QUIET HEROES:: STORIES OF INNOVATION IN ONCOLOGY SOCIAL WORK

by

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ABSTRACT

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This dissertation describes an exploratory study which was undertaken to identify the conditions which enhance practitioner innovation in oncology social work. Fifty seven oncology social workers from four leading cancer institutions in the United States volunteered to be interviewed. Data for this study were collected using qualitative research methods involving open ended, semi-structured, focused interviews which were tape recorded. The responses to the interview questions were coded into categories by the author using a grounded theory approach to data analysis.

The study yielded an understanding of the process of innovation and participant recommendations for organizational structures to encourage innovation. An unanticipated discovery was the emergence of a typology of innovators: The Reactor, who innovates in response to situational need; The Academic, who innovates in response to new learning/training; and The Initiator, who innovates in response to an inner drive to try new things. Many respondents note the tragic and crisis nature of the work as stimuli to try something new. This unanticipated discovery of a typology of innovators merits further study.

The findings have implications for supervisors and administrators in oncology social work, as well as schools of social work. The study suggests that the nature of oncology social work serves as a catalyst to mobilize some practitioners to innovate and that innovative practice may serve as an antidote to the stressful nature of the work. These topics would provide fruitful areas for future research.

Although the findings must be approached with some caution due to the limited sample size and sampling methods employed, the study identifies the role of the culture of the setting in promoting and inhibiting innovation. The study implies that training programs for middle managers and administrators need to be developed to foster the growth of work cultures which promote innovation. This study identifies an important area for future research. Although the study is specific to oncology social work, the findings may be viewed as applicable to social workers in other settings.

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Introduction: The Science of Cancer, Oncology Social Work and Innovation

Introduction

Cancer, as a disease, carries with it so many associations both for persons diagnosed with cancer, their family, friends and healthcare professionals. It is a dread disease, much like tuberculosis in previous centuries. Although heart disease is the major cause of death in the United States, the public's perception of cancer includes: death, fear, stigma, lingering suffering, unrelenting pain, loss of control, helplessness and economic ruin. These images of cancer affect not only the lay public and people living with cancer, but also the scientific community, healthcare providers and oncology social workers. Indeed, these powerfully aversive impressions of cancer contribute to the late detection of many cancers. In addition, so many people in the United States have no or limited health insurance and access to healthcare. This further compounds the problem of the early detection and treatment of cancer.

Many writers have tried to describe the human condition in confronting illness and cancer. Some of the classic works include: The Death of Ivan Ilyich (Tolstoy, 1886); On Death and Dying (Kubler-Ross, 1969); The Denial of Death (Becker, 1973); Illness as Metaphor (Sontag, 1978); Vital Signs (Mullan, 1983); Illness and Healing (Pope, 1997); and The Human Side of Cancer (Holland & Lewis, 2000). Each of these, although written at different times in history, echo with poignance the terror, ordeal, crisis and havoc that this disease presents at point of diagnosis and at various stages along the trajectory of living with a cancer diagnosis. Although these works span two centuries, in many respects, little has changed regarding the individual patient's personal drama, angst and existential confrontation with a potentially life threatening illness. In spite of the many new technological innovations in the medical treatment of cancer, including the management of treatment side effects and pain, the impact of the cancer diagnosis, the daily ravages, terror, uncertainties, tragedies, concerns, isolation and upheaval of facing cancer remain somewhat the same. Nonetheless, there are increasing survival rates for many types of cancer, even cures for some cancers, better pain control and the availability of free psychosocial supports for patients and their significant others.

The Science of Cancer

"Cancer is a general term for the abnormal growth of cells" (Dollinger, Rosenbaum & Cable, 1997) There are more than 100 different types of cancers. They all begin with a cell that does not follow the rules of normal cell growth and begins to reproduce at a rapid rate. In many ways, these abnormal cells do not follow the "social mores" of cell reproduction and become rogue cells, at first taking over a part of the body and destroying nearby tissue and then having the potential to spread or metastasize to other parts of the body.

Cancers can originate in different parts of the body. The most common cancer sites are: lung, colorectal, breast (for women) and prostate (for men).Early detection of cancer is critical prognostically in increasing survival. Nevertheless, with many of the newest cancer treatments, many cancers which have metastasized at the time of diagnosis or are discovered at a later stage, may respond very well to current cancer treatments.

Cancer is treated using four major approaches: surgery, when possible; chemotherapy, radiation therapy and biologic treatments. One of the most significant factors in the treatment of cancer is the increasingly important role of chemotherapy drugs to treat cancer. Cancer is one of the few diseases in which the treatment on the short run can cause a patient significant and potentially life threatening side effects, unless properly managed. Ten years ago, the advent of an innovative drug to combat the nausea and vomiting, often associated with cancer treatments, revolutionized cancer treatments, enabling patients to obtain their treatments as outpatients and to get on with their lives, work, school, care of children, household, significant others and self . More recently, the introduction of colony stimulating agents to increase the production of red cells, white cells and platelets, depleted from cancer treatments again made it more possible for many people living with cancer to better tolerate oncology chemotherapy treatments. The debilitating short and long term side effects of fatigue as a result of radiation treatments has still not been eradicated, as well as hair loss, alopecia, due to some chemotherapy protocols. Both are areas of continued research to better improve the quality-of-life of people living with cancer.

Approximately one million Americans are diagnosed with cancer each year. (Cancer Facts & Figures 2002). The first question facing each of these individuals is: “Am I going to die?” In most instances, statistically speaking, the answer is no. Since record keeping for cancer began in the 1930’s, the current era has ushered in the first sustained decline in the population death rate (Eyre, Lange & Morris, 2002). In the medical/ scientific community, cancer is now viewed as a chronic illness, much like hypertension, heart disease and diabetes. Cancer has been described as far back as 3500 years ago in Egyptian medical tracts. 2500 years ago, in the fourth century BC in Greece, Hippocrates named cancer because of its resemblance to a crab "with claw like tentacles buried deep within the flesh" (Pope, 1997).

Although cancer has been reported since ancient times, it was a relatively uncommon disease until the seventeenth century, with the advent of the Industrial Revolution, which coincided with an increase in the incidence of cancer (Pope, 1997). The American Cancer Society was established in 1913; and then in 1937, the National Cancer Institute (NCI) was established to conduct biomedical research to advance the state-of-the-art in cancer treatments (Holland, 1998). In the 1960's, the dramatic success in the use of chemotherapy for the treatment of childhood cancers created a new sense of hope in the scientific world that other cancers could be cured. President Nixon's "War on Cancer" ushered in a heightened national effort to combat and cure cancer. Since that time, a huge increase in research dollars and effort have been harnessed to develop novel treatments to advance the standard of care for people living with cancer. Some of the most significant innovations in the treatment of cancer were and continue to be collaborative partnerships between the pharmaceutical industry, academic medicine and the National Cancer Institute.

Research or clinical trials to discover new approaches to treat cancer also must acknowledge the courage and altruism of heroic people living with cancer who are willing to participate in research trials, as well as researchers who choose to endure the rigors of tireless years of scientific research in the hope of finding a new method or approach to advance cancer treatments.

Despite the potential benefits associated with participation, less than three percent of adult cancer patients enroll in clinical trials. There is currently a significant effort by the NCI to educate the public about the importance of medical research and the benefits and risks of participating in clinical trials. Many adults in the African American community respond with horror to the abuses of the Tuskegee research and harbor distrust of research protocols. Currently, this is a major educational initiative by all cancer organizations, including advocacy groups, to help the public better understand that the treatment for cancer can only be advanced through rigorous, scientific research with carefully developed, stringent protections for participation in clinical trials. Interesting to note, however is that in the field of pediatric cancers, over eighty percent of children with cancer participate in clinical trials. As a result of this support of research for children, the majority of childhood cancers are now successfully treated and often cured. The best cancer treatments of today, known as the standard of care, are based on yesterday's innovative research. The millennium confronts the challenge of increasing adult participation in all clinical trials so that further advances in cancer treatments may be achieved for current and future generations.

Oncology Social Work

The recognition that social workers could contribute to the care of the medically ill occurred in the early twentieth century. These medical social workers usually practiced in hospital settings with the goal of helping patients and families make social and emotional adjustments to illness; assisting with practical issues, including financial problems, transportation, and planning for post hospital care and working with policy makers to advocate for the specific needs of the medically ill (Lauria, Clark, Hermann & Stearns, 2001).

In the mid nineteen seventies, with the proliferation of cancer hospitals and oncology centers within medical settings, to exclusively focus on the treatment, care and cure of cancer, oncology social work emerged as a sub specialty of medical social work. It's goals are very much in keeping with those of medical social workers, except the focus and arena of practice is dedicated exclusively to the provision of professional social work services to cancer patients. In 1983, the National Association of Oncology Social Workers was established as a membership organization for oncology social workers offering an annual national conference, guidelines for standards of practice and networking opportunities for this relatively new field of social work practice (Stearns, Lauria,Hermann & Fogelberg, 1993).

Oncology social workers are required to have attained a Masters Degree in Social Work as the basic academic degree. In addition, they need to have specialized oncologic training, often provided by their work setting, staff development meetings, their supervisors and colleagues supplemented by attending oncology social work workshops, symposia and conferences to increase: their sensitivity to the needs of people living with cancer and their repertoire of clinical interventions. The need to make accurate biopsychosocial assessments is critical to the work of oncology social workers. Oncology social workers need to understand cancer as a disease, its impact, as well as its treatment's impact, on various organ systems. They need to evaluate problems that are confronting clients from an awareness of the medical impact of the disease of cancer. For example, if a cancer patient presents extreme fatigue to an oncology social worker, rather than making the differential diagnosis of depression, the oncology social worker needs to work with the patient, family and healthcare team to assess whether there is a biologic cause to this presenting symptom. The exquisite understanding of the science of cancer is a critical component to the success of the oncology social worker's ability to help clients and function effectively on the healthcare team (Smith, Walsh-Burke, Crusan, 1998).

Oncology social workers must be well versed in the psychosocial issues that confront people living with cancer. These issues include: the impact of the cancer diagnosis; crisis points in dealing with cancer; communication challenges of diagnosis disclosure with family, children, friends; workplace and insurance; existential dilemmas of living with a potentially life threatening illness; the role of hope in coping with cancer; grief, loss, bereavement and the practical day-to-day needs that cancer patients and their families face. Oncology social workers are often described as "troubleshooters/ problem solvers" for patients and their families (Bruning, 2002).

These social work specialists are expected to be able to work with clients in crisis as well as provide support to other members of the healthcare team. Their ability to make appropriate biopsychosocial assessments informs their choice of intervention and underpins best practice. The oncology social worker is required to work with individuals, families, couples and groups. The role is often fraught with stress and tension however. Additionally, the current managed care environment creates many challenges in the helping role. In addition to the extraordinary knowledge, training and skill required, people living with cancer value the relationship, interpersonal sensitivity, care and compassion of these healthcare professionals (Nouwen, 1972; Vachon, 1987; Hermann, 2002; Roter & Fallowfield, 1998).

There are many tensions and stresses inherent in the role of oncology social worker. Some of these include: limited resources to meet concrete needs of this population; lack of certainty and predictability re: patient survival/outcome; the sights, smells and sounds of cancer ; advocacy within an imperfect health care system; high standards/ expectations imposed on oncology mental health professionals; workload; and tensions arising within the supervisory setting, as well as workplace barriers and conflicts.(Auchincloss, 2002; Vachon, 1987; Lederberg, 1998; Smith,Reese & Sontag, 2001). Thus, the risk of burnout has been well documented in the literature (Vachon, 1987; Blum, 1983; Reese & Sontag, 2001; Lederberg, 1998; Lauria, Clark, Hermann & Stearns, 2001; Christ & Sormanti,1999). In contrast to those who experience burnout from this complex work, there are many oncology social workers who find meaning and purpose in this field, recognize that they make a vital difference, experience the rewards of " playing a positive role in profound human experiences"(Lederberg, 1998) and obtain job satisfaction (Peteet, Murray-Ross, Medeiros et al, 1989; Vachon, 1987).

Innovation

The potential for stress and burnout for social service professionals has been a prevalent theme in the literature since the 1970's (Beemsterboer & Baum, 1984; Cournoyer, 1988; Daley, 1979; Dillon, 1990; Epstein, 1981; Freudenberger, 1975; Lewis, 1980; Maslach, 1978; Munson, 2002; Pines & Kafry, 1978; Ratliff, 1988; Watson, 1979). Likewise, there is an increasing body of knowledge about professional caregivers in the field of psychosocial oncology and the impact on them of their close proximity to illness and death in their caseloads (Christ, 1989; Goldberg & Tull, 1983; Handzo, 1989; Hansell, 1989; Holland, 1998; Klagsbrun, 1983; Koocher, 1979; Lederberg, 1998; Moynihan & Outlaw, 1984; Prichard, 1998; Smith, Walsh-Burke & Crusan, 1998; Vachon, 1987; Vachon, 1979; Vachon, 1978; Vachon, 1975; Vachon, Lyall & Freeman, 1978; Weisman, 1981; Yancik, 1984; Zimberg,1989). Oncology social workers frequently confront death and dying and existential despair in their work with chronically and terminally ill cancer patients (Nouwen, 1992; Nouwen, 1979; Stearns, 2001; Vachon, 1987). These social workers run a high risk of burnout from the day to day stresses inherent in their work with cancer patients as well as with their families (Blum & Fisher, 1983; Davidson, 1985; Davidson, 1983; Koocher, 1979; Lederberg, 1998; Vachon, 1987).

Opposed to the recurrent theme of stress and burnout is the theme of creativity and innovation in oncology social work practice. Oncology social workers are constantly confronted with complex and profound human problems which require creative problem solving and innovative interventions.

Oncology social workers now conceptualize cancer as a chronic illness with various "psychosocial stages" (Weisman, 1979). The social context of cancer is ever changing as new advances in biomedical research and technologies are made. Some patients are living longer but with a host of new needs. Cancer patients require a continuum of care due to their varied needs. These changing and eclectic needs require innovative staff to develop new psychosocial programs and interventions for effective service delivery to this patient population. Although practice innovations and creativity are frequently observed in the work of oncology social workers, no published research has been conducted which systematically examines the factors, work climate and environment that affect and nurture practitioner innovation in oncology social work practice.

The term creativity has many meanings and definitions. Boehm (1961) described the characteristics of the creative practitioner to include: commitment, intensity, devotion, spontaneity and inventiveness." Creativity is defined in the literature on this subject as a tool or skill which enables people to look at problems from a different angle; generate many new ideas; solve problems in new ways; discover new relationships between ideas; develop unique combinations of thoughts and ideas; and develop numerous perspectives in assessing a problem (Gelfand, 1988; Heus & Pincus, 1986; Rapoport, 1968; Weissman,1990; Wheeler, 1978). Additionally, it enables people to make new linkages and connections between ideas and concepts and express these linkages through analogy and metaphor (Gelfand, 1988; Heus & Pincus, 1986; Wheeler, 1978). Creativity requires persistence and flexibility (Gelfand, 1988). Heus and Pincus (1986) identify the attributes of a creative product which include: fit, i.e. relevance; novelty, i.e. originality; alchemy, i.e. transformation; and elegance, i.e. simplicity.

The successful implementation of creativity is innovation. In practice, creativity is operationalized or translates into innovation, which is the "introduction of something novel" (Thomas, 1988) or the trying of something new or different to improve clinical practice or service delivery. "Innovation provides the bridge between the creative idea and the development of a useable product/ service" (Pointer, 1985). Drucker (1999) looks at changes, including new knowledge, demographics, incongruities and unexpected successes or failures as "windows of opportunity" for innovation which require hard work.

Since the 1960's, the creativity literature in business and industry has focused on innovation. These writings have identified the role of corporate culture, leadership, supervision and rewards in promoting and stimulating innovation in organizations (Argyris, 1965; Delbecq & Mills, 1985; Drucker, 1999; Drucker, 1954; Hitt, 1975; Kanter, 1983; Kanter & Stein, 1979; Livingston, 1988; Mars, 1971; Morgan, 1989; Morgan, 1986; Peters & Waterman,1982; Senn, 1986; Sinetar, 1985).

Although this topic has received less attention in social work, social work has addressed the need for new problem solving methods and innovations in dealing with human service problems (Davidson, 1990; Gelfand, 1988; Gelfand, 1982; Heus & Pincus, 1986;

McNeely, 1988; Rapoport, 1968; Siporin, 1988; Weissman, 1990) and the need for organizational support for staff attempting to innovate (Brager & Holloway, 1978; Delbecq & Pierce, 1978; Glicken, 1980; Gummer, 1986; McNeely, 1988; Rapoport, 1968). Schon (1983 & 1987) attempted to describe the way other professionals think in action and artfully apply what they have learned to meet current problem situations that they encounter as they perform their work. However, there are no published articles to date which focus upon the factors that stimulate innovation and the process of innovation in oncology social work practice.

The goal of this doctoral dissertation is to describe those factors which influence innovation in oncology social work practice. To accomplish this goal, qualitative research methodology was utilized to capture the firsthand experiences, observations and perceptions of innovative oncology social workers. To do this, open-ended, semi-structured, focused interviews with follow-up probes were utilized. Data gathering and data analysis techniques proposed by Glaser and Strauss (1967), Miles and Huberman (1984 & 1994) and Strauss and Corbin (1990) were followed. Data analysis included a search for "recurring patterns and themes" leading to the development of categorical saturation and coding of the data (Miles & Huberman, 1984 & 1994).

In other words, this study is intended to explicate the factors which influence innovation in oncology social work. The findings will provide guidelines to others interested in innovation and will have implications for practitioners, supervisors, program coordinators and administrators. The following is an overview of the succeeding chapters: Chapter II will review the relevant literature; Chapter III will describe the methodology employed; Chapter IV will offer participant stories; Chapter V will present the data analysis; and Chapter VI will address the recommendations and implications for practice

Chapter II

Literature Review: The Cancer Population, The Crisis Nature of the Work, Reflective Practice; Stress and Coping; The Work Environment and Innovation

Although there is no literature which focuses upon the process and dynamics of innovation in oncology social work, there exists a considerable body of knowledge which is necessary to review to understand and explicate the context of innovation in oncology social work. This comprehensive account provides the framework for this research and has informed the investigator's thinking and approach to this dissertation topic. The literature review includes a description of contextual phenomena which exist in the background, foreground and practice of oncology social work. These phenomena include: the cancer patient population; the work environment; and reflective practice. The interaction, confluence and synergy of these phenomena may influence innovation in oncology social work practice.

The Cancer Patient Population

"People with cancer face many fears: they are frightened by lack of knowledge, they face an uncertain future, they have to deal with fear in others, but most of all they fear being alone" (Pope, 1997, p.33). They are not immune to the dread which society associates with cancer. A diagnosis of cancer has a profound impact on most people and is a traumatic life event which threatens one's physical, emotional and social existence (Pope, 1997; Holland & Lewis, 2000; Weiss & Weiss, 1997; Bruning, 2002; Black, 1989;

Capone, 1979; Christ, 1983; Jevne, 1987; Oppenheimer, 1967; Stonberg, 1981; Weisman, 1979). It upsets one's core existence and equilibrium and threatens, at times, to annihilate all that is known, important and dear to one (Trillin, 1981). The "phenomenon of initial diagnostic shock" has far reaching and universal implications for the cancer patient and family members (Gorman & Anderson, 1982). Each patient has their own interpretation, belief system and understanding of cancer, which influences their attitude toward self and medical care (Cassileth, 1979).

