ensure your confidentiality. If you choose to remain confidential, I am the only person who will know the name and corresponding pseudonym. No identifying information will be included in written documents without your approval. For confidentiality, all data including paper data, electronic data and audiotapes will be stored securely in my apartment. In terms of the final disposal, all data will be destroyed after two years from completion of research.

Please be aware that participation is voluntary and you have the right to withdraw from the research at any time without need for explanation of any reason and without recrimination.

If you have any questions about your rights as a research participant, you can contact the Brock University Research Ethics Officer (905 688-5550 ext. 3035, reb@brocku.ca)

Thank you for considering participating in this study.

Yours truly,

Philomena McGill

Principal Investigator
Philomena McGill, Graduate Student
Telephone: 905-680-4457
Email : pm03gg@brocku.ca

Faculty Supervisor
Dr. Anne Elliott, Faculty of Education
Telephone: 905-688-5550, ext. 3934
Email: Anne.Elliott@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 04-398-McGill) Brock U. Research Ethics Officer : 905-688-5550 ext. 3035, reb@brocku.ca

Appendix C

Guiding Questions for the Interview

**Title of Study - <u>Wellspring: A Case Study of Community-based Education
For Adults Living With Cancer</u>**

1. What is the connection between Anne Armstrong Gibson's story and the history of Wellspring's first centre in Toronto in 1992?

2. How did Anne's vision evolve into the Wellspring model?

3. Who assisted Anne to initiate Wellspring? What were their contributions?

4. What other factors were involved in helping to establish the first Wellspring?

5. What were some of the early obstacles that had to be overcome?

6. What strategies were found most helpful in soliciting community support to establish this non-profit community-based centre?

7. How is Wellspring organized? Has this organizational model changed over time?

8. What assistance does the Wellspring organization provide to communities that are interested in establishing a local Wellspring centre?

9. How does Wellspring select education and support programs that best suit the non-medical needs of the local community?

10. Is there a mission statement or guiding philosophy for Wellspring?

11. Is there anything else I could have asked you to help me better understand your perceptions? Is there anything else you would like to add to the discussion?

Principal Investigator
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Email : pm03gg@brocku.ca

Faculty Supervisor
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Appendix D
Informed Consent Form

Study Title: Wellspring: A Case Study of Community-based Education
For Adults Living With Cancer
Researcher: Philomena McGill, Graduate Student, Master of Education
Faculty Supervisor: Dr. Anne Elliott, Faculty of Education, Brock University

Name of Participant: _____ Date: _____

I understand that:

- I am being asked to participate in the research of "Wellspring: A Case Study of Community-based Education for Adults Living With Cancer".

- The researcher will be using the data from this research for a Masters Thesis in partial fulfillment of her Master of Education degree.

- This study in which I have agreed to participate will involve one audio-taped, individual interview of approximately 45-60 minutes.

- The procedure to be followed includes an individual semi-structured interview, which will be conducted, tape-recorded, transcribed and analyzed by Philomena McGill, the researcher.

- Following the interview, I will receive a copy of the interview transcript plus a synopsis of the researcher's interpretations to prepare for a discussion of any feedback I want to provide, and questions I may want to ask to address any concerns I may have around interpretations and clarifications.

- I may comment, correct or clarify any information on the transcript, sign it and then return it to Philomena McGill, the researcher, within 10 days.

- If I would like a copy of the transcript for my records, a copy will be provided to me.

- There will be no financial compensation for my participation.

- My participation in this study is voluntary.

- I may withdraw from the study at any time and for any reason without penalty or recrimination.

- There is no obligation to answer any question when I do not feel comfortable.

- I will be asked if I would like to select a pseudonym to ensure my confidentiality. If I choose to do so, only Philomena McGill, the researcher knows the names and corresponding pseudonyms of the participants.

- All paper data, electronic data, audiotapes will be stored securely in the apartment of Philomena McGill, the researcher.

- In terms of the final disposal of all information, the researcher will destroy all the data two years after completion of the research study, December, 2007.

- No professor, student nor other researcher will reanalyze this data in the future.

- The results of this study may be published in a research journal or other publication.

- I may request and obtain a copy of the research results.

- I have read and understood the above information.

- I reserve the right to ask questions about the project at any time.

- By signing this Informed Consent Form, I am indicating free consent to research participation.

- **If I have any pertinent questions about my rights as a research participant, I can contact the Brock University Research Ethics Officer @ 905-688-5550, Ext. 3035 or I can email to: reb@brocku.ca**

Participant Signature _____ Date _____

I have fully explained the procedures of this study to the above participant. Should the participant be interested, copies of a final summary report will be made available upon request.

Researcher _____ Date _____

Principal Investigator   Faculty Supervisor
Philomena McGill, Graduate Student   Dr. Anne Elliott, Faculty of Education
Telephone: 905-680-4457   Telephone: 905-688-5550, ext. 3934
 Email : pm03gg@brocku.ca   Email: Anne.Elliott@brocku.ca
This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 04-398-McGill) Brock U. Research Ethics Officer : 905-688-5550 ext. 3035, reb@brocku.ca

PLEASE TAKE ONE COPY OF THIS FORM WITH YOU FOR FURTHER REFERENCE.
. *Thank you for your interest in this study!*

Brock University

DATE: June 14, 2005

FROM: Linda Rose-Krasnor, Chair
Research Ethics Board (REB)

TO: Anne Elliot, Education
Philomena McGILL

FILE: 04-398 - McGILL

TITLE: Wellspring: A Case Study of Community-based Education for Adults Living with
Cancer

The Brock University Research Ethics Board has reviewed the above research proposal.

DECISION: Accepted as clarified

This project has received ethics clearance for the period of June 14, 2005 to December 31, 2005
subject to full REB ratification at the Research Ethics Board's next scheduled meeting. The clearance
may be extended upon request. *The study may now proceed.*

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last
reviewed and approved by the REB. During the course of research no deviations from, or changes to,
the protocol, recruitment, or consent form may be initiated without prior written approval from the
REB. The Board must approve any modifications before they can be implemented. If you wish to
modify your research project, please refer to http://www.brocku.ca/researchservices/forms to
complete the appropriate form **Revision or Modification to an Ongoing Application.**

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of
how these events affect, in the view of the Principal Investigator, the safety of the participants and the
continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community
organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines
and approvals of those facilities or institutions are obtained and filed with the REB prior to the
initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is
required for all projects upon completion of the project. Researchers with projects lasting more than
one year are required to submit a Continuing Review Report annually. The Office of Research Services
will contact you when this form *Continuing Review/Final Report* is required.

Please quote your REB file number on all future correspondence.