The diagnosis of cancer is a life crisis to the patient and family members (Oppenheimer, 1967; Harpham, 1992; Holland, 1998; Hoffman, 1996). "One of the most common elements of the cancer experience is dealing with the spectrum of emotions that accompanies a diagnosis" (Schimmel & Fox, 1999). Powerful feelings of fear, anguish, sadness, anger, hopelessness, uncertainty, loss, anxiety, terror, loneliness, isolation, shame and guilt are not uncommon responses to cancer (Black, 1989; Jevne, 1987; Weisman, 1979; Holland, 1998; Pope, 1997; Errico et al, 1999). Patients often feel stigmatized by their cancer, as if they had leprosy (Holland, 1989; Stahly, 1989). They perceive themselves as different from others who do not have cancer. Patients often report that there is a collapse of their social support network; friends seem fearful of contagion and may discontinue visiting them or eating food in their homes (Stahly, 1988; Holland,1997; Eyre et al, 2002).

Cancer is a "large scale disruption" of one's life (Mullan, 1085). Patients may feel alienated from family and friends (Rowland, 1989; Trillin, 1981; Pope, 1997; Hermann, 2002; Holland,1998). Alice Trillin poignantly described these sentiments:

> What changed was other people's perception of me. Everyone regarded me as someone who had been altered irrevocably. I had become special, no longer like them. Their genuine concern for what had happened to me, and their complete separateness from it, expressed exactly what I had felt all my life about anyone I had ever known who had experienced tragedy (Trillin, 1981).

Cancer has the potential to affect all aspects of psychosocial functioning (Jevne, 1987; Oppenheimer, 1967; Rowland, 1989; Stonberg, 1981;Holland, 1998). As patients deal with the daily vicissitudes of the disease, they frequently experience loss of self esteem and control, uncertainty, panic, disbelief and worry about the cause, as well as, the course of the disease (Freidenbergs et al, 1982; Heinrich & Schag, 1987; Northouse & Northouse, 1987;Holland & Lewis, 2002: Schimmel & Fox, 1999). The "seven areas of concern" identified for patients include: "health; self appraisal; work and finances; family and significant relationships; religion; friends and associates; and existential" (Weisman, 1979, pp. 72-82).

The hallmarks of the cancer experience for many patients are feelings of vulnerability and uncertainty (Heinrich & Schag, 1987; Northouse & Northouse, 1987; Holland, 1989). Many patients and their family members report the sense of being on a rollercoaster while living with cancer, while being terrified of a recurrence when in remission. On the other hand, numerous anecdotal case examples exist in which people living with cancer and their families report that the cancer experience provided an opportunity or catalyst for personal growth and creativity for the person with cancer.

The "constellation of needs" of cancer patients include concrete and practical service needs, as well as psychosocial needs (Black, 1989; Mor et al, 1987; Stonberg, 1981; Bruning,2002). Concrete service needs can be categorized into: "physical," i.e. house chores and "administrative," i.e. help getting benefits (Mor et al, 1987).

People living with cancer may have visible, as well as, invisible scars. The site or location of the cancer compounds the individual's response. Cancers of the head and neck or those necessitating surgical removal of a part of the body trigger very basic, intrinsic responses to one's identity of wholeness and integrity. The unpredictable aspect of cancer further inflicts loss of control and mastery (Lydiatt & Johnson, 2001). Patients often feel "damaged" as a result of their illness (Siegel, 1990). This "subjective sense of impairment" may have a negative impact on identity, self esteem, spirituality, social relationships and sexuality (Ibid). Although the well public believe that they are going to live "a long time into the future," cancer patients are forced "to confront their own mortality" (Mullan, 1985).

Patients worry about cancer recurrence (Jevne, 1987; Northouse & Northouse, 1987; Weisman & Worden, 1985) and live with the "Sword of Damocles" wondering when their cancer will recur (Weisman & Worden, 1985; Weiss & Weiss, 1997; Bruning, 2002). For many, the background music in their lives is no longer the same, now filled with spiked, ominous portents. When patients complete their acute treatment for cancer, they enter a phase of "watchful waiting" - a period of eternal worry that the cancer will recur "to resume its perfidious work" (Mullan, 1985). Patients check and examine themselves for signs and symptoms of recurrence (Weisman & Worden, 1985; Weiss & Weiss, 1997; Bruning, 2002). The patient Alice Trillin described her concerns about recurrence in this way: " The dragons are never quite dead and might at any time be aroused, ready for another fight (Trillin, 1981). For people living with cancer, recurrence is a distinct fear, followed by concerns of death (Brady & Helgeson, 1999). Of note, in a study of breast cancer patients, psychological adjustment to recurrence is significantly predicted by the extent to which patients believe that they would be disease free in the future (Brady & Helgeson, 1999).

Cancer is considered a chronic illness with various psychosocial stages (Weisman, 1979; Holland & Lewis, 2000). The literature has identified the following crisis points that cancer patients universally experience at different stages of their illness: diagnosis, treatment, termination of treatment, recurrence, remission, deterioration and terminality (Blum,1984; Christ, 1983; Weisman, 1979; Holland, 1998). These crisis points can create particular stress and "dis-synchrony of coping" between patients, their families and friends (Christ, 1983). The "impact of cancer on a family" is influenced by its pre-illness "level of functioning" (Caroff & Mailick, 1985). An additional crisis for families is the death of the patient and bereavement (Blum, 1984; Christ, 1983; Weisman, 1979: Holland,1989).

In working with cancer patients and their families, it is important to recognize that each patient and family member brings a unique personality constellation, lifestyle, belief systems and history to their coping with cancer (Holland & Lewis, 2000). Each has strengths and assets in coping, as well as challenges and problems (Black, 1989;

Rowland, 1989; Weisman, 1979; Hill, 1991; Holland & Lewis, 2000; Bruning, 2002; Eyre et al,1997). Rowland (1989) stresses the importance of recognizing "the developmental stage of the patient" in assessing the impact of cancer on the individual. She identifies five common disruptions which cancer may cause throughout the life cycle: "altered interpersonal relationships; dependence-independence; achievement disruption; body-sexual image and integrity; and existential issues" (Rowland, 1989). The extent of each of these disruptions may vary in accordance with the patient's developmental stage as well as the unique personality traits of the individual (Rowland, 1989; Holland & Lewis, 2000; Hill,1991). Thus, the particular significance of the cancer diagnosis is unique to each individual, the site of the cancer, its course and the patient's place in the life cycle (Rowland, 1989; Lewis & Holland, 2000; Hill, 1991; Harpham, 1998).

The universal impact of the cancer experience intensifies the cancer patient's pain and suffering and that of the family/friend support system (Black, 1989; Holland, 1998; Stahly,1988; Trillin, 1981; Weisman, 1979; Hill, 1991). In addition, cancer is one of the few diseases in which the treatment does not bring relief to the patient, but causes the patient additional pain and suffering (Glajchen, 1989). The toxicity of many cancer treatments causes unpleasant side effects - hair loss, nausea, vomiting, diarrhea, mouth sores (mucositis), dry mouth (xerostomia), increased susceptibility to infection, weight gain or loss, fatigue and weakness (Rowland, 1989; Pope, 1997; Ganz, 1996; Bruning, 2002). Uncontrolled cell growth symbolizes to the patient that his or her body has turned against itself and is out of control. This exacerbates the patient's sense of helplessness to alter the course of the illness (Northouse & Northouse, 1987). There frequently can be the feeling that life would have been exquisitely better if only cancer had not reared its ugly hydra head to permeate the essence of one's life. Learning to develop a sense of mastery over the disease, with all of its sequelae, is a major life challenge for people living with cancer.

From the point of diagnosis, cancer patients and their families are beset with a variety of treatment choices. The need to get credible information, in a short period of time, is a major psychosocial issue for patients to handle. Their relationship and capacity to communicate effectively with the treating health care team are critical to their care, medical outcome and satisfaction with care (Hack et al, 2002; Weiss & Weiss, 1998; Northouse & Northouse, 1987; Eyre et al, 2002; Schimmel & Fox, 1999). Communication is a central theme in coping with cancer, whether it be communication with physician, nurse, partner, spouse, children, siblings, parents, employer, co-workers, supervisor, neighbor and friends (Holland, 2000; Pope, 1997; Christ, 1993; Wells & Turney, 2001). Patients confront a myriad of issues that require psychosocial adaptation. As cancer intersects with patients' daily living, there are opportunities for psychosocial intervention and programs to assist patients and families to continue the momentum of their lives in spite of the assault of cancer.

There are a host of psychosocial interventions which exist to provide patients and their families with support as they encounter the vicissitudes of cancer. These interventions may be categorized as follows: informational/cognitive - provision of information and guidance; emotional/affective - demonstration of concern and care; and instrumental - contribution of concrete, tangible assistance (Brady & Helgeson, 1999; Wells & Turney, 2001; Delbar & Benor, 2001; Bucher et al, 2001; Cwickel & Behar, 1999). The counseling methods employed to provide psychosocial support to cancer patients and their families include: individual, family, behavioral, psychoeducational and group (Blum, 1993; Cwikel & Behar, 1999; Massie, Holland & Straker, 1989; Mastrovito, 1989; Levy, 2002). Meta analysis of published studies of the effects of psychosocial interventions on adult cancer patients' coping demonstrated positive impact on the quality-of-life of patients (Meyer & Mark, 1995). The challenge to the health care professional is to assess the need and tailor a treatment plan to best suit the individual patient and family.

The Crisis Nature of the Work

"The diagnosis of cancer with all of its implications can be counted on to precipitate a state of crisis of varying intensity and duration for nearly every patient and family" (Oppenheimer,1967). For the oncology social worker, the crisis intervention model is an invaluable tool to help patients and their families cope with the impact of cancer (Blum, 1984;Capone, 1979; Christ, 1989; Christ, 1983; Oppenheimer, 1967; Hermann, 2001). Stonberg (1981) describes the role of the social worker: "The social worker must recognize the true nature of the threat and help the patient and family achieve an equilibrium in their response to the disease." The crisis intervention model not only empowers the client, but also the practitioner. The efficacy of this approach with this client population enables the worker to make a significant difference in the lives of patients and their families (Capone et al, 1979; Christ, 1983; Oppenheimer, 1967; Clark, 1996).

Crisis theory advocates immediate access to services for clients (Oppenheimer, 1967; Perlman, 1963; Sands,1983). The crisis approach champions no waiting list and the need to reach the client when “the iron is hot” (Perlman, 1963). Rapoport (1952) recognized that clients in a state of crisis are more accessible to help and often help is more effective at this time. “A little help, rationally directed and purposefully focused at a strategic time is more effective than more extensive help given at a period of less emotional accessibility” (Rapoport, 1962).

A crisis is “an upset in a steady state,” whereas, a state of crisis is a period of disequilibrium when the person’s usual problem solving methods fail to reestablish homeostasis (Rapoport,1962). Basic to the theory is the ideology that human beings possess “natural growth tendencies” and there is the potential for growth in each crisis state (Rapoport, 1970).

A major hallmark of this theory is its universal appeal - the notion that a crisis can happen to anyone, even the well adjusted (Baldwin, 1977; Pope, 1997; Nouwen, 1992; Nouwen, 1979). This theory moves away from the medical model, with its disease orientation, and places less stigma on the individual (Baldwin, 1977; Capone et al, 1979; Sands, 1983).The crisis intervention approach cognitively reframes a crisis state and normalizes the experience for clients (Baldwin, 1977; Sands, 1983).

The crisis intervention model describes four factors which lead to the crisis state: “the hazardous event; the vulnerable state; the precipitating factor and the state of active crisis" (Golan, 1969; Golan, 1966; Golan, 1987). This model offers a concise framework in assessing the factors contributing to the client's current crisis state. Rapoport identifies three possible reactions of the client to the hazardous event: "threat, loss or challenge" (Rapoport,1962). The precipitating factor is described in the literature as "the straw that breaks the camel's back" and is viewed as an often manageable and meaningful locus of intervention (Golan, 1969).

The crisis intervention approach acknowledges that persons in a state of crisis frequently have to find "novel solutions" to cope with the crisis (Parad & Caplan, 1965; Rapoport,1967). This model also articulates that old conflicts are frequently reawakened in a crisis situation and that during a crisis, the opportunity presents for a client to not only resolve the current crisis, but to rework and possibly resolve an old conflict (Parad & Caplan,1965).

Crisis theory stresses the need to develop services and to offer them to clients in a timely fashion in crisis situations (Rapoport, 1962; Hermann, 2001; Ross, 1993). This is most relevant to oncology social work practice. Patients and their families frequently experience an ongoing series of crises as they attempt to deal with the acute and chronic phases of cancer (Berger, 1984; Blum, 1984; Capone et al, 1979; Christ, 1983; Oppenheimer,1967; Hermann, 2001). The timing of interventions to coincide with critical periods of stress during the patient's illness maximizes the impact of these interventions in facilitating coping with crisis (Oppenheimer, 1967; Sands, 1983;

Hermann, 2001).

The capacity of the oncology social worker to engage the patient in problem definition and resolution is essential in crisis intervention work. The goal of the intervention is to mobilize the patient's and family's resources to cope more adaptively with the crisis; to, at least, restore the "pre-crisis level of functioning" and to try to prepare the client to learn new coping skills for future crises (Capone et al, 1979; Sands. 1983; Hermann, 2001).

The crisis theory paradigm encourages the practitioner to take an active role in the therapeutic process and to communicate to the client " a sense of confidence and hope" in problem resolution (Lukton, 1974). Cancer patients and their families often feel that they are on a rollercoaster, experiencing one crisis after another. This crisis model helps to stabilize the client's experience of the world and restore their equilibrium and balance.

The Chinese write the word crisis with two characters, one of which means danger and The other opportunity (Sands, 1983). When in a state of crisis, a person is frequently more amenable to outside intervention. If the practitioner can seize that moment of accessibility, the opportunity to enable the client to cope more adaptively exists. If the client is able to utilize that moment with the worker, then together a novel resolution of the crisis is often attainable. The client is helped to gain a sense of autonomy, empowerment, control and mastery in a situation in which the client had felt helpless during the crisis state (Black, 1989; Capone et al, 1979; Oppenheimer, 19657; Hermann, 2001)

"The realities of physical illness make practical remedies more imperative than in some forms of casework" (Reynolds, 1951). Bertha Capon Reynolds' words are as true today as they were in 1951. Cancer patients and their families need "practical remedies" (Reynolds,1951). The crisis intervention model is an essential part of the repertoire of clinical interventions of oncology social workers (Hermann, 2001; Blum, 1993).

In oncology practice, patients, families and staff frequently experience a state of crisis. For each, novel solutions may be possible if they can be engaged at the moment of accessibility or the teachable moment. For patients and staff, crises arouse a sense of danger, but also provide challenges and the opportunity for growth, creative problem solving and innovation (Sands, 1983).

Reflective Practice

Social work practice in the field of oncology is specialized from a technical assessment and intervention perspective, as well as from a philosophical and existential stance. Practitioners often perceive themselves as "breaking the rules" which they learned in graduate school and supervision with physically healthy clients (Holland, 1989; Klagsbrun, 1983; Nouwen,1992; Nouwen, 1979; Kubler-Ross, 1969). Working with people with cancer requires a number of accommodations in the practice of clinical social work, with significant program implications. Areas of particular note include: episodic, short term work based on client's health status; emphasis on supportive rather than exploratory counseling; openness to assisting patient/family consider treatment options; evaluation of constructiveness of patient's adaptive defenses in coping with cancer, particularly denial; awareness of oncology social worker's personal and countertransference issues elicited by this work, especially practitioner's own experience with loss and cancer (Holland, 1989; Klagsbrun, 1983; Nouwen, 1979; Nouwen, 1992; Mailick, 1990;Hill, 1991). Trained to maintain professional distance and boundaries, oncology social workers quickly learn that to be effective they need to struggle with the ongoing challenge of achieving "the right balance between professional distance, human connection and closeness" so needed by patients.(Hill, 1991). The art of oncology social work includes such capacity to bridge the gap between "professional knowledge and the demands of real-world practice" (Schon, 1983). Schon has coined the phrase "reflection-in-action" to describe the "reflective practitioner" who, equipped with the requisite training, discipline and knowledge of the field, is able to step outside of traditional training and perform as an artist to handle "situations of uncertainty, uniqueness and conflict" (Schon, 1987). Many professionals acknowledge that in addition to technical skill that there is much in their field that is akin to art (Schon, 1987; Schon,1983). In oncology social work, the intersection of the exigencies of patient and family needs, with existing knowledge and gaps in what is known to be effective, create the opportunity in daily practice for "reflection- in -action" for novel problem solving and use of self (Schon, 1987; Klagsbrun, 1983; Holland, 1989; Hill, 1991). Oncology social work practice is a crucible for "reflective practice."

Stress and Coping

Practitioners in oncology settings experience significant stress in their day-to-day practice (Hill, 1991; Lederberg, 1998; Walsh-Burke & Crusan, 1998; Blum & Fisher, 1983;

Christ, 1989; Davidson, 1985; Davidson, 1983; Koocher, 1979; Vachon, 1987; Vachon, 1987; Weisman, 1981; Worden, 1982; Yancik,1984). They are not immune from the dread which society attaches to cancer and the fears of developing cancer in oneself or a loved one (Holland, 1989; Koocher, 1979; Vachon, 1987; Weisman, 1981; Davidson, 1985; Lederberg, 1998; Blum & Fisher, 1983).

Practitioners who work with oncology patients over an extended period of time often feel that they have known intimately more patients who have died than people who are currently living. These workers may experience feelings of helplessness, sadness and hopelessness as they enter into helping relationships with patients and their families (Hill, 1991; Lederberg, 1998; Davidson, 1985; Holland, 1989; Vachon, 1987). The existential despair of oncology social workers has been well documented in studies of professional caregivers (Holland, 1989; Koocher, 1979; Vachon, 1987; Weisman, 1979; Lederberg, 1998; Walsh-Burke & Crusan,1998; Nouwen, 1972; Nouwen, 1992). Henri Nouwen (1979) poignantly describes the plight of the professional helper: "No one can help anyone without entering with his whole person into the painful situation, without taking the risk of becoming hurt or wounded." This perspective is again echoed by Hester Lampert-Hill:

> While in training, mental health practitioners are taught to consider the issues of transference and countertransference in all clinical interactions. Such intellectual exercises, although fascinating and important, quickly fade from center stage in our kind of patient care. Instead, we discover that patients demand that we be human.

There are four primary sources of stress for the oncology social worker: the patient's cancer; social and interpersonal characteristics of patients and their families; the work environment and a personal crisis (Vachon,. 1987; Lederberg, 1998). Vachon (1987) undertook and completed the most comprehensive descriptive study to date of professional caregivers in oncology. She asked 581 professional caregivers from a variety of professions and specialty areas to describe sources of stress in their work and how they cope with stress (Vachon, 1987).

The patient's cancer can be a major source of stress (Holland, 1989; Koocher, 1979; Lederberg, 1998; Vachon, 1987; Weisman, 1981; Yancik, 1984; Walsh-Burke & Crusan, 1998). The head and neck cancer patient with significant facial disfigurement; the patient who is not responding to treatment; the dying patient; the patient with severe treatment side effects; the patient with a complex and painful treatment course; the death of a favorite patient or multiple deaths can create strain and emotional distress for the oncology social worker (Vachon, 1987; Lederberg, 1998; Weisman, 1981).

Particular social and interpersonal characteristics of patients and their families can be additional sources of stress (Groves, 1972; Holland, 1989; Hyland et al, 1987; Koocher; 1979; Weisman, 1981; Vachon,1987; Lederberg, 1998). The difficult or demanding patient and/ or family member; the patient with complex family communication problems, the isolated and alone patient with no family or significant others, the patient with dependent others and/ or young children and the patient with a history of psychiatric problems are all potentially more needy and pose a greater strain for the clinician (Koocher,1979; Vachon, 1987; Lederberg, 1998). The practitioner's close identification with and attachment to a patient can exact a heavy toll on the worker when the patient begins to deteriorate or dies (Koocher, 1979; Vachon, 1987; Worden, 1982; Yancik, 1984; Lederberg,1998).

The work environment can pose its particular set of stresses on the oncology social worker (Christ, 1989; Holland, 1989; Vachon, 1987; Lederberg, 1998). Staff shortages; heavy caseloads; team, management or administrative communication problems; staff conflict; inadequate staff training and supervision; poor leadership; poor career or non existent career mobility ladder; unrealistic expectations regarding work performance; role ambiguity; lack of recognition and organizational support for the work done contribute to making the practitioner's daily work life more stressful (Koocher, 1979; Lederberg, 1998; Vachon,1989; Yancik, 1984). The professional role of the worker can be a source of strain when the worker experiences a lack of clarity about role expectations or role performance which poses ethical or moral conflicts for the worker (Klagsbrun, 1983; Vachon,1987; Lederberg, 1998; Rosenberg, 1983).

A personal crisis in the life of the oncology social worker can also impact on work with patients and families (Vachon, 1987; Lederberg, 1998; Balsam & Balsam, 1984). In addition to work related losses, personal losses and bereavement are experiences which can exact a heavy toll on the already stressed practitioner (Worden, 1982; Lederberg, 1998; Balsam & Balsam,1984).

The distress that oncology social workers experience because of their proximity to illness and death in their caseloads is often compounded by the life cycle crises during their adult years. Some of these life cycle crises include: starting and ending relationships;

marriage; pregnancy; adoption; parenthood; separation; divorce; illness in self or illness or death of a loved one; and retirement (Balsam & Balsam, 1984; Lidz, 1983; Lederberg, 1998).

Points of transition in the social worker's life may cause the clinician to focus on personal concerns with less energy to look at the client's needs (Schwartz, 1975):

> Although social workers stress that clients go through many crucial life struggles that profoundly affect their functioning, they rarely acknowledge that workers are also in process, growing and changing with all the psychic conflict, struggle and excitement that this process involves (Schwartz, 1975).

Life cycle crises include happy and joyful events, as well as painful and sad events in the life of the clinician (Balsam & Balsam, 1984). These events have far reaching implications for practice (Balsam & Balsam, 1984; Schwartz, 1975; Lederberg, 1998). Life cycle crises are usually accompanied by anxiety, feelings of vulnerability, fragility, disequilibrium, ambivalence, preoccupation and reassessment (Balsam & Balsam, 1984). These crises are particularly challenging to the oncology social worker since the worker as well as the population served are facing crises and reassessment of their lives.

Identifying effective coping strategies for oncology social workers to enable them to cope with the stresses of their work and to provide optimal services to cancer patients and their families is a major concern to the oncology social work profession (Walsh-Burke & Crusan, 1998; Christ, 1989; Davidson, 1985; Koocher, 1979; Lederberg, 1998; Vachon, 1987; Weisman, 1981;Worden, 1982). Efforts have been made to begin to discover how oncology social workers adapt and cope with the stress of their work (McMillen, 1999; Blum & Fisher, 1983; Christ, 1989; Davidson, 1985; Koocher, 1979; Lederberg, 1998;

Vachon,1987; Weisman, 1981; Worden, 1982; Peteet et al, 1989). In general, "the greater the scope and variety of the individual's coping repertoire, the more protection the coping affords"(Pearlin & Schooler, 1978).

Effective coping strategies enable oncology social workers to deal with some of the stresses identified thus far, and continue to provide and deliver a range of services to cancer patients and their families. Non-productive stress management can lead to avoidance of patients, anger, sadness, frustration, exhaustion, irritability and staff and team conflict (Lederberg, 1998; Davidson,1985; Koocher, 1977; Maslach, 1976; Vachon, 1987; Peteet et al,1989).

A variety of coping techniques have been identified to counteract the stresses of oncology practice. Worden (1982) stresses the need for practitioners to be aware of their personal experiences with cancer, death and loss. Since psychosocial oncology is replete with grief and loss, workers need to be especially aware of their personal experiences in this area and any unresolved grief. Workers are advised to make a personal assessment of their limitations in handling certain cases (Worden, 1982; Lederberg, 1998; Hill, 1991). Recently bereaved workers may want the option to reject cases that replicate the worker's loss. For a period of time, the worker may need to transfer such cases to colleagues if possible. This option provides the worker with a sense of control in a situation where the worker might feel vulnerable (Worden,1982; Lederberg, 1998; Hill, 1991; McMillen, 1999). Likewise, some workers find it more difficult to work with certain types of dying patients and may need the option of case transfer (Vachon, 1987; Worden, 1982; Reese

& Sontag,2001).

The need to seek and receive support from colleagues is a major coping strategy for many practitioners (Davidson, 1985; Holland, 1989; Koocher, 1979; Lederberg,1998; Pines & Kafry, 1978; Vachon, 1987; Weisman,1981; Reese & Sontag, 1999). Colleagues, team members and supervisors can be major sources of replenishment and support in carrying on with the daily work. Workers need an opportunity to discuss the pain in their caseloads with co-workers. Informal support is particularly important because of the intensity of the work and the isolation clinicians experience in their non work lives with friends and family, who may ask them, “Isn’t the work depressing?” and “How do you do it?” (Blum & Fisher, 1983; Holland, 1989; Lederberg, 1998;Reese & Sontag, 1999).

Successful copers tend to take care of themselves (Koocher, 1979; Vachon, 1987; Lederberg, 1998; Peteet et al, 1989). They do this both at work and in their personal lives. At work, these workers diversify their work assignments and work with a variety of patients (Koocher, 1979; Vachon, 1987; Lederberg,1998). They participate in organizational planning (Ibid). They utilize conferences and educational training to enhance their skills, sense of control and mastery of the work (Christ, 1989; Peteet et al, 1989; Koocher, 1979; Vachon,1987).

Outside of work, these practitioners know when to take time off - vacation, personal and sick days - to give themselves time away from the hectic pace of work (Koocher,1979). In Vachon’s study (1987) of experienced health care professionals, she found that many reported that they created a “decompression routine” or “buffer zone” between work and home in which they engaged in an activity en route from work to home which clearly served to separate them from work worries (Vachon, 1987). For example, some exercised after work or took a scenic drive home (Ibid). In addition, successful copers have interests and hobbies outside of work which serve to revitalize and nourish them (Koocher,1979).

Successful copers also know how to partialize problems and to set clear and limited goals for themselves (Koocher, 1979; Vachon, 1987; Weisman, 1981; Peteet et al, 1989; Lederberg, 1998). Weisman (1981) describes the attributes of the good coper as a "combination of optimism, resourcefulness, flexibility and pragmatism." He advises not to promise more than he or she can deliver.

The discrete coping strategies identified thus far largely emanate from the descriptive studies undertaken by Koocher and Vachon in which they asked experienced practitioners how they coped with the stresses of oncology work. Experienced workers were chosen so that their insights and experiences could be taught to others to enable them to survive the intensity of this work (Koocher, 1979; Vachon, 1987). The specific coping strategies presented thus far represent the major "how to" cookbook variety survival and coping guidelines which oncology social workers try to implement in their practice to cope with the stresses inherent in the work. These strategies serve as important benchmarks in the field of psychosocial oncology. "The single coping mechanism regardless of its efficacy, may be less effective than bringing to bear a range of responses to life strains"(Pearlin & Schooner, 1978).. Having a repertoire of coping strategies increases the possibilities of effective coping with stress.

Recognizing that there are limits to individual efforts in coping with the stress of oncology work, a number of authors recommend organizational supports to help workers cope with,the work demands. Vachon (1987) suggests that cancer settings provide supports for staff, clinical ladders, recognition and set reasonable and achievable goals for staff. Christ (1989) stresses the importance of maintaining good staff morale. She emphasizes the need to help staff develop expertise, competence and mastery of the complexities of the work. She also recommends the importance of establishing supportive work environments and well functioning multi-disciplinary teams. Lederberg (1989) identifies a host of organizational interventions and strategies which maximize staff coping and productivity. These include: effective leadership; clear lines of authority; unambiguous work assignments; realistic expectations; team approach; open communication about work and burnout issues; respect for time off and vacations; encouragement of group cohesion; good orientation procedures; provision for positive feedback and career enhancement opportunities. Dillon (1990) suggests that department leadership involve line staff, whenever possible, in decision making in which workers might exercise some control over issues of concern to them. The efficacy of staff support groups and supervision is reported by a number of authors in helping staff to cope with their work (Christ, 1989; Holland, 1989; Lederberg, 1998; Moynihan & Outlaw, 1984; Vachon, 1987; Zimberg, 1989; Walsh-Burke & Crusan, 1998).

Oncology social workers need to have specialized knowledge, skill and training to work with cancer patients effectively. The practitioner not only has to be grounded in clinical social work which stresses the “importance of an organized knowledge base and the use of a theoretical framework to inform practice” (Caroff & Mailick, 1985), but also has to be knowledgeable about the patient’s particular medical situation, how the patient and family are coping, community resources and the worker’s own countertransference issues (Black, 1989; Blum & Fisher, 1983; Christ, 1989; Vachon, 1987; Lederberg, 1998; Walsh- Burke & Crusan, 1998).

Many oncology social workers negotiate the stresses of the work and experience satisfaction and rewards in working with a cancer population (Klagsbrun, 1983; Lederberg, 1998; Peteet et al, 1989; Reese & Sontag, 2001; Stearns, 2001). . A major reward cited in a multi-institutional study conducted at the Dana Farber Cancer Center is “helping patients” (Peteet et al, 1989). Staff often feel “privileged to share powerful, deeply private moments that are seldom shared with others” (Lederberg, 1989; Lederberg, 1998). Some staff in oncology are able to utilize their rich clinical experiences to enrich their personal lives (Lederberg, 1989; Lederberg, 1998; Stearns, 2001; Blum et al, 2001). To conclude, oncology social work is a double edged sword for the practitioner - those dimensions of the work which are stressful may also have the potential to make practitioners feel “special, valuable and worthwhile” (Lederberg, 1989).

The Work Environment and Innovation

“The problem of bureaucracy as it interferes with creativity has been given a good deal of attention in both industry and scientific organizations. There have been many creative innovations to break through the inherent limitations of conventional, hierarchical structure, to open up new channels of communication and to release as well as reward creativity. It seems to me that in social work we need to think more deeply about this problem in order to maximize the real contribution that a professionally qualified practitioner can make" (Rapoport, 1968, p.158).

Most people spend large segments of their lives, if not their entire lives, in organizations (Kanter & Stein, 1979; Many social workers work in formal, organizational settings. This is particularly true for oncology social workers who frequently work in hospitals and healthcare institutions. Social work is considered an "organizational profession" (Finch, 1980). Social workers' dual allegiance to their profession as well as their workplace often creates dilemmas for the practitioner (Finch, 1980; Hopkins, 2002; Auchincloss, 2003; Smith et al, 1998).

Blau and Scott (1962) identified the three "dilemmas of formal organizations" which include: "coordination and communication; bureaucratic discipline and professional expertness; and managerial planning and initiatives." Thus, the constant conflict between "order and freedom" (Blau & Scott, 1962). A major dialectical conflict which confronts contemporary organizations is the need for creative management of the tension between the maintenance (routine) functions of the organization and the innovative and creative needs of the organization (Ibid).

The word organization has its origins in the Greek work, organon, which means a "tool or instrument (Morgan, 1989). The earliest known formal organizations are those that built the pyramids (Ibid). During the industrial revolution in Europe and North America, many people stopped working in their homes and became workers in machine oriented, mechanized organizations, known as bureaucratic organizations (Morgan, 1989; Perrow, 1986; Pugh,1985; Drucker, 1974). With the publication of his book, Principles of Scientific Management in 1917, Frederick Taylor founded the “scientific management” movement with the goal of increasing efficiency and profits. This mechanistic bureaucratic approach to organizations results in a dehumanization of the workforce; worker passivity; rigid bureaucratic rules; an inability to adapt to changing environments; and a rigid hierarchical structure (Hage & Aiken, 1970; Morgan, 1989; Perrow, 1986; Pugh, 1985; Drucker,1974). Power and control are centralized in the organization. There is a formal chain of command with little or no worker participation in decision making (Ibid). These organizations are more resistant to change, less apt to innovate and geared to maintaining the status quo (Ibid). This mechanistic model views the creative employee as problematic, difficult, temperamental, not punctual and “paradoxical” (McMullen, 1976). These individuals are seen as non-conformist and not interested in the ordinary routines of the organization (Lyman, 1989; McMullen, 1976; Sinetar, 1985).

Another model of organization, known as the organic model, uses the metaphor of a “living organism” to describe the organization, in contrast to the “machine” metaphor of the mechanistic model (Morgan, 1989). This organization is decentralized, interested in the needs of its employees, less formal and less stratified (Hage & Aiken, 1970; Morgan, 1989). Unlike the mechanistic model which depends on a stable environment, the organic model is responsive to the changing needs of the environment (Ibid). This model views the organization as an “open system” which is able to scan its environment for change and adapt to the changing world (Morgan, 1989). This model encourages employee participation in decision making, adaptation and innovation (Hage & Aiken, 1970; Morgan,1989).

Hage and Aiken (1970) identify seven organizational variables which impact on organizational innovation: complexity; centralization; formalization; stratification; production; efficiency and job satisfaction. The rate of organizational innovation decreases as any one of the following increases: centralization; formalization; stratification; production and efficiency (Hage & Aiken, 1970). The rate of organizational innovation increases as any one of the following variables increases: complexity and job satisfaction (Ibid).

Although innovation can be the introduction of something novel, it also includes: invention, adaptation, modification, novel application, adoption of someone else's technique or tool (Drucker, 1985: Peters & Waterman, 1982; Thomas, 1988; Thomas, 1984), creative imitation (Gummer,1986); and repackaging of existing concepts (Keys, 1989). Thus, in this context, innovation has a broad and inclusive definition rather than a narrow, exclusive one.

Some people contend that innovation "springs from a flash of genius" (Drucker, 1985). In reality, most successful innovations require hard work and a "purposeful search for opportunities" (Drucker, 1985). Drucker (1985) identifies four areas of opportunity which exist within an organization or industry: unexpected occurrences; incongruities; process needs; and industry and market changes. He also describes three additional sources of opportunity existing outside of a corporation: demographic changes; changes in perception; and new knowledge. Thomas (1984) delineates nine sources of information for innovation: basic research; applied research; scientific technology; allied technology; legal policy; indigenous innovation; practice; personal experience; and professional experience.

There are four stages in successful innovation: idea generation; preliminary analysis; decision to adopt; and implementation (Delbecq & Mills, 1985). High innovation organizations characteristically provide adequate support and sponsorship to encourage innovation (Delbecq & Mills, 1985; Peters & Waterman, 1982). High innovation organizations set aside special funds for new projects; help make proposals feasible; start small; and provide clear organizational commitment to the implementation of innovation (Delbecq & Mills,1985; Peters & Waterman, 1982). Low innovation organizations provide ambivalent support to new ideas and projects (Delbecq & Mills, 1985). Peters & Waterman (1982) note that a considerable tolerance for failure is an important attribute of innovative corporate environments.

Key factors needed to enhance innovation in corporations are time, money, resources, leadership and support (Peters & Waterman, 1982). Important organizational dimensions include: the culture of the organization - the work environment; the incentive system - both tangible and intangible rewards; leadership from the top; and the role of the supervisor (Kanter, 1984; Peters & Waterman, 1982; Drucker, 1986). The more innovative organizations are described as having "open communication" patterns; an environment of collaboration; easy access to top executives; a "culture of pride" in employees; and locally accessible extra resources (Kanter, 1984). Kanter (1984) depicts "power tools" as tools that enable employees to turn ideas into successful innovation. These tools include: information, support and resources.

Four significant roles have been depicted which promote innovation in organizations: ideator, champion, benefactor and orchestrator (Pointer, 1985). The ideator is the person with the new idea; the champion is the person willing to assume professional risk to promote a new idea; the benefactor is the person in a position to grant legitimacy, priority and funding to a new project; and the orchestrator is the person who assumes primary responsibility for managing the innovation phase of the project (Ibid).

The middle manager occupies a strategic position within the organization to support and encourage innovation (Mars, 1971). The middle manager can help and support employees in the generation and production of creative ideas; and provide an open sympathetic transmission of such ideas to top management (Mars, 1971). Livingston (1988) proposes that a manager's expectations are the key to a subordinate's performance and development. Superior managers have high expectations for themselves as well as their subordinates (Ibid). However, expectations must be realistic and achievable before subordinates will attempt to meet them (Ibid).The supervisor is able to cushion the negative effects of bureaucracy on staff (Munson, 2002) and to counteract some of the stresses that "erode human talent" (Zischka & Fox, 1983). "The modern supervisor has a responsibility, a heritage, a philosophy, a set of values and knowledge to pass along to the next generation of practitioners, represented by their supervisees" (Munson, 2002).

Corporate culture includes the norms, values and unwritten rules of conduct of an organization; as well as the management style, priorities, beliefs and interpersonal communication patterns that exist in the organization (Senn, 1986). The culture of the organization emanates from the “shadow” of the leader and leadership team (Senn, 1986). Innovation is more likely to occur in organizations where innovation is a clearly stated corporate value and there is a tolerance for failure (Peters & Waterman, 1982; Pointer, 1985). Peters & Waterman (1982) stress the importance of support which includes a protective buffer and a value system which stresses: “Thou shalt not kill a new product idea.”

Summary

Innovation is frequently observed in oncology social work practice and is much needed to develop services to effectively meet the multiple and evolving needs of cancer patients and their families. Oncology social workers confront complex problems on a day-to-day basis which require tremendous energy, persistence and innovation to resolve. The literature review delineated important contextual factors which could potentially influence innovation. These include: the cancer patient population; the crisis nature of the work; reflective practice; stress and coping; and the work environment and innovation. The interaction and confluence of these phenomena may influence innovation in oncology social work. Based on the literature review and the need to better understand the phenomena of innovation in oncology social work practice, an exploratory study was undertaken to discover the factors which influence innovation in this practice field.

Chapter III

Research Design and Methodology: Exploring the World of Quiet Heroes in Oncology Social Work and Their Innovations

The objective of this qualitative study is to fully describe the factors which might influence innovation in oncology social work practice and the nature of those innovations. For the purpose of this study, innovation is described as the trying of something new or different in one's oncology social work practice. Since there is no published research to date on this topic in oncology social work, the study is exploratory.

The study will attempt to describe "potentially relevant variables" (Epstein, 1981) that influence innovation in oncology social work practice. To accomplish this goal, the investigator conducted an exploratory study, designed to obtain the observations and perceptions of oncology social workers regarding this phenomenon. In the tradition of qualitative research, the subject's own language and perceptions were obtained and rendered (Ammon-Gaberson, 1988; Babbie, 1986; Duffy, 1987; Epstein, 1988; Glaser & Strauss, 1967; Jorgensen, 1989; Miles & Huberman, 1994; Patton, 1990; Porter, 1989) Open ended, semi-structured, focused individual interviews were used to give the participants the latitude to respond, using their own words, concepts, theories and metaphors. As such, the intent of this study is to obtain data from the participants' - the insiders' - subjective perspective (Duffy, 1987; Epstein, 1988; Porter, 1989).

Pilot Study Summary

The literature review identified several contextual factors which may influence innovation in oncology social work. The significance of some of these factors was illustrated in a pilot study the investigator conducted in 1989. The pilot study was conducted at Cancer Help, a non profit organization in an urban center. (Pseudonym for the institution will be used to protect the confidentiality of the institution and those who participated in this study.) The purpose of the study was to identify the conditions which enhance practitioner innovation. The data for the study was collected in open-ended, semi- structured, focused interviews which were tape recorded and later coded into categories. Data coding was challenging and required multiple occasion and repeated listening to the taped interviews, with extensive note taking to "discover and name categories" which emerged from the data, "moving between inductive and deductive thinking" in "proposing and checking" the categories (Strauss & Corbin, 1990).

In the pilot study, eighteen out of thirty two MSW oncology social workers volunteered to participate in this study. The findings cite the feelings of difficulty associated with innovation and the need for a supportive work environment which fosters innovation. Study participants reported that the following factors inhibit innovation: a non-supportive, bureaucratic structure; fear of failure; volume of work and burnout. Conditions reported to promote innovation include: client need; boredom; culture of the organization; the profound nature of the work, increased educational opportunities, training and staff development. All respondents in this study recommended that oncology social work departments develop internal structures which support innovation. An important study finding suggested that the high level of client need and the profoundly stressful nature of the work are catalysts for practitioner innovation.

This pilot study represented an initial effort to identify factors that enhance practitioner innovation. Further research is needed to expand the scope of the study to other settings. A major limitation of the pilot study was its sample, which was drawn from only one site. Further research is also needed to tease out more of the internal organizational factors which were reported to foster innovation, as well as more data about client need and the profoundly stressful nature of the work, and how and with whom it fosters innovative practice. Both the literature review and the pilot study inform the design and methodology of the current study.

Sample and Study Sites

The current study was undertaken to broaden the scope of the pilot study by utilizing a "multiple-case study" approach. (Yin,1984). Yin suggests that "the evidence from multiple cases is often considered more compelling, and the overall study is therefore regarded as being more robust" (Yin, 1984, p. 48).

The sample for this study is drawn from oncology social work departments at four sites: Cancer Help; Caring Cancer Center; Country Cancer Center and Research Cancer Center (Pseudonyms for the institutions will be used to protect the confidentiality of the institution and those participating in this study.) These institutional sites were chosen because of:1) their national reputation for innovative, state-of-the-art oncology social work practice, good programs and services; and 2) the investigator's access to these settings due to professional contacts through the Association of Oncology Social Work.

The literature on organizations and innovation suggests that structural differences can impact on employee innovation. Potentially relevant structural variations include: access to top management; centralization of power; openness of communication; and adherence to bureaucratic rules (Argyris, 1965; Backer, 1988; Delbecq & Mills, 1985; Drucker, 1999; Drucker, 1985; Drucker, 1990; Drucker, 1954; Hitt, 1975; Kanter, 1983; Kanter & Stein, 1979; Livingston, 1988; Mars, 1971; Morgan, 1989; Mulroy & Shay, 1997; Pawlak, 1976; Peters & Waterman, 1982; Senn, 1986; Shin & McClomb, 1998; Sinetar,1985; Weimer, 1993; Zanz, 1998).

The social work departments in each site proved consistent in these areas, without variation. These sites share a commitment to high quality delivery of social services to cancer patients and their families. All four sites are nationally and internationally recognized for excellence in oncology social work. Three of the sites are comprehensive cancer centers with a major commitment to medical education and oncology clinical trial research. All of the social work departments in each of the four sites share a commitment to advancing the state-of-the-art of oncology social work via presentations at national/ international meetings, as well as adding to the body of published literature on current practices/ research in oncology social work. The oncology social workers in each of these institutions are professionally trained social workers, with at least a master's degree in social work, with special expertise in the delivery of services to cancer patients and their families.

This study was open to all levels of oncology social work staff, from line practitioner to supervisory and administrative staff. The sampling method utilized was non probability, purposive sampling techniques. The sample bias in favor of more innovative practitioners is reflective of the investigator's attempt to discover what factors influenced them to innovate. By studying the perceptions and experience of these innovative oncology social workers, it may then be possible to identify those contextual factors which influence innovation.

Description of the Study Sites

This section includes a brief description of each of the study sites. During the course of the research study descriptive information was gathered on all the sites from a variety of sources. Primary sources of information about each site include: documentation; interviews; direct observation; and participant observation (Yin, 1984, pp. 78-89).

Cancer Help

Cancer Help is a national, non-profit organization founded fifty years ago. . The mission of Cancer Help is to help cancer patients, their families and friends cope with the impact of cancer. At the time of the study, the social service department was comprised of thirty two MSW oncology social workers. The organization has very dynamic leadership with a commitment to hands on, high quality, effective and timely service delivery. The department, as well as the agency, has a relatively flat organizational structure with a lot of interaction between hierarchical layers, an open communication system,. and easy access to top executives. In addition to their clinical work, all staff are involved in the provision of educational workshops to community groups, workplaces and/or professionals. The department conducts research studies in psychosocial oncology. At least one third of the staff present professional papers at national conferences. The central office is located in an urban center. The office space is well maintained and attractive. This fifty plus old organization has a culture of assuring that the space in which clients are seen is appealing to counteract any stigma associated with cancer.

Caring Cancer Center

Caring Cancer Center, located in an urban area, is a comprehensive cancer center and is the primary oncology teaching affiliate of Major Medical School. Caring (as it is affectionately called) is a small cancer center with a strong commitment to patient service and medical research. It is most noted for its early pioneering medical research to cure cancer. From the moment one enters Caring, staff are warmly available to give directions and assist patients, families and visitors to find their way in this caring hospital. The director of the social service department is very active in AOSW (Association of Oncology Social Workers) and is committed to service delivery and proud of her staff and their accomplishments. There are ten MSW oncology social workers in the department. The resources of the department are primarily devoted to the direct provision of clinical and advocacy services to cancer patients . This department has an open and informal communication system, with easy access to top management. Social work services are an integral part of Caring. Caring is part of Major Medical School/ Hospital complex and as such has a huge network of medical resources and expertise available. Caring is one of the oldest cancer hospitals in the country.

Country Cancer Center

Country Cancer Center is one of the newer comprehensive cancer centers built on a large tract of land in the suburbs of an urban center. Legend has it that deer roam the property. It is a beautiful center with patient waiting rooms and in-patient rooms having scenic views of the land on which the hospital was built. Patients waiting to be seen for their clinic appointments look out over the lovely landscape of the hospital grounds. There are fifteen MSW oncology social workers in the social work department. The department has developed a strong local and national reputation due to its dynamic leadership and director, who has mentored many social workers in the oncology social work field nationally. The department is actively engaged in professional education and training. There is considerable collegial interchange among the oncology social workers in this small department. The director and supervisory staff are accessible to line staff, with an open communication system in the department.

Research Cancer Center

At the time of the study, Research Cancer Center was a small comprehensive cancer center with an eighty four bed in-hospital unit and affiliated with Prestigious School of

Medicine. The Cancer Center is located in an inner city community in an economically challenged urban area. The oncology social work department at Research Cancer Center was a relatively new department at the time of the study. The chief oncologist insisted on having his own oncology social work department separate and apart from the medical social work department. The chief oncologist wanted his social work department to report directly to him and to be accountable to him for the provision of excellent psychoscial support to oncology patients and their families. The director of the oncology social work department and his ten MSW staff function autonomously from the medical social work department, with their own budget and funding sources. The director of the oncology social work department is a researcher with a strong commitment to psychosocial research. The department is characterized by fairly open lines of communication, easy access to the director and a sense of pride in what the department stands for.

Study Instruments

During the initial phase of the study, the investigator contacted each director of oncology social work for the four selected sites. A letter of introduction, describing the study, was mailed to each director and followed up by a telephone call, within one week of posting the letter (See letter, Appendix A). After discussion with each director and with their stated permission, a memo was sent to each of the oncology social workers in the department. The memo was sent by the investigator and described the study and its purpose. The memo stated clearly that participation in the study was voluntary and that all responses would be confidential (i.e. will not be shared outside the interview) and that the data would be handled anonymously (See memo, Appendix B). Staff wishing to participate in the study were asked to contact the investigator directly. The study was developed in accordance with research guidelines to protect the rights of the institution and staff by: 1) making participation in the study voluntary; and 2) assuring the participants of and maintaining confidentiality and anonymity in data analysis and use of the data. Both the oncology social workers and the institutions would be protected re: confidentiality and anonymity in data reporting.

The interviews were designed to last no longer than twenty to thirty minutes due to the time constraints which oncology social workers confront in their daily efforts to provide oncology supportive services to cancer patients and their families. Considerations to the length of time of the interview were intended to: 1) cause the least amount of disruption to the staff's day-to-day provision of care to a population in crisis; and 2) maximize staff's willingness to participate in this study.

The primary source for data collection for this study was open-ended, semi-structured, focused interviews with the staff at the four sites, who volunteered to participate in the study. The interviews were tape recorded with the consent of the participants. An open - ended interview format was selected rather than hand written questionnaires because interviews provide an opportunity to collect rich qualitative data (Miles & Huberman,. 1994 &1984). In order to best capture the subject's first hand experiences, the investigator interviewed each study participant on site in their natural real life work surroundings (Duffy, 1987; Porter, 1989; Taylor, 1977). Since this study is exploratory, the investigator wished to obtain and present the respondent's own verbal, descriptive responses to the study questions. Open-ended questions allowed the participants the flexibility and freedom to structure the response.

The investigator conducted all of the interviews and utilized a semi-structured interview schedule (See Interview Schedule, Appendix C). At the beginning of each interview, the investigator explained the purpose of the study. Confidentiality and anonymity of data analysis and use was stressed. Permission to tape the interview was requested. Participants in this study were told that the tapes will assist the investigator in aggregating the data, discerning trends and patterns and in coding the responses. Respondents were told that the tapes will be destroyed after the investigator completes doctoral work on this study.

There were seven closed -ended demographic questions regarding age, gender, race, marital status, years of MSW experience, years in oncology practice and years at the study site which describe the study sample. There were eight semi-structured, open ended questions which provide the descriptive data of the study (See Interview Schedule, Appendix C). These questions served to focus the interviews and the investigator utilized probes to encourage the respondents to expand upon their responses. These questions were designed to elicit responses from the respondents which would provide data on their perceptions of those factors that influence innovation in oncology social work practice. A total of fifty seven oncology social workers were interviewed from the four sites of the study.

Methodology

With the permission of each of the study participants, all the interviews were tape recorded. The investigator also took brief notes during each interview. Each interview was fully transcribed from the beginning of the interview to the end of the interview, including doorknob remarks. The investigator transcribed twenty nine interviews and hired an experienced transcriber to transcribe the remaining twenty eight interviews. The investigator reviewed on numerous occasions all of the transcriptions, as well as the live taped interviews. "Recurring patterns, themes or 'Gestalts'" (Miles & Huberman, 1994) were noted from the transcriptions. These "recurring themes" (Ibid.) were noted from the raw data and identified by the investigator. Repeated review of all the transcribed interviews led to the investigator's construction of a coding system of major categorical responses to the study's open-ended questions.

Since the investigator constructed the coding system and coded the responses, intra-coder reliability was tested by the investigator coding the same interview on multiple occasions. Coding the raw data "represents the operations by which data are broken down, conceptualized and put back together in new ways (Strauss & Corbin, 1990, p.57). Data analysis techniques proposed by Strauss & Corbin (1990), Miles & Huberman (1994), Glaser & Strauss, (1967) and Patton (1990) were followed. Since qualitative data analysis is " a continuous, iterative enterprise (Miles & Huberman, 1994), the investigator took part in a lengthy review and categorization of the data with every effort during the data analysis to not jump too quickly to categories to oversimplify the rigors of qualitative data analysis (Miles & Huberman, 1994; Patton, 1990; Glaser & Strauss).

In this study, data analysis was based on a "grounded theory" approach in which "theory is derived from data and then illustrated by characteristic examples of data" (Glaser & Strauss,1967, p. 5). The data for this study are the participants' responses in their own words. The central task of data analysis was to look for "similar instances over and over again," until the researcher was "empirically confident that a category was saturated" (Glaser & Strauss, 1967, p. 61).

The methodology developed by Miles & Huberman (1994) for data reduction, data display and conclusion drawing/verification was used. Data reduction was seen as an ongoing process and part of the data analysis process (Glaser & Strauss, 1967; Miles & Huberman, 1994 & 1984; Strauss & Corbin,1990; Patton, 1990). The qualitative data of this study was reduced and transformed in many ways, including: summary, paraphrase, metaphor, and "subsumed in a larger pattern" (Miles & Huberman, 1994; Patton, 1990) to elucidate the factors that stimulate innovation in oncology social work.

Careful and systematic analysis of the data led to the emergence of themes, patterns and categories from the raw data (Glaser & Strauss, 1967; Miles & Huberman, 1994 and 1984). The investigator followed Glaser & Strauss's recommendation of using the constant comparative method, an inductive method and "delimiting process," which allowed the researcher to "discover underlying uniformities in the original set of categories and to formulate the theory with a smaller set of higher level concepts" (p. 114).

Data analysis involved “reducing the bulk of the data” to find patterns in them (Miles & Huberman, 1984, p. 224). Activities such as subsuming particulars into the general, factoring, clustering, making metaphors and moving up the abstraction ladder were all devices employed to find patterns and meaning in the raw data (Miles & Huberman, 1984, pp. 223-224). Tools utilized for evaluating the data of these interviews included: tabulating coded segments, classifying, categorizing, ranking, seeing a Gestalt, counting frequencies, clustering, metaphor making and generating key words (Miles & Huberman, 1984; Patton, 1990). Charts and tables were used for basic data display.

To sum up, analysis of the data for this study was a rigorous, challenging and creative process. Analysis involved diligent and systematic coding of the data and the use of exemplar citations from the taped interviews for illustration. This analysis led to the discovery of the factors which influence innovation in oncology social work practice and their suggested relationship to the phenomenon studied and to each other.

Researcher Reflections

The researcher in this study of the phenomenon of innovation in oncology social work practice engaged in heuristic inquiry as well as phenomenological inquiry, since the researcher brought a body of oncology social work practice into the formulation of the study focus, as well as the questions asked and the data analysis. Consequently, the data analysis using all the rigors of qualitative analysis, “challenged traditional scientific concerns about researcher objectivity and detachment” (Patton, 1990). The process of data analysis and the development of a framework to better understand innovation in oncology social work has been a long and, and at times, elusive journey of discovery. For the author, a practicing oncology social worker and administrator, the lived experiences of the participants in this study, have resonated deeply, sometimes with pain and sometimes with insight and joy, as the researcher was both an investigator in this study, but brought to the study the professional experience of being an 'insider' in the very world being researched. (Jorgensen,1989).

The focus of this dissertation has enriched the author's practice in the complex field of oncology social work. The participants' willingness to share the intimate nature of this work, its impact on their lives and their innovative and compassionate practice is a credit to each of the study participants.

Chapter IV

Quiet Heroes: Metaphors of Innovative Practice

Participant Stories

This chapter will introduce you to six participants who shared their experiences about innovative practice in oncology social work. Their stories are presented in the first person, using the participants' own words. Each section is preceded by a direct quote which is representative of the participant. Each division is given a metaphorical name based on the quiet hero discussed and the words used by the participant in describing their work.. You will hear their experience of being an oncology social worker, their commitment, their energy, their challenges, their fears, what prompted their innovation and how their work impacts their lives. If they had not been oncology social workers, they would never have had these varied and unique life experiences. Hopefully, you will understand what motivated them to innovate in their practice and how their work and these innovations affected their lives. As you move from one story to the next, you may begin to see patterns and similarities in their experiences. These patterns are the basis of the categories and themes presented in Chapter V.

The Metaphor Maker

I think oncology social work in itself is innovative.

I work primarily with cancer patients and their families at the Cancer Center. That involves a lot of different things - psychosocial assessments, usually more supportive therapy, networking and creating different practical supports. Generally I do more supportive work - emotional support and a lot of liaison with staff and advocacy. We are a comprehensive cancer center, so some roles that social workers would have in other acute care hospitals, we have the privilege of referring off to financial specialists or patient care coordinators, like transportation or other concrete needs. So, we are uniquely free to do a lot of creative work and a lot of counseling, mostly supportive counseling.

I see patients in both the clinic and inpatient setting and that really dictates how much I really see of them - because if it's someone coming in once a week in the clinic versus someone who is an inpatient in the hospital whom I see daily. I like to do a lot of different, diverse things to kind of balance my work. I come from a background in creative arts. I have all these different ideas that I'm playing around with - you know I still teach dance. There is a whole range of issues when they come for the initial consult. Usually I develop fairly good relationships with patients. If the need is there and it is beneficial to the patient, I'll continue with them even when they finish treatment. There are quite a few people I continue to see long term - that makes me feel better about my practice rather than it being so fragmented.

As a beginner here, I'm kind of exploring the whole field. I don't know if I do anything new or different than anyone else does. I think I try to focus on the individuality of the patients and try to bring as much creative applications as I can, such as making individualized behavioral cognitive tapes for patients - things of that nature to really tailor something individual. I try to find different ways to meet different needs and diversify my experience here to get more involved and to give me a little more sense of balance in my work.

I think oncology social work is so different anyway. It is not like the schooling I got - doing the therapeutic hour setting which is my training. I think oncology social work in itself is innovative - has to be - because it is so different. The boundaries are all different. The practical boundaries in terms of talking with a patient when she is throwing up or people, walking in and out, while you are talking with a patient or family member. And the emotional boundaries with how close you get to people and monitoring those boundaries. All this feels like the basis from which I would be doing something different.

Last year, I did a fellowship in oncology social work. One of the things that I started doing there, which I really love, is working more in metaphors with people - being much more aware of the symbolic ways in which people are able to talk about what is going on. My being willing to join with them in that - not always having to pull it back into reality, but knowing that that's where sometimes people are able to talk. So, that has become a new approach for me, which has really helped in my work here.

I am thinking about a case that I did a lot of work with last year. Charlotte, who was getting a bone marrow transplant. People are so scared to come here and have lots of misconceptions about what it's like to have a bone marrow transplant. I find that people are far too anxious, I give them information. I tell them what life on the floor is like. I show them that it is not nearly as isolating as people think it's going to be. I don't do a big assessment. I may find out a little bit about them before they come. I usually see them just a few days prior to admission, and then it's nice because there's continuity and I follow them as inpatients, so they know me. People require varying degrees of intervention. Some people have a wonderful support system the entire time and I find they need me less. A lot of women are here alone, because their husbands and families can only come on the weekends and those women I find I spend a lot more time with.

I remember Charlotte. She was so fearful of the transplant. She had decided to go ahead with it, but with lots of trepidation. It turned out the she loved gardening and was an avid gardener. She would talk a lot about having plants and putting seeds into the ground and watching them grow. She would describe what you have to do to take care of them and a lot of that talking was around the time she was getting her bone marrow transplant. My being willing to work within that with her, using metaphors and helping her make those connections was powerful for both of us. I saw her throughout the seasons. It was good to have an experience like that - it was really useful for Charlotte. I know it helped her get through her transplant and it was worth the risk. And I think that part of that knowing wasn't something that my training in graduate school had prepared me for. It helped me to have had the fellowship training in working in metaphors.

The seminar that I took during my fellowship coupled with the oncology social workers here enabled me to take this risk in working in metaphors with Charlotte. We have a very open and pretty safe feeling forum for us to talk about things we are trying . We talk about things we are trying so I was able to hear other people who had tried some of this. It was talking about the work we do and the real work we do - not the work that we don't like to say to others - that we sit on beds to talk to people and some of the reality of the work versus what is OK or not OK, so it felt like a real forum. And there was one social worker, who works a lot in metaphors when it seems appropriate, and she was really an inspiration to me. Because so many oncology social workers were excited about this approach, it felt like there was a safety net, you could try it and if you fell on your face and that was OK - that trying it was important enough.

But deep down, I felt like I was going out on a limb. I had this idea that there is a way you should do oncology social work and a way that you shouldn't. The way I had been trained was not really oncology social work anyway, so knowing that it was very different from what I had been taught was right. I think that made me feel a little reticent about talking about that with other people who are in that realm. I think what really helped me was the supportive group I was with and trying it and having it fly.

I had heard others in the group talk about using metaphors and had had the training. So I had learned how it had worked with other people and then it seemed to fit with Charlotte. She presented this situation to me and then trying it and seeing how that was the language she wanted to use. So, each step reinforced itself. What really made me try this was hearing other people doing it and then having Charlotte being a pretty symbolic speaking woman anyway. Working with Charlotte in metaphors, asking her how it was for her getting through those days - shifting from that to letting her talk about her garden and how much she loved it and being willing to not constantly bring her back to days on the transplant unit.

I think actually a lot about the fact that I'm new here so that almost everything I'm doing feels like I'm trying a new thing. For me, I feel like I'm creating my base now from which I hope I can feel like I can stand on to go and try new things. But all of it feels pretty new, work everyday feels kind of innovative. I think I never know what the day's gonna bring. I have to kind of remind myself that it's all pretty new still to me, it's helpful to think about that actually. So, I say to myself, wait a minute, walking in the door counts.

What is stressful and good is that the oncology social work role is so versatile, but unclear whose expectations - we're answering so many different expectations - so I think that makes it very challenging. And I think one of the hard things is living in the ambiguity and uncertainty of how people are going to do. I actually found it less stressful to do Hospice work because it was pretty clear that most people we dealt with were already terminal - so the uncertainty was so parallel with everybody else going through it, patients and families - but I think that is one of the real challenges.

I think taking care of ourselves - it has to happen - we have to do it ourselves or get encouragement to do it as well. We have to keep in touch with what our own loss is and how to take care of that part of us without it always being woven into the work. I think it is the sheer numbers of people going from a new case to a case where someone just found out they relapsed to trying to garner up energy to start anew. Oncology social workers work very close to the edge. Very close to life and death, very close to life - the threat to life. And we share that very intimately with patients, families and staff members. And that's very draining. And it's very touching to be included in very intimate, very significant times in people's lives. And it's very stressful perhaps not to be able to do something, but only to share it. But to have to sit with it. There are a lot of things that we hear about that we cannot change, but just tolerate, accept and know that by our hearing about it, that in and of itself may have been beneficial. But there is a lot that we have to kind of hear and know about that's difficult. You know we rarely see the airplanes that land safely, we usually see the ones that crash. It's hard.

The Reactive Innovator

My own self image is not of myself as an innovator. All of my innovations have come about by situations calling for it. So, it was more rising to the occasion that presented itself. I think it's always a reactive phenomenon on my part.

For the past five years, I've been an oncology social worker. I work in a place called Cancer Rehab, the outpatient component of a large cancer center. The focus of the work is crisis intervention, concrete services and counseling for patients and their families. When I talk to people, I try to help their passage from one point to another, in terms of their acceptance of their disease and just how they deal with it. And I hope that I can become a part of that process in a way that is useful for patients. I try to help them identify their coping abilities and reinforce the things that are positive for them in terms of their ability to cope. For example, if a patient who is receiving radiation treatment became panicky about getting on the table, I would intervene at that time. So, I intervene using counseling in the medical setting with patients in crisis. I work with individuals, families and groups. Because cancer strikes every level of existence, I end up helping with a variety of pragmatic things as well, like where people can learn to put on make-up, where they can get wigs and prostheses, transportation to appointments, financial assistance and home care.

Something I really like about my work is that there is a lot of flexibility in how I do work with my clientele. I get to call the shots in terms of what I assess will be helpful to someone: whether they should be seen once, twice or in an ongoing way, and whether they should be seen alone or as a family. I get to make determinations about what would be most helpful for people.

When I first heard what the subject of your interviews would be, I got sort of nervous because I haven't innovated. I haven't done any programs that are innovative. And I thought I have nothing to say. But when I think about the crisis of cancer, you have to be flexible. Because I can see someone one day who's very well, healthy and comes in to see me, and the next week they've become bed-bound, and then what do you do? So right there you have to be creative. Do you work on the phone? Do you make a home visit? Is it more helpful for you to see the family? So you're doing a lot of creative stuff.

I think probably one of the most creative things that I did was to go to a patient's, Amanda's, home. Unfortunately, I cannot do this too frequently, but this is a patient I had worked with for a pretty long time. And she wouldn't, certainly could not have engaged with anybody new. She was dying, actively dying. A young woman, thirty nine, my own age, which made it hard. Dying at home with her sisters. She had a big family of sisters, all nurses, helping her, creating a hospice for her. And I went to the home and I helped her plan her funeral, literally plan what would happen at her funeral. We talked about it together. And she told me what songs she wanted played, her favorite songs. She sang the songs in bed. She took off her oxygen mask to sing the songs, to be sure that we knew what she really meant. And I think that kind of thing you don't think of as creative. But you know, she couldn't make it to us, so I came to her. And that is something that you do with a lot of medically ill people. You end up meeting them halfway, literally and figuratively. This is a good example of other cases like this one where I really met the person in their own surroundings. Start where the client is, the most elementary social work dictum. With cancer patients, it has very real meaning. Because if people are too ill to be here, throwing up, too weak, you really have to meet them halfway.

My own self image is not of myself as an innovator. All of my innovations have always come about by situations calling for it. What was I going to do? I promised Amanda that I would be there for her. How was I going to fulfill that promise? That was an implicit promise to a dying person and I had to fulfill it, come hell or high water. So I had to think of a way to be sure that I was with her to the end and I also promised to make sure her wishes would be fulfilled. So, it was more rising to the occasion that presented itself rather than sitting back in my chair, which I never have the luxury to do, and nobody does, and thinking of ways to innovate. I think it's always a reactive phenomenon. Given the size of our caseloads as oncology social workers, and the emergent condition that a lot of patients are in, I think it is reactive instead of proactive. It's good to be resourceful. It would be nice if we had more luxury to sit back and innovate in a programmatic way, but it ends up always being whatever is needed at the time.

At the time that I made the home visit to Amanda, my caseload was such that home visits really were not possible. They weren't built into the system. My supervisor supported my being out of the hospital for virtually half a day because she knew this case. She knew that this woman was not going to be hooked up to a hospice, because she was being cared for by her sisters. Although we do transfer people to hospices, where they get psychosocial supports, Amanda wasn't getting that component because she was getting the hospice care from her family of nurses. So, my supervisor was flexible enough to see that this was a case where it really made sense for me to make a home visit. It wasn't just my overidentification with the patient, although that might have been there. But she really understood that this was a case where no one else could fulfill that role, and then it made sense for me to step in. So, I have a very supportive supervisor in permitting me to be away. But there was this administrative obstacle in that I wasn't supposed to be making home visits at this point in my work. I just had too big a caseload and too many commitments. Fortunately, my supervisor made an exception.

My other worry during this time was whether the family really wanted to include me in this process at such an intimate and private time in their lives. This was an extended Irish Catholic family who had always supported themselves through everything, even the way they were handling the death, being their own hospice. And I really wondered if there was a role for me. And was I extending my boundaries too much? Even though I had been asked by the patient to be there, how would her sisters receive me? Since her mother had died recently of cancer after the whole family had rallied around her, how would her father regard my being there? It was a very religious family. They had called in a priest. How would they feel about me being there and not being Catholic? Would I seem intrusive with the priest? How would the family feel about this alien person being there. So, I think it was very much a risk to join that family group.

I had no choice but to go on that home visit. I had made a total commitment to this patient. Without question, I said to her: Whatever happens, I'm there. Once having said that to her, that was it. And that's not something I would say to every patient. You have to pick and choose carefully who you can say that to. But I really knew what the course of her illness - time frame - would be. And I felt like making that commitment to her.

Doing the work I did with Amanda was very hard for me. In general, I find that it is hard for me to try new things for a number of reasons. One is characterological. I love things to be tidy and neat. Trying something new is never tidy and neat. That's a small piece of it. I think we all lack confidence a little bit. And I like to stick with the tried and true because I've seen how I've helped people in the past. It is hard to go out on a limb. Not only because you don't want to be embarrassed, which is a big part of it, but also, you know what's been helpful to people in the past. You don't want to ask a question or make a suggestion that you think might be painful or hurtful to people. So, you tend to go with the tried and true. And for me, I really do, because I am insecure about my work, and I tend to rely on the tried and true.

Another component is that social workers usually have too many cases, even when they are in relatively luxurious settings compared to an emergency room in an inner city hospital. And I think that is the biggest stumbling block. Because how can you do fresh work, when creative things are usually time-consuming. You might have to get materials together. You might have to go out of your way physically. And when you have things just stacked up, sometimes all you can do is the bare minimum.

So, I think caseloads and the weight of caseloads is a big problem. I often feel I haven't even done an adequate bare minimum for patients and families. So, to go the extra mile is a real problem. Also, because of our administrative duties, it is hard for our host settings to permit us to do so. It is not that they are stodgy, but it's hard for my hospital to let me go for half a day. I had to respond to my beeper, I had to cover the emergency room and I couldn't be gone when that was my duty. I could not foist my responsibilities on someone else.

Listening to people who are struggling with cancer for themselves or their family creates a certain amount of pain in the listener. I consider oncology social work painful work, not stressful. I think stress is when you're torn in two different directions. Stress is when your heart and your gut say two different things. The definition of stress is when you have to smile and say "yes sir" instead of saying "shove it" to someone. It's always when you're torn. That's what stress is to me. Stress in the hospital was wanting to sit and talk with a family about what was happening for them with the cancer, but knowing that I had to put together a discharge plan and enter a chart note in fifteen minutes because the computer was going to be down. It tore me in terms of what my mission and goal was. And having so many cases that I could not possibly give the weight, the importance and the proper amount of time to counsel and support that a cancer diagnosis required. When I was working with inpatients, that was the worst in terms of stress. Because that tore me in the most directions. It gave me the most mixed messages about what my role was. That creates stress.

I think that another cause of stress cited in the literature and recent studies is high responsibility, low status. And for social workers, this is frequently the combination that characterizes their work, especially in a hospital setting. That is what is most familiar to me. I was really responsible for an enormous component of the patient's care. A safe discharge plan that would have them safely cared for, their medical condition adequately addressed, once they left the hospital, leaving earlier than they used to, needing more help than they used to. I was responsible for that plan. I was responsible for their entitlements, for whether they got Medicaid, Public Assistance or Disability. I played a great role in that. And yet my status in the eyes of the wider medical community and our society is very low. I am not considered like a doctor, an attorney or a researcher. I am considered a sort of workaday job. But yet I have grave responsibilities on my shoulders and an enormous amount of energy that I put into my work. And that's stress. That's the dsfinition of stress for me. It is that grave responsibility combined with having very little power. And not really having your name on anything. Your head is sort of on the table and your ass is on the line, but your name is not on anything and you don't get credit. That is stress. It is not stressful for me to be with people who are sad. It's rewarding to me to be with people who are sad. We're human beings and sadness is so much a part of the fabric of life. So, that is not stressful for me. I think working in an advertising agency would be more stressful than listening to people cry all day, because it is meaningful and it is real. I don't feel like my gut is in one place, my heart's in another and my brain's in another. And that's a wonderful feeling. Stress often comes from the setting you are in. I don't think that it is inherent in listening to cancer patients. Painful and stressful to me are really different. Touching and stressful are different.

I think that having the freedom to try new things makes the work less stressful. No question about that. Being in a setting that gives you that license and says "we want you to do that" is wonderful, because that is a supportive message. I think attempting something new in a conservative, hidebound system makes the job more stressful. I think trying to swim upstream in a situation that doesn't permit it, you add to your stress. But I think being in a place that says,"innovate and do things differently" is a wonderful, supportive message to get.

The Legacy Keeper

You know when you have an innovative intervention, you've got to have an innovative patient.

I provide clinical social work services to an outpatient and sometimes, inpatient, oncology population that is solely adult. I work at this large teaching and research cancer center, where I do provide some consultation to the hospital staff. My practice primarily focuses on providing counseling and advice related to emotional issues connected with cancer and the practical issues of helping people cope better with the illness. There is little or no discharge planning in this position, except periodic placements in the community to inpatient hospices.

Essentially, I help people do adjustment to illness - concentrating on new information, decision making, treatment changes, pain management, doctor/patient communication, depression, drug and alcohol abuse and then, all the other problems of the world that come along, including marital issues, children and a wide range of topics not specific to the disease or its treatment. Having been in the field now for almost ten years, I also supervise three positions, two clinical and one support staff, as well as handle some administrative responsibilities to assist the director.

Sometimes, I get into a niche - it's worked for me in the past, it's comfortable and I stay there. It's not that the patients are mundane or anything like that, it's just the day-to-day gets mundane. The reality of the day-to-day, when all you have is papers on your desk and phone calls to make and there's nothing more challenging than moving that stuff along. I'm in an energy lull, just going about my paces and God, suddenly this is driving me nuts. This usually happens when I'm working with a patient and have tried my old bag of tricks that feel comfortable for me, and it doesn't seem to work. And the patient keeps saying the same thing over and over and over again to me, and it's clear that I haven't heard them because my interventions haven't worked. It is then that I am willing to try something a teeny bit innovative and that's usually how I present it to patients. I've been working with you and we've been going in this direction - a little bit if that doesn't work, and then we'll come back. More or less reluctant, but willing to give it a shot.

The strangest thing that I've ever been labeled with is asking people to pull together a photo album - a kind of life review in pictures and ask them to write below each picture what story was going on. I started doing this because of several young moms who were anticipating dying and who were leaving small children behind. The issues for them were not so much that I'm dying, but the fact that I will never see - I will never see them graduating, never see their marriage and so on and I so want to be a part of that. So, we worked on ways to do that and made audio and video tapes, as well as wrote letters to be opened on the day of their wedding. We said we would give this to dad and ask him to store them away and not to open them until the right time. And a couple of moms had been risk taking enough to do that - you know when you have an innovative intervention, you've got to have an innovative patient who is willing not to think you're strange. I've had a couple of young ones who've said hum all right, I'll try anything once.

In the bereavement world, I've asked people who were struggling with - gee, I wish I had said or I wish I had fixed - I have asked them to write letters to the person or if the letter writing was tough, to put it on tape and really do a couple of things with that - one is that they had a choice to burn it, to bury it, bring it to the grave or give it to someone else to read. They could do whatever they chose or they could do absolutely nothing with it and toss it away. Some folks have done these things and were able to put away some issues.

But my favorite intervention is the photo album because it is fun when you get into doing it. I was hearing more and more from moms in their terminal phase with little children the repeating theme - the importance of passing on my wisdom - these kids are really small and there is no way for me to teach them the do's and don'ts in life. I want to be able to do this as a way to participate in that - to train and teach them. These moms wanted to be remembered. These little guys were very, very small and the biggest issue for the moms was they'll never remember me and it was a really crucial point that they be remembered.

The photo album is a real neat clinical piece because it gives me a chance to do a concrete life review so that you get to see in picture and story where the person had come from, what obstacles they've overcome, and it's a way to engage with somebody on a much deeper level.

I wish I could remember where I'd originally heard about this intervention - it must have been seminar level, but I also had direct support from my supervisor. At the time I tried this, I had just left the hospice experience - had been real frustrated in hearing recurrent themes with little practical interventions to use. I had moved on to a teaching hospital and was working under the department of psychiatry there. I had a real fortunate experience to have a very young, innovative psychiatrist who was great fun to work with. And he said, well so you heard this thing and you got these recurring themes and process that with me. And we processed this thing out and I said well I have this idea and he said, well, why haven't you tried it. And I said, well, it's different, it's weird; it's strange. Now, of course, what I do everyday is different, weird and strange, so certainly there was great permission to risk and he was able to say, what's the worst thing that could happen. Well, to be a social worker under the realm of psychiatry was an interesting position. It was wonderful because what he said was, take a risk, and if you fail, so we'll go on from there.

Certainly, this is kind of on the edge. You know, God, I'm working with Jessica, a young woman, a mom, with small children, and I want this mom to sit with a box of pictures and go through the stuff. Some folks, the nurses and house staff, said gee, that's kind of painful for her to go through this stuff and it will just make her more depressed. She'll see all the things that she'll never get to do again. Certainly, that could have been the outcome here and it was to a degree. During the life review, there was pain, but again, she was able to work through that. So, no matter what work you are doing with patients, even with a physically healthy person, there is pain attached to growth. So, the really big obstacle, was getting the nursing staff to recognize that it's OK that she is hurting, it's OK that she cries, it's OK that she is in pain - she's working through that and she needs to express it and get rid of it. I'd rather see her cry and get upset than sit there with a smile on her face. So, it was really hard for her, but she obviously had some really good growth.

And when I look back on this, what really made me try this was that I was frustrated and tired of hearing her say the same thing over and over and I didn't have anything else to give her - my empty kind of words and interventions for her when she was looking for something really tangible. She wanted to participate. This was a gal I had worked with for quite a long time. There was continuity throughout her disease and so we weren't new to each other. She had her surgeon who followed her and I jointly worked for his program. He was very supportive - what she was saying to both of us and he, of course, said there's gotta be something we can give her so she can do this. So, it was just this level of frustration - OK - why not, we'll see what happens. We had nothing to lose and only to gain and so.....Thank God.

But still it was very hard. There were hospital rules - hospital norms. I was asking a patient to do something - make this photo album - in the midst of an institution. And if it wasn't the rules and norms of the hospital, it may have been those of the staff. This was really over the edge. What is this crazy lady doing with Jessica. I needed to sit down with the primary care staff and say, this is what I am doing - this is my plan to help this patient. I met with the nursing staff and explained that Jessica might be upset when they go in to her room and she may have her bed covered with pictures. I don't know what else to do, I'm gonna give it a shot and see what happens. I'm making a contract with her, that I'll be back every day and we'll see how this rolls out.

You know, it wasn't all smooth in the beginning. It was tough and rocky and so the criticism came forth. God, you gotta stop this. She's got to put those pictures away. I kept trying to get the staff to sit back and not pull the plug yet - let her do a little more. Let her husband bring in more pictures. Let's see what happens. Well, she did come through, but a lot of pieces had to be in place to have any of these successes. Jessica had a good support system on her side as a patient and the staff had to be willing and trusting enough in me, with the backing of the psychiatrist and the surgeon. You know what happens if you present a strange intervention and it doesn't work the first time, then it's kind of the back door to make sure that that gets stopped - sabotage in some way. So, when that started to occur directly with my supervisor, he stepped forth and said, Yeah, I know all about it. I think it's a great intervention and let's give it a shot and see. And then they went to the surgeon and tried to get him to stop me and he said we don't have anything else for this poor lady, let's give it a try. So, I kind of got my ducks in the line. Docs rolled on the floor and they said do you know what's going on in there. Yeah, I do and isn't that great! So I had my ducks in a row. I had a really good relationship with these two fellas. If I didn't and they didn't trust me - that would have ended right there and that would have been the end of it. And I was just fortunate enough that things played out and she subsequently got discharged. I followed her through with it and she continued her work on her own and then came back to clinic with this wonderful photo album. It was really neat.

When I think about my work with Jessica, I am also reminded that we've got two thousand new patients in this clinic a year, not that I see all of them, but that gives you a sense of the pace of new people - consultations and figure how many of these I keep and they add to the patients that have already existed from year to year. The volume here is over one hundred a day, six days a week, so there's just me and multiply that by families and an inpatient component, administrative duties, supervision, meetings and committees - enough said. There is little time left over. So, I think that is one of the big obstacles to trying something new. Along the same line is that you have little time to sit down, read and do research and to even think of a concept you want to study. I wanted last year to start doing some decent research and I want to start moving in that direction. December, here we are and every year I stick it on my goals but those things get tucked away. Oh, when I have time, I'll do those - so for me, it's the time and the energy level. That's what inhibits me.

You know the old story when you meet someone for the first time and they say, what do you do for a living. My friend and I had a running joke, let's watch how fast we can clear out a room when someone asks us what we do. I worked with adult cancer patients and she worked in neonatal intensive care, including deformed and cocaine babies. What do you do for a living - adult cancer patients or dying babies. Well, I couldn't do child abuse, work with pediatric oncology or kids. I identified that early on. I had a few experiences, I was a mess. I took the cases home with me every night. So, I learned through enough agony what I wanted to stay away from.

My early days, I started out working in a hospice in the community, and people said, Oh, God, how can you do that. That must be awful. It really wasn't. I found it the most intimate, stimulating experience. And if things didn't change, I'd probably still be there. So, I guess it's all relative. I don't think you survive in oncology period, unless you've worked on some issues of being comfortable with other people's mortality and your own mortality. Usually there is something that makes you do this work. You don't just decide to do it because there is an ad in the newspaper - or those people who do, my sense is that they don't make it long term.

There's got to be a reason for you to be here and that for me makes it less stressful. There's a reason and I've become comfortable in it - it's almost a foreign concept that I could work at anything else. I look in the want ads. I don't know anything about protective services or about this or that. This is where I feel whole and when I do teaching to students or with a group or a lecture, I could go on and on about the benefits and how wonderful it is to work in this area. I want to get more people in oncology social work because there are so few of us. We are not a dime a dozen. We know that everytime we have an ad in the newspaper, it's so hard to recruit.

My work with Jessica, trying something new, stimulates me to jump back in again and try new angles. It has to do with rejuvenation and getting a new energy level. There's such a feeling when I see a patient say ahah!. It's an acceptance of what is going on. There's no more struggle. There's a kind of peace when you've done your job. When I think back to what a mess Jessica was before I started working with her - so anxious and sad. She was really a wonderful woman. She had some goals in life and that photo album became real important to her to complete for her children as her legacy to them. And she was able to accomplish that. There was this ahah. We worked real, real hard, with lots of complications. My only goal with her was to help her complete the photo album so she could say good-bye to her kids. And when she finished it, she sat back and just had an incredible look of being at peace. She would kind of huddle amongst other patients, just watch them and we could see her - whatever you want to label it - acceptance, I don't know, at peace where she was. That makes it all worth what I am doing and makes the job less stressful for me. When I can see that I've actually done something. There are so few tangible outcomes and when I get to see the slightest tangible outcome every so often, it kind of rejuvenates me that I am making a difference. When I can see an outcome from my work, it makes me want to get up in the morning. There is a spiritual feeling that I sometimes feel when I make a difference for one of my patients.

The Quiet Risk Taker

I kept it quiet for a long time. There was a voice in my head saying - you're not supposed to be doing this. I felt a risk to my status and position. I worried that I could get fired for this.

I offer supportive therapy to adult in-patients who are dealing with the diagnosis and treatment of cancer. It is more crisis oriented than the general population. I do some couples work. I clearly work with the family; more often than not, I'm working with one member of the family at a time, instead of all at once. I do more formal intake assessments with patients and their families throughout the whole period of time they are here at our cancer center. When I meet a family, I generally try to meet the whole family initially. Then after that, it's sort of catch as catch can.

I provide a safe holding ground, just to get them through. And it's frustrating because I know even once they get out of here, even if they get through this, which is a feat in and of itself, they still got lots of other issues to face. So advocating for them has been another important role. I also serve to offer up educational information about the cancer, its treatment and the concepts of clinical trials. I help with more concrete psychosocial support, although that is a tricky issue for us here. We have a resource specialist so the delivery of concrete services and entitlements is handled by the resource specialist. But it is funneled through us and depending upon what our countertransference reactions are to each patient and family, we get either more or less involved with these specifics, depending upon how badly I feel I want to do something concrete.

But I would say it's an incredibly flexible role that I see myself play. I've struggled with this. I'm clearly a social worker, but the boundaries are just pretty fuzzy. I find even more than I did in working with other populations. I think it borders on sometimes being more of what I think clients would think of as a friend to them, which sometimes feels OK and sometimes doesn't feel so OK.

Actually, a big part of what I do is work with other staff. Over the past year, I've become a strong advocate for patients. Our patient population, for whatever reason and there's a study in there somewhere, many of our patients have multi-problem families and most are in dire financial straits. We also have lots of patients, who are single parents. I've seen a lot of prejudice by staff to single Moms who are patients coming into appointments with their kids. I have really tried to advocate for them and educate staff about my role in helping these families.

I've been here two and a half years now. When I first came here, I was sort of instructed that we don't do long term bereavement work here. We just don't have the capacity for it, with people coming for treatment here from all over the country. Nevertheless, I do it and I don't do it with everybody, but there have been a handful of people that for lots of reasons, I have chosen to do that with. Now because of the reality of our population, I do bereavement work over the telephone. It's actually something I'm trying to do a little bit of research on. I've done some long term bereavement work over the phone which has been incredible on many accounts.

And one of them was Pam, I think it was the first bereavement case I picked up, in

August, when I started. And I think that within two to three weeks Pam, who was twenty four years old, recently married with a two year old, lost her husband to a brain tumor. I would say that even now to some extent I'm still doing some bereavement work with her. Because she lives so far away and she couldn't come here, we don't do home visits, so we did it all over the phone. She lives an hour and a half away. It was daily initially because there was some fear that she was suicidal, and then I'd say it was several times a day for awhile, then once a day, then a couple of times a week, then once a week and then gradually worked its way down to a point where I felt that she needed to break the tie from here, from me.

We negotiated all that over the phone. She did come in a few times in person.
It's interesting, in some ways, I think it was somewhat freeing maybe to be over the phone, but in some ways we listened to the words, the intonation, The words, the sounds were so important, but there was none of the facial, body language, no gestures that could be seen so it was challenging in that regard. I think there was a lot of institutional transference - that she could not say good-bye completely to her husband yet, and hanging on here was helpful - a lot of families do that to one extent or another.
I don't know how innovative my telephone bereavement work was. I think I did it out of <u>practical reasons</u>. Simply practical reasons, that's why it was initiated. This woman was too far away, actually, too far away to come in to see me in my office. But I think that even if she were within close proximity, that I still would have talked with her on the phone because it was too difficult for her to immediately come back here. And I think it continued over the phone because of the distance, occasionally she would come

in, and we would have coffee, but it was not here. The farthest she came was the lobby, where we met and then we went elsewhere, to a nearby coffee shop to talk.

There was always in the back of my mind the concept, sort of remembering, that we do not do long term bereavement work here and that somehow in the back of my mind I was thinking, Hum, I'm supposed to be transferring her to somebody out in the community. Actually, that was attempted, but it failed for lots of reasons, myself included. So, my work with her was really <u>prompted out of necessity</u>.

Pam hooked up with a priest in her community awhile after her husband died. In an odd way, I found his presence in the community a support for me. I felt, and I still feel, that we worked together with Pam, although we never met. We've never even spoken, but he knew that I was there and I knew that he was there and that was support.

To some extent, and I don't know if it's inherent to telephone work or to this case, but the risks I felt were initially due to our talking about her not killing herself. We made a contract and reevaluated a contract to make her not kill herself by telephone, so that was risky. I would hang up the phone and there she was in her house, very upset. But I don't know if that has to do so much with the phone or just the responsibility that I felt at the time in working with her. And in all honesty, the only other risk I felt - just that voice in my head saying: You're not supposed to be doing this; you're supposed to transfer this case; we don't do long term bereavement.

I kept it quiet for a long time. This wasn't a case I brought up in group consultation because I guess at the time I was new here, and was breaking with tradition of what I was told was acceptable practice. Whereas now I could say: Hey, in my clinical judgment, this is what needs to be done. At that time, I don't think I felt as convinced that that was right and so I couldn't talk about it. And then as I felt more and more comfortable that this was the right thing to do, I could talk about it more. But it sure felt like a risk at the time. It didn't feel so much as a risk clinically for Pam in the work we did together; but more of a risk for my status and my position. I worried that I could get fired for this.

When I owned my feelings about Pam and the work I did with her, I felt incredibly overwhelmed at times with this woman. There were times when I would sit at this desk for hours with the thought of this woman and there were times when I would feel so very overwhelmed. Just being a holding ground for so much pain and suffering is so very stressful.

And the frustration isn't what lay people think it is, which is: Boy, it must be so hard, what can you do for these people. I feel that I actually can do a lot for these people, but the bottom line is: there is still an incredible amount of pain in all of the losses that are involved. And I think that multiplied by all the people that you meet is what makes it very hard. It's hard to leave this place; it's hard to come to this place; and particularly for me, for this job, what makes it stressful is just the limitations of feeling like: Boy, I barely get to offer; I can't offer each patient and their family the amount of attention I want to give them, so instead I feel like I spread it out more evenly amongst patients. Therefore, in my mind, they are each getting a little less than I would like them to get. It's just hard to accept that. I separate myself from it to a certain extent because my focus is working with the psychosocial needs of patients and their families. But I think in the back of my mind, all of these sick people and they're not supposed to be. I think that adds to the stress – the sheer numbers of people.

Working with Pam on the telephone, as stressful as that was, it was something that I spent a lot of time thinking about in a different way; and I felt better because not only did I feel that I was helping her, but above and beyond that, I felt like I was learning something new, which has the ultimate goal of being able to use it with other people. Also, it was a perk for myself. You know I sort of learned that for myself - I feel better when I'm being creative. I went back to school (doctoral study) for lots of reasons, one of which was to feel like I'm being more creative than I felt like I was being here everyday.

In my role as an oncology social worker, it's the numbers of people that I work with. I speak for myself and looking at my colleagues, I feel that everybody feels like they are spread very thin. And the numbers keep you from - the numbers keep you running so much that you feel that you're so busy, you don't have a lot of time to think about trying new things. I tell myself I don't have time.

The other thing I hope will change for me the further along I am in my career, the structure, if you will, that is imparted in school. These are sort of the ways you do things and this is how you introduce yourself to a client; this is how you make a contract. All of those things that get tucked away in the back of your mind, but are not focused on anymore day-to-day. But I think here I feel that sometimes I sort of toss those aside, I say it doesn't matter what the books say about you're not supposed to touch a client - those things seem ridiculous. I mean to not touch someone in a certain situation would feel completely wrong to me. But those kind of things, I don't know if they actually fully inhibit me from being creative, but they make me stop and think about it and question it, which maybe isn't such a bad thing.

For me there are periods of time that go by that I think - it's almost like I don't know what I'm doing - I just do it and there will be a moment of: Oh boy, did I forget something. I just do what I'm doing and there is no time to reflect upon it. It is in these periods of reflection that you really learn and if there were only some way to structure in those periods of reflection. Working with Pam, I had to reflect and for me that work was very special and rewarding, because I could be creative and thoughtful. Part of why I was able to do what I did with Pam was because I was new and I didn't have a drawer full of people that I would like to be in touch with. So I was fortunate - I had more time, more time to reflect and now I don't and it's frustrating as all hell!

The Path Finder

I was reaching places of outgrowing the setting. It was a place in my career that I would have either stayed here or I was going to go off because it was time for me to go. There were pros and cons consequences to whatever I chose to do.

I have been an oncology social worker for the past twelve years and worked at the Cancer Center, for most of this time. I am the clinical coordinator of the Cancer Counseling Center at the hospital. I'm not exactly sure what that means - it seems to be evolving. I am the only paid staff person. I see clients in individual, family and group therapy. I'm also the administrator, so I do all the paper work - like creating the forms that need to be used. I also do data collection - I can't say that I am a researcher, but I am doing research. I'm also the advertiser, as this program is developing and I have to decide how we are going to market this Counseling Center. I worked with the Departmental Director last year to get a brochure made up and sent out. I also do educational talks and presentations to people about the Center and it's work.

The Cancer Counseling Center provides services for patients and family members who had premorbid histories of psychosocial problems prior to the cancer diagnosis. They had functioned prior to the cancer diagnosis, they were not manic-depressive or schizophrenic, but they were people with living problems, call it that, and the diagnosis of cancer has put them over the line so that they cannot any longer function well. So, we are really looking at what kind of problems people are going to bring. There aren't many places in the country doing this, so there isn't a place to go and say what have you done and follow the lead. So, we are really doing this all from scratch and that's the research.

Scary, exciting, all kinds of feelings, the gamut has been raised since I started this new position the past year. The nice thing about being here and working with my boss, the Departmental Director - he lets my creativity kind of go, that has meant facing my demons and my fear of failure. and all that goes with it. But it has allowed me to continue growing and to stay here. I don't know that I would have stayed in this kind of setting otherwise. I had been here for twelve years and I think I was reaching places of outgrowing the setting. It happened that my boss was also developing programs as a director and so he allowed me some free flow so that I have been able to stay and grow, which is very nice. You know, not many places can do that because there are limitations within a setting realistically that stand in the way of creative opportunities for people like me.

The idea for the Center came from my clinical work over the past seven years as the BMT (Bone Marrow Transplant) inpatient and outpatient social worker. I was following a couple of patients who were local and who had long term marital problems. And there was this particular family, that I had been seeing long term, the wife had a transplant and then her husband was diagnosed with cancer. So, it was a tremendous amount of stress when her husband died. And I remember coming to my boss and saying, I think we need a Cancer Counseling Center. Having someone to help me process this was very helpful to me. I'm somebody who kind of thinks process so I was walking through the steps and learning what kind of questions I had to ask, going through the changes and really needed someone who would listen and get me through this.

There were so many things when I started. The economy is in an entirely different place than it was four years ago; the insurance industry is in an entirely different place; hospitals are as well. And my learning to follow through and set up enough of a plan so that it is going to stay regardless of whether there are all of these changes. I couldn't have told you that when I first started all this. I couldn't have told you all the different aspects of the hospital I would have to deal with that I have learned. So, it's been a real expanding role, not always easy. There have been resistances from places in the hospital about this. There has been resistance from our social workers about this. It's breaking the traditional way of doing social work here. So, there has been that internal struggle inside myself about charging a fee, as opposed to giving services for free to poorer populations that we social workers identify with. And my questioning whether that was OK with me as well as getting feedback from colleagues about the acceptable way to practice sound social work practice. So, I guess I am saying that there was a lot of growing that was involved on many different levels and in many different ways for me.

But, in addition to the patients, it is inside me to make this change. It's a double edged sword. I didn't go back to undergraduate school until I was in my thirties, so it's been a process in my life of growing and changing, looking, formulating and seeing problems and things in terms of thinking what can be done because I've been able to do this. I got through undergraduate school and graduate school. I changed a whole way of doing my life. I have seen patients be able to make changes and do things and so also can programs. It's that kind of changing from the individual, to the client, to now the system in terms of developing new programs. I don't think I could stay someplace and not think about and see the gaps in places and try to do something about it. I don't know what other people do with that, but that's me. And again, I've been lucky enough to be around people who have been willing to go along with me on that. Because it could be very different with a different kind of boss. I've not thought about this clearly, but there was a psychiatrist who was called in as a consultant on a case, and he said to me you are really writing the text book on this because we don't know what happens to people through these kind of treatments. In oncology, we really haven't been dealing with psychosocial issues long enough, compiling them and putting them together to know long term outcomes of interventions. Therefore, it feels like uncharted territory to be able to expand because there is so little known in this area of practice. It's been only the past ten to fifteen years of cancer treatments, that people are thinking of cancer as a chronic disease as opposed to a terminal illness which opens a whole new door.

Deciding to work in the Counseling Center, was a huge financial risk for me. My husband had just gone back to undergraduate school, so I was the main support of the family. So I was leaving my job at the medical center with all of its security and benefits. I was a hospital employee with eight years worth of benefits built up. I had to make that decision to go to the university because of double-dipping. The hospital social workers are paid out of basic insurance. If I was to charge a fee, it would be a double fee on top. I had to go to the School of Medicine and be separate from the hospital and charge fees like the physicians charge.

I'm very dependent on all kinds of systems for supporting this program. I know how this place works. Change is very difficult. It is a very established patriarchal hospital system.

I am not a physician. I am female. I am starting something new and that is risky. It has been a struggle this year whether people have been supportive or not, verbally, but not in terms of sending patients. I spoke to the radiation docs and they wanted to know how they were going to know what was going on and I had to say there is a right to confidentiality. This is different from my being your social worker on your floor. That is hard for them, so there are lots of issues.

This whole venture was risky. It was a place in my career that I would have either stayed here and put in my time for two years, because my husband had two more years of school, or I was going to go off because it was time for me to go. And I knew internally that if I was finding myself being burned out, depressed and not wanting to come to work because it was time for me to move on. Very clearly, so it was stay put for two years or go into private practice or start this Counseling Center. And I said to my boss if I don't do it here, I may establish myself out in the community and do private practice with this specialty and he said, I think we can do it here. Well, then I had to decide which I wanted to do. And there were pros and cons and consequences to whatever I chose to do.

I chose to do it here. I don't think any kind of decision like this is made without risks. In addition to the financial risk, the other risk is to my reputation. Because if this fails, I'm laying myself out. So, there is a certain amount of anxiety about how I would save face if this doesn't work. I feel a bit like a mountain climber tethered by a rope. And I feel perilously close to falling over the edge. I don't think any of us feel really good about heights. I mean I can climb heights, I'm not phobic about it, but I don't think anybody would like to fall off from a high point. I guess that implies failure because in our culture, you're always striving for high points. So, I carry a lot of fear and insecurities about whether it will really work and the right to do things differently.

There are shame issues about whether someone will think this is crazy and kind of do this sort of number to put down a new idea. And it was hard. I think that my experience in social work is that we are not real supportive of ourselves and it is kind of painful to say that. But I think that it is true. I see that particularly in teaching hospitals, where there is an atmosphere of competition. Instead of each of us saying, Oh, isn't that wonderful, you have this line, I have this. No, it is typically, she's doing that, I should have, so therefore, let me tear her down in order for me to be OK. And I don't just see that in social work, I see this in nursing as well; not so sure about physicians. But I see this in nursing and social work and other ancillary health care programs, where women are the majority of the profession. And I don't think that we know how to support each other very well. I think people would try more new things, but that kind of message pervades and everyone knows it at some level, whether it is conscious or not. And that message keeps people from trying and being innovative.

The struggle between the traditional social work role of who we are, our identity per se, there's a real struggle within our profession about that and I feel like it keeps us down. You're supposed to do it a certain way and if you do it differently, and I'm obviously generalizing now, but there is not a lot of support for doing it differently. Either one has to have already faced the demons and risked before and decided that this is OK to do or be in a very safe place, their life is safe enough to take that jump. But for many people that safe, comfort zone, makes it harder and they are not able to take a risk because of that. They want to stay in that safe place, it's nice there and they accept it that way.

I remember in my previous job, the social work department was at war. The director of the department did not know what to do. It broke down to his bringing back to all of us from his vacation little pill boxes, exactly the same, so that no one would be jealous of one another. I don't think he did that by chance. I think that is how we were, I'm not sure why that was, but that's what I saw. And I don't think that kind of thing supports individual growth. It's like we're all supposed to stay the same glom, and if you leave, you are disloyal. I don't mean literally leave, I mean somehow professionally move on.

It's been very hard, very painful for me this past year with some of the responses from social work. I've had to struggle with that because there is in me that wanting everybody to support and say I'm wonderful too. Going against that has been very hard. It's been lonely. That's the other side whether people want to deal with it or not. I went into social work in a hospital because I'm a social person. I made the decision to not go solely into private practice, but rather to stay here because I am a social person. Yet, by definition, doing this differently, being innovative, I'm isolated and have had to deal with that. For me it came down to I can't sell out in order to have this, there's too much of a push in me, a challenge, a whole aspect of me, I would be ignoring if I didn't do it and the cost was too high.

It is hard for me, looking back, to know where I got the stamina to do this. My roots are traditional blue collar. Growing up in the 40's and 50's, one stayed in the same neighborhood and grew up in the same community and knew what you did from the time you were first in diapers to the time you left high school. I think it was part of the times, the 60's came in and change came through that. The feminist movement for me, going to school at a later time in my life, which I absolutely loved , and if I find someone to fund me, I would still be in school. I loved every minute of it. So life, and how I have come and evolved to view life, I think has been that change is part of life. Working in oncology, I've learned a lot from my patients and their families. Change happens to us whether we want it or not. This is my personal philosophy that I have come to through all of this. It isn't because people are good or bad - the saying in the street - shit happens. It's adapting. My particular philosophy is that our task in life is to adapt and how we are going to handle that change. I'm somebody, I've learned in my life, I like to be in control, so I'm doing change myself, it's much better when it's under my control than when it's forced on me. It's a mastery thing as I have come to do it and found that it can work and really is fun. As I get older, I can begin to see the process slowing down some, some of my life review at fifty, there is an end point to my being able to work. So, I better have my things in a row for retirement, that is really a new concept for me. There's a process for me, what do I want in terms of change even in this part of my life for whatever time I have left. I don't know if that all makes sense, but it all goes into making me who I am in doing this.

I don't believe that you can stay in this business of oncology social work very long if you don't deal with your own mortality. I don't think you're any good if you stay in this and deny and use defense mechanisms that keep you away from your feelings because our feelings are who we are. We are our tools. We're it and as much as we understand about ourselves is as good as we are is my philosophy. And all the intellectualization of theory doesn't mean a tinker's damn if I can't bring my feelings and understanding into it. We are in a profession in health care that is codependent. It is very hard to take care of yourself in this kind of setting. You are punished for taking care of yourself, covertly punished and not supported in taking time off and doing what you need to do to take care of yourself. I mean death, pain and suffering are primitive. It's all human beings fear – loss of control, what's going to happen to me, trust issues - it's as basic as you get. I think that'shard. You're faced with it. You're confronted with it daily.

The first couple of years here, my boss kept saying to me you have to have other things to do other than just seeing patients all the time. You're not going to be here very long if you do that. At that time, I had the time and energy to see patients. I'm a one tracker and that was my passion at that time. I fought him tooth and nail, but he kept staying around and kept after me. After a while, I started a new group and then I wrote a whole research proposal for support groups. It was a very intellectual process and helped me because I have a tendency to be much more into the feeling level and sometimes need help being pulled out of that. It helped me keep balanced. I became a supervisor here after a while and that helped balance me because I had to learn new skills. I hyperventilated through half of the speeches in the beginning. I thought I was going to pass out all the time. I was terrified. I had panic attacks. I mastered that. It took the focus away from the intensity of the unit and kept me growing. For me being in a university setting in itself is stimulating. Since it is a research center, there are always new treatments. There is a grounding to this place. There are always new ideas. It is part of the bricks and cement.

Initially trying new things, on the short term, it makes it more stressful. It was very anxiety producing at that moment I had to make that speech. I said Oh, my God, I want to be anywhere but here, but the sense of mastery and pulling me away and keeping me growing in the long run was much better. I think that trying new things makes it less stressful in the long run, but in the short run, if it is new to you, it makes it more stressful. It's also important in developing new things, it builds a sense of self esteem. There was support for me in different places in trying new things. I'm the oldest in my family. I'm probably from the very beginning the path person. I was the first in my family to go to college and graduate school. I was the first person in our department to do family support groups. It was real nice to have other people starting doing support groups afterwards. There was a sense of building something. And now I am building the Counseling Center.

The Opportunity Grabber

I took a couple of days to think about it. I began to say to myself: Is this a problem, a challenge or an opportunity? Eventually, after processing it, I saw it as an opportunity, that probably was not going to present itself possibly ever again. So, there was this little window of opportunity and I decided to grab it.

I am the Director of Oncology Social Work in a comprehensive cancer center and also hold a faculty position in the Medical School. I have attempted to develop psychosocial programs that cover the continuum of cancer, including diagnosis, treatment, remission, recurrence and end-of-life care. We have learned that there is more to the experience than just diagnosis, treatment and, hopefully, remission. So, consequently, I have attempted to identify other needs and develop programs to meet those needs. I have engaged my staff in doing research looking at psychosocial vulnerability, to try to explain the different tracks that patients can take after diagnosis, so we can differentiate who really needs social work services and who would benefit from social work services and which patients may well adapt on their own without intervention. I have also worked with my staff to develop a model to identify which families are most vulnerable to the experience of cancer. My Department also trains our own patients to be patient counselors for newly diagnosed patients. We also are concerned about the long term consequences of living with cancer and have begun to develop programs for long term survivors.

I have secured funding for a cancer education outreach program to the local community, which will focus on screening programs for breast and cervical cancer in collaboration with physicians. It will provide education to community leaders, specifically the Clergy

Coalition, a group of two hundred and forty eight ministers banded together to take on health care issues. As a consortium, we will work together to make sure the community is well informed about resources, and increase advocacy programs and access for this community to our Medical Center. Our hospital zip code has one of the highest mortality rates in the country, and there is a regional cancer center within walking distance, and we are trying to solve the problem of why does this area have such a high cancer rate. And finally we are trying to further develop psychosocial support programs that are culturally sensitive, including more contacts with key leaders in the Hispanic and African American community.

So, if you think of cancer as a continuum, at some point we would have a program along the entire continuum - from pre-diagnosis to a palliative care program rather than hospice, because we would like to individualize the dying process, so if the patient is terminally ill and wants to continue on treatment, that option is available vs. hospice which precludes aggressive treatment. So, that's the plan and I take care of all that - that's my responsibility, including patient, family, staff and community and national leader for professional organizations.

I want to tell you more about our residential care program, because of the way it happened. I would like to say that I went out to find a benefactor, but I didn't. The benefactor found us. And basically walked into the Cancer Center and said to the administrator/director, there is a small dirt lot near your hospital and I want to build a residential facility for adult cancer patients. My mother died of cancer and there is nothing here in this city for adult cancer patients to stay with their families when they are undergoing treatment. I want to build something in memory of my mother and I want to donate it to the oncology center. Now, when an offer like that comes along, you obviously pay attention. So, I was called into the administrator's office and basically told to begin to plan for a residential program. And I very politely tried to decline the offer, stating that I didn't know anything about residential care. I've never worked in residential care and it's a lot like running a hotel. Since the hospital runs a hotel, they would be better off talking to the people over at the hotel as to how to do this. Since I didn't have any experience in this, I really did not want to pursue this. And the administrator said, I suggest that you think it over because I see it as being part of your responsibility. In a broad sense this is not a clinical activity, but it should be a social work activity and I suggest that you learn about residential care as quickly as you can. He and I had a pretty good relationship, but it was very clear where he was coming from. So I took a couple of days to think about that. And then I began to say to yourself: Is this a problem, a challenge or an opportunity? Eventually, after processing it, I saw it as an opportunity that probably was not going to present itself possibly ever again. So, there was this little window of opportunity and I decided to grab it.

I was the Director of Oncology Social Work, doing social work, and just beginning to develop a Research Program. I felt that I had enough to do let alone take on the development of something that I did not know anything about. So, I consented reluctantly, even though I saw it as an opportunity. I then began to meet to educate myself by meeting with hotel people and others that had been involved with residential care. I spent a lot of time on this, and the house got off the ground quickly and two years later, we duplicated it with another house on the street. Then we were able, because we were successful, to define a second benefactor to build a third house for us. And what I feel good about is the fact that starting with almost zero knowledge, I was able to pull it off and give it what it needs. What I often tell our Director is that our thank you notes probably outrun his ten to one because of what patients and their families have said this house means to them. So, that's obviously very positive. The other positive is that we've done it on our own. We recently calculated that between both houses since their inception, we've provided just over three million dollars worth of care without costing the institution any money. So, as far as I know, there is no other major cancer center that has a residential program.

In hindsight, I had to redefine the initial request as an opportunity. I had to move past my reluctance and my feeling very overwhelmed. After I felt I had to do it and once I developed some confidence by getting information and spending time with hotel staff, then it became an exciting project. And it has continued to be that and a challenge. You know, for many nonprofits the past eighteen months have been extremely difficult and fundraising is not easy. We keep our fees very low for patients and families to stay at the house, so most of the cost for running the house involves major fundraising. The houses are 501(c)3 status, so fundraising is difficult to do. But we have been successful, and that means a lot to the Social Work Department, in terms of our credibility. So, if an opportunity presented itself again, it may well come to social work rather than another discipline.

It was interesting that the concept of a residential program had been here before I had been hired. The hospital was working on a model to build a large hotel. When I first came here, I was asked what I thought about it. At that time, I said I didn't like it because it was a hotel and it would not be a very friendly place. And I said that if we were going to do something, it would be nicer to do it on a smaller scale. At that time, the funding never developed, so the project was dropped. This was kind of a pet project for the Director and I don't think he appreciated anybody being critical about it, but I just didn't like the idea of building a hotel. I wanted something smaller, more intimate, comfortable and more humane. Slowly, we talked with one another. He's probably been one of the most supportive people, not only on the residential programs, but pretty much everything.

In spite of his support, my biggest risk was failure. I think that is true of any time you try to be new or innovative. There is a risk of failure because you are dealing with so many unknowns. I think that we are committed to innovation at this Center. We are constantly asking the question: Can we do it differently? Can we do it better? But inherent in that is the risk that you will fail at times, but if we do , we'll learn from that and go on. I think that too many people are not innovative because the fear of failure overwhelms them.

Being in an academic setting, you are either successful or you fail. There aren't many gray areas. In the early planning for the residential program, I ran into some major problems between the way I wanted to do it, and the way the administration of the hospital wanted me to do it, which at one point almost caused us to lose the donor, the benefactor. There were plenty of obstacles along the way in the first year. The first time we broke ground, some of the soil samples that had been done were not accurate and we hit a lot of sand and the entire site collapsed. At that point, the project was shut down and we really felt the hospital would not let us continue. The benefactor was at the site every day of construction, as he was building this in memory of his mother. He gave the project his personal supervision. And at one point, someone said, we are not going to be able to pull this off. And normally, that's all I need to hear, it can't be done, because that really gets me going. Then, I really get into a kind of challenge mode. So, some of those early episodes probably really energized me into: We will get this done.

It's stressful just being in a cancer field. Just walking in the door of the Cancer Center, as I walk up that little brown ramp, my blood pressure changes. I think it is stressful due to the nature of what's happening in that particular building. Every patient is coming in with a potentially life threatening illness. Sure, sixty percent will survive five years, but we don't know who those sixty percent are going to be. And the stress just gets intensified for a number of reasons. We would like to think of the concept of team, that we are in this together. There is a physician, a nurse, a social worker, a nutritionist and a physical therapist. And everyone clearly understands each other's roles, acknowledges each other's expertise and respects their point of view. There are those times when it does work well, and there are those times that it breaks down, where someone doesn't go along with the pact of abiding by and staying within your role. Obviously, the most constant issues are probably between nursing and social work, in terms of which issues belong with which discipline. Certainly with more experienced nurses, they work very well with social workers. New nurses coming out of nursing school, particularly in the program here, who have one course or a lecture in psychosocial care, suddenly feel they are psychosocial experts. So, there is that constant educational process that goes on which unfortunately does create stress.

The other thing that causes stress here and again this is part of an academic setting, particularly the one we are in, is the expectation of nothing less than excellence. The expectation that you will never make a mistake. That is an unfair burden to put on anyone, no matter what their discipline is. All you have to do is sit in on the monthly quality assurance meetings and you can find and hear all the errors that were made in a given month that we were able to detect, not the errors we couldn't detect. So, I think all of those things really intensify stress.

There is a book called <u>Loss and Change</u> written by a British author which says that with any change, there is what he calls a conservative impulse not to change, because if you are going to try something new, you cannot fully predict the outcome. If you knew what the outcome would be, then you could make a decision whether or not you could do it, you could do something in advance. But if you don't know what the outcome will be, you don't know if you're gonna be successful or to what degree, consequently, there is a conservative impulse not to change. When you lose the ability to predict the future and you're doing something different, your stress/anxiety will go up. I think it is a natural by-product, but ultimately, when you are balancing what you are doing on the short term, your clinical work with those long term projects, I think overall, there is a reduction in stress, which allows people to stay in oncology longer. We have a very simple philosophy here, clinical work is short term gratification. You can have a great Monday, and a bad Tuesday. It's that simple and you are up and down. Some days you are good, and some you're not. What I have tried to say to my staff is that needs to be balanced with activities that promote long term gratification: things like education and research projects because those things are long-lasting. If you do a presentation at a national conference, you put it on your resume, that's something you can take with you so there is a sense of long term gratification. I have tried to encourage my staff to diversify and not get locked into one activity. A bit like Wall Street, would you take your ten thousand dollars and invest only in a utility company? Of course, you wouldn't do that. You would diversify and buy into a service company, a bank, a utility company and an airline. You're not going to put ten thousand dollars just in a utility company, you don't want to take that risk. So, it is more of a risk focusing strictly on one activity than diversifying one's professional roles. And I have mentored my staff to couple their short term activities with long term professional growth and gratification to extend their survival in this field.

Chapter V

Data Analysis

Quiet Heroes & The Process of Innovation in Oncology Social Work: Their Stories and Challenges

Preface

This chapter could not have been written without the tremendous support of the fifty seven oncology social workers who participated in this study. Their candid reflections about their work, its impact on their lives, their daily bearing witness to life threatening illness, their commitment to help and their innovations are chronicled in this chapter. Their poignant and thoughtful comments during the interviews suggest that the study offered them an unexpected vehicle for catharsis about the powerful nature of oncology social work practice. All the respondents refer to the theme of death. They felt that the work brought them in touch with deep seated, existential dilemmas about illness, death, pain and isolation. “We work very close to the edge - very close to life and death.”

The Powerful Context of Practice

As I walk up that little brown ramp, my blood pressure changes. It’s stressful walking in the door of the cancer center because of the nature of what’s happening in that building. Every person is coming in with a potentially life threatening illness.

The ongoing devastation of loss and mourning surfaced in all the interviews:

> The reality of getting close to people and having them die - that terrible reality of death. Going to a room to see somebody and the bed is empty: and you know, they’re dead. I experience a kind of sadness when one of my patients dies.

The patient’s plight was a reverberating motif for each respondent. “The issues of chronic illness and people possibly dying make me look at my life - my mortality - and the people I love." Part of the legacy of this work is a changed world view - a skewed vision of life. "It all takes a toll. I never worried about my children's and my health before I came here. Your vantage point on life changes irrevocably." These rich and poignant themes comprise the stark reality of their daily world of work:

> It is very stressful to be exposed to illness, suffering and death. It's developmentally dissonant for a lot of people. You've got thirty year olds who are constantly exposed to the fact that people die. And most people don't have to begin to believe that until they are sixty, seventy or eighty.

Many struggle to maintain a sense of balance in their own lives:

> I keep an eye on myself. Life's too short to waste time complaining. I try not to get upset about little things. If you've got your health and nice people around you - that's perspective. I work on being a cheerful person.

Still others identify a philosophical cycle to life's pain:

> When you see so much hardship, you tend to minimize your own problems because things could be so much worse. Or feel guilty about being happy or having good health. But I've come to the point, I don't feel guilty because I know that I will have troubles in my life too. So I don't need to feel guilty that right now things are okay. Because someday it will be my turn. I will be in as much anguish as these other people.

The foreboding specter of misery haunts each of these participants.

Others acknowledge the role of spirituality:

> We deal with impermanence and mortality all of the time. I believe very strongly in the divine. I bring my spiritual practice into my life and work every day. I work hard on my inner healing from all of this pain.

And many encountered an enduring quality in their work:

> People are so vulnerable and it is important to be a part of that. When you do your work well, the amount of satisfaction that comes from that is very rewarding. It's

> also very humbling. Death and hope are such powerful emotions. There's mysticism about it.

The majority speak of their internalization of these experiences and their need to interpret and assimilate the events they had witnessed. "It's hard to do this work for an extended period of time without having some kind of internal philosophy develop." Others reflect upon their journey of understanding:

> With bereavement, I didn't know what was normal. When I think of what I have learned and know today and how I can really help people anticipate. It's not just words; I really know. Sometimes people think I'm some kind of guru. But again, it's something that I have come to know. I didn't know that for years. And I was just mouthing things. But now I know.

The Study Participants

Demographics of the Sample

And so when you first told me what the subject of the research was, I got sort of nervous because I haven't innovated. I haven't done any programs that are innovative. And I thought I have nothing. But when I think about the crisis of cancer, you have to be flexible. Because you can see someone, for instance, one day who's very well and healthy and comes in to see you, and the next week they've become bed-bound, and then what do you do? So right there you have to be creative. Do you work on the phone? Do you make a home visit? Is it more helpful for you to see the family? So you're doing a lot of creative stuff.

Fifty seven out of the sixty seven oncology social workers initially contacted participated in this study. Almost all of the study participants expressed curiosity about the subject of the study and their interest in a fellow oncology social worker's research as the motivating factors for their participation. Many were not sure that they would have much to contribute to the study, but their desire to help, their curiosity, their director's sanction to participate, the anonymity and the opportunity to talk about their work for a half hour with a fellow oncology social worker prevailed.

The majority of the participants in this study are female (89%), married (68%) and white (95%). The age range is twenty five years to sixty four years with over half (54%) forty years of age or older (See Appendix D). The participants' work experience indicates that the majority (85%) had five years or more post MSW experience. . Once again, the majority (70%) had been oncology social workers for five years or more and 51% had worked at their current institution for five years or more. This data suggests a population which is relatively stable and experienced in oncology social work (See Appendix E).

The Work: Job Responsibilities

My role has grown and expanded along the way. I end up doing many different things in a day, which I like a lot. So I never get bored with any one thing. I wear many different hats.

When asked about their job responsibilities, most of the study participants focused on their provision of clinical services to cancer patients and their families and stressed the role diversity, flexibility and job satisfaction their positions afforded them. The majority of those interviewed discussed their work, citing the specific tasks and responsibilities of their job:

> In a nutshell, I work with patients and families of adult cancer patients around issues of adjustment. I try to promote optimal adjusting under difficult circumstances. In the process of doing that, I will often assist with concrete services, such as transportation, housing, prostheses, gathering information or making referrals to community agencies. But I would say it is a luxurious job in the sense that we have as our main mandate to focus on the emotional, psychological and social adjustment of people at a difficult time.

In this and the following example, critical to job satisfaction is the recurring theme of the department's structure and commitment to the psychosocial care of cancer patients and their families.

> Because we are a major cancer center as opposed to an acute care hospital, we have the privilege of kind of referring off to financial specialists or patient care coordinators. So we are uniquely free to do a lot of supportive counseling with individuals, couples, family and group work and a lot of different special projects. I like to do a lot of diverse things to kind of balance more direct casework.

The importance of the clinician's autonomy in carrying out job tasks is highlighted by this participant:

> I do counseling and concrete services for patients and their families in the outpatient department of the cancer center.. I also do crisis intervention. For example, if a patient, receiving radiation treatment became frightened and panicked about getting on the radiation table, I would intervene. So, I intervene in the medical setting with patients in a crisis situation or in ongoing counseling, individual, family and group. There's a lot of flexibility in how I work with my clients. And I really get to call the shots in terms of what I think, in my best clinical judgment, will be helpful to someone in terms of whether they should be seen once, twice, in an ongoing way, whether they should be seen alone or with family. I get to make some determinations about what would be most helpful for people.

The helping role is echoed poignantly by this participant:

> I'm the surgical social worker and my assignment basically is to see primarily inpatients, although I see a fair number of outpatients as well, who have received some kind of either curative or palliative surgery for cancer. And I follow those patients from the time that they come in for pre-admission screening through their operative day, which is when I spend time with the family in the family room and help them deal with that long day. And basically what I do is try to help people, especially in this institution, as it may be the first time they're learning of their cancer. So we do some of the initial coping strategies of how you deal with the diagnosis. How you deal with the site of surgery, wherever it may be. A loss of a body part or an adjustment or alteration of a body part, such as a colostomy, loss of a voice box due to laryngectomy and so forth. And during that time, I work a lot with patients, family and their staff, especially while they're in the intensive care unit, because families are not familiar with that kind of setting. And they may have

> a lot of fears and apprehensions that other patients may not have in another part of the hospital. So, I do a lot of work with that.

This participant graphically describes the various nuances of the particular expertise required for this inpatient surgical setting and testifies to the many specialty skills encompassed in oncology social work.

Only a few of those interviewed discussed their role using metaphors to describe the transformative nature of their work:

> If I had to describe it in one sentence it would be to offer supportive therapy to patients and their families dealing with the diagnosis and treatment of cancer. I clearly work with the family, more often than not I'm working with one member of the family at a time, instead of all at once. I would say it is an incredibly flexible role that I see myself play. I've struggled with this, I'm clearly a social worker, but the boundaries are just pretty fuzzy. I think it borders on sometimes being more of what I think clients would think of as a friend to them which sometimes feels okay and sometimes does not feel so okay. So, in a lot of ways, I see my role as providing a safe holding ground, just to get them through.

And this participant provides a broader, conceptual perspective on oncology social work with adult patients:

> I cover the adult service and see patients and their families. In terms of what I do for clients and when I talk to them, I try to help their passage from one point to another. In terms of their acceptance of their disease and just how they deal with it. And you hope that you can become a part of that process in a way that is useful for patients. And trying to help them identify their coping abilities and really reinforce the things that are positive for them in terms of their ability to cope.

These two study participants used the metaphors of "providing a safe holding ground" and "helping their passage from one point to another." which seem to capture the essence of the work of oncology social workers.

Stories of Innovation

Oncology social work is so different from what we were taught in graduate school training about the therapeutic hour. I think oncology social work in itself is innovative. It has to be. The practical boundaries are all different. Like comforting someone who is sitting next to a loved one throwing up or medical staff walking in and out while we are talking to a patient. People are being bombarded from all sides by so many threats: economic, life and death, damage to relationships. I think you need to try new things to help. We need to try new things as an antidote to all the sad, difficult, dying and stuff we witness and work with. It's like you never see all the planes that land safely, only hear about the crashes. We're more often involved in the crashes in our work and not so much the ones that go beautifully.

The exemplar innovations identified in Chapter IV, The Metaphor Maker, The Reactive Innovator, The Legacy Keeper, The Quiet Risk Taker, The Path Finder and The Opportunity` Grabber all share this context of practice. Each were presented with a problem which required their intervention. To quote a question posed by one of the participants: "You see a problem and you try to do something about it. Is that being innovative?" In this study, each of the participants came across a perceived need of a particular client or population that came under the mantle of their care and responsibility and, given their role, adapted their help in a novel manner to offer best practice. A review, discussion and analysis of their innovations cited in Chapter IV will follow.

The Metaphor Maker

The Metaphor Maker (MM) works on a Bone Marrow Transplant Unit in a major cancer center. She was presented with Charlotte, who needed a bone marrow transplant, but was terrified of this procedure. Her fear might have prevented her from getting the standard-of-care medical treatment for her cancer. The oncology social worker assigned to the

Unit was committed to helping Charlotte. In her psychosocial assessment, she discovered that Charlotte was an avid gardener. In tailoring her interventions with this patient, MM chose to engage her by working in metaphors and helping Charlotte to understand the parallels between gardening and a bone marrow transplant. She saw Charlotte daily on the Unit and spoke with her about the analogy of the process of transplanting in her garden and the process of bone marrow transplantation. Charlotte was comforted by this familiar gardening concept which also helped her to better understand and cope with her bone marrow transplant. The practitioner was familiar with working in metaphors as she had taken a fellowship in oncology which included this type of work, with an emphasis on the value of symbolic communication. That training, coupled with open discussion with colleagues and on-site role models, who also worked in metaphors, strengthened MM's conviction to try working in metaphors with Charlotte. In addition, the patient came across to MM as a "pretty symbolic speaking woman" so the work in metaphors appeared consistent with Charlotte's speech patterns and thinking.

This intervention enabled Charlotte to tolerate the bone marrow transplant and the oncology social worker was able to visit this patient regularly on the Unit to reinforce the metaphor of gardening with the bone marrow transplant. MM chose to discuss this intervention in the interview as reflecting something new and different that she had tried in her practice. This particular example illustrates the approach, "If you see a problem, you try and fix it." In this instance, the oncology social worker utilized a novel avenue clinically to effect a solution to a problem in spite of feeling "deep down, I was going out on a limb." What appeared to sustain MM throughout was her dedication to help

Charlotte, her interest in working with metaphors as a result of her fellowship training, her willingness to try something new in spite of her reservations and her support from social work colleagues. All of these factors came together so that MM provided a tailored, best practice intervention to Charlotte. The artistry of MM's intervention bridges the gap between "professional knowledge and the demands of real world practice" (Schon, 1983). MM's work with Charlotte demonstrates the confluence of "reflection-in-action" for creative problem solving and use of self (Schon, 1987; Klagsbrun, 1983; Holland, 1989; Hill,1991). The innovative care that MM provided to Charlotte, MM's capacity to draw from a repertoire of possibilities and select the appropriate tailored new intervention to enable Charlotte to receive life saving medical care demonstrates both best and innovative practice in oncology social work. This case study and the skill involved have not been published in the oncology social work literature. The work was done quietly in the service of a needy patient. It was mentioned in the course of this study, as it was fresh in the mind of MM, and resonated for her something new and different that she had tried in her practice.

The Reactive Innovator

The Reactive Innovator (RI) works in Cancer Rehab, the outpatient department of a large cancer center. RI does not perceive herself as an innovator. She has a large caseload and feels that most of her innovations are reactive to a situation in which she rises to the occasion. In this instance, she chose to describe her work with Amanda as illustrative of the way she innovates. Amanda, a 39 year old woman, the same age as RI, was dying at home. RI had worked with Amanda for a long time on an outpatient basis. Suddenly, Amanda was too ill to come in for her appointments. She was homebound and dying. RI felt that she had made a commitment to Amanda to be there for her. RI felt that ethically, she had to follow up with her commitment to this long term client. Her solution was to go to the client, since Amanda could no longer come to her. She decided that she would need to make home visits to Amanda to help her as she was dying with Amanda's request to plan her own funeral. During these visits, Amanda removed her oxygen mask and sang the songs she wanted at her funeral.

Although home visits are not in and of themselves considered innovative in oncology social work practice, the context in which the home visit was made is critical. For RI, home visiting was not part of what she did nor did the setting support this. She was able to influence the setting, tweak the system, so that a novel adaptation to the institution's usual and customary practice could be implemented.. She worked through her supervisor and hospital administration, so that she could maintain the integrity of her ethical and carefully thought out commitment to Amanda. To be effective in her work with Amanda, RI had to "break the rules" of her institution - no time for home visits - setting a precedent for the future (Holland, 1989; Klagsbrun, 1983; Nouwen, 1992; Nouwen, 1979; Kubler-Ross, 1969). Like MM, RI had to step outside the familiar path and perform as an artist to handle a unique situation (Schon, 1987). In these instances, best practice was also innovative practice and would not have been possible without each worker stepping outside traditional work. Their total commitment to help served to further drive the innovation.

The Legacy Keeper

The Legacy Keeper (LK) provides clinical social work services to inpatients and outpatients at a large teaching and research cancer center. She describes herself as someone who works with the day-to-day reality, using her usual bag of tricks to help patients. Her innovations occur when her usual interventions do not work. It is then that she will consider doing something novel. In these instances, she usually alerts her patients that she would like to modify her work with them to see if a new approach might be more helpful to them.

LK works with a lot of young moms who are dying and who want to leave something tangible for their very small children. Jessica was such a young mom with whom LK had worked for some time. Jessica's biggest worry was that her children would not remember her after she died. She and LK spent time talking about these concerns and their work was stymied. LK was frustrated by "my empty kind of words and interventions, when she was looking for something really tangible."

LK had taken a seminar on the use of the photo album as a novel intervention to use with moms, in which they would do a life review, including pictures of their children with their writing comments in the photo album. LK wanted to try this novel approach with the patient. However, LK also knew that because Jessica was an inpatient, and this work would cause her to become tearful and appear more depressed on the short run, that she would have to "get her ducks in a row" if this intervention was going to be successful. She knew how easily the nursing and house staff could sabotage her clinical work, because of their misunderstanding of what the purpose of her work with Jessica was. So, she worked with her supervisor, the surgeon and the consulting psychiatrist to obtain their support of what she planned to do. She then spent time educating the nursing staff about the photo album intervention, the meaning of short term tears as she conducted the life review and the ultimate goal to help this mom leave a tangible legacy, the photo album, for her children. She also worked closely with Jessica's husband who had to bring in the photos and select an album with Jessica to house these pictures and her notes to her children.

LK not only did a careful psychosocial assessment of Jessica and her family, but also a diagnostic evaluation of the key medical personnel to involve in her innovation so that they could take some ownership with her on this novel approach to Jessica. Involving the staff prevented sabotage and also allowed them to learn about this intervention and participate in its positive outcome. Like RI, LK to be successful, had to get the institution's sanction, but in addition, LK critically involved key personnel to educate them about this novel intervention so that they could work with her in carrying out the intervention. The work of LK demonstrates that oncology social work is a crucible for "reflective practice" and creates many opportunities for "reflection-in-action" (Schon, 1987; Schon, 1983; Hill,1991). Both RI and LK worked in settings in which middle management, as well as administration, supported their innovations. This organizational support is critical to the practitioner trying to innovate (Delbecq & Mills, 1985; Peters & Waterman, 1982; Drucker, 1986; Kanter, 1984; Pointer, 1985; Mars,. 1971; Munson, 2002). MM, RI and LK appear to be highly committed oncology social workers who innovate to enhance their clients' coping with extraordinary life circumstances. When LK reflects back on her work with Jessica, her innovative practice provided her with:

> .....a kind of peace when you've done your job. I think back to what a mess Jessica was before I started working with her, so anxious and sad. That photo album became real important to her to complete for her children as her legacy to them. And she was able to accomplish that. My only goal with her was to help her complete the photo album so she could say good-bye to her kids. And when she finished it, she sat back and just had an incredible look of being at peace. That makes it all worthwhile and makes the job less stressful for me.

Not only did the patient, Jessica, benefit from innovative practice, but the clinician, LK, found that her creative intervention had a powerful impact on her enduring capacity to do oncology social work (Schnipper, 2003; Klagsbrun, 1983; Lederberg, 1998; Lederberg, 1989; Peteet et al, 1989; Reese & Sontag, 2001: Stearns, 2001). For LK, "reflection-in-action" allowed her to provide a novel method to help Jessica and an unanticipated antidote to the stressful nature of oncology social work (Schon, 1983).

The Quiet Risk Taker

The Quiet Risk Taker (QRT) spends her worklife on an in-patient adult oncology unit at a major cancer hospital. QRT works a lot with family members as well as patients. QRT sees her role as providing "a safe holding ground for so much pain and suffering" by providing supportive, crisis oriented therapy. At times, she feels overwhelmed by the sheer numbers of patients and families and their multitude of losses. She feels that she does make a difference in the lives of patients and families with her interventions as an oncology social worker. Her frustration is that she feels that due to the sheer numbers, she is unable to offer each client the amount of attention that she would like to. In her mind, "they are each getting a little less than I would like them to get, which is hard to accept."

When asked to describe something new or different that she had tried, she chose to discuss her bereavement work with Pam, whose husband died of a brain tumor. Pam is twenty four years old with a two and half year old son. Pam lives two hours away from the cancer center. QRT conducted the bereavement counseling over the telephone with Pam and considered this an innovative approach in her clinical work. Although QRT feels that telephone bereavement counseling may not be considered innovative in oncology social work, it is new and different in her institutional setting and her practice Follow up bereavement counseling is discouraged by her setting, due to sheer numbers and the staff are encouraged to refer clients to their local communities for bereavement counseling. The practice is so frowned upon that QRT did not discuss her work with Pam in supervision, group supervision/ consultation nor with colleagues. She was fearful that if word got out about her doing long term bereavement counseling over the phone, that she might be fired.

What kept her going was that clinically she felt that she was doing the best thing for Pam, and so worked closely with her over the telephone during her bereavement and suicidal ideation. QRT's rationale was that Pam had developed a close relationship with QRT , had a lot of "institutional transference," and was too far away to come in for appointments and too connected to the center to successfully be transferred for bereavement counseling. Although QRT knew that she was not following institutional protocol, she felt confident about her clinical work with Pam and Pam's need for counseling. QRT feels that her work with Pam was "prompted by necessity." After phone sessions with Pam, QRT would find herself overwhelmed with Pam's "pain and suffering."

What sustained QRT in her work with Pam were a number of things: QRT knew that she was helping Pam, and "above and beyond that felt that I was learning something new, which has the ultimate goal of being able to use it with other people." QRT felt that her work with Pam was creative. She spent a lot of time thinking and reflecting upon her work with Pam. "Working with Pam, I had to reflect and for me that work was very special and rewarding, because I could be creative and thoughtful." QRT felt strongly that: " It is in these periods of reflection that you really learn." QRT described her work with Pam as difficult as it was, as a "perk" for herself. QRT felt that she learned a lot about herself in her work and her risk taking with Pam. QRT is also in school pursuing doctoral work and one of her reasons for so doing was that she had sanction in her doctoral work to be more reflective than is possible everyday at the cancer center.

QRT's innovative practice with Pam provided her the opportunity for "reflection-in-action and novel problem solving (Schon, 1987; Holland, 1989; Hill, 1991). QRT learned that to be effective she needed to struggle with the ongoing challenge of achieving "the right balance between professional distance, human connection and closeness" so needed by Pam (Hill, 1991). QRT's innovative use of the telephone to provide bereavement counseling for Pam, who otherwise would not have been able to access such help, was done initially in secrecy, without institutional sanction. Over time, QRT was able to work with a handful of such clients and to undertake some preliminary research on her work. This initially non-sanctioned approach afforded QRT a lot of time to reflect on her practice with Pam and enabled her to consciously "reflect-in-action" and creatively adapt her practice to provide needed care to her client in a unique situation (Schon, 1987; Schon, 1983). MM, RI, LK and QRT all stepped outside the everyday practice and tried a novel approach to provide the best care possible to a client. In so doing, they each took risks and ultimately reaped the rewards of successful innovative approaches with their clients. Their basic belief that they were doing best practice for the client ultimately propelled their innovation and the tremendous service they provided. Their innovations gave them time to reflect on their work. QRT wishes there were some way to " structure in more periods of reflection" in her work at the cancer center. Her personal solution was to enter doctoral study which by its very nature would require her to reflect more on her work.

The Path Finder

The Path Finder (PF) works at a major cancer center and found herself at a place in her career in which she could stay on doing what she had been doing for twelve years or make a change in her career path. She knew she had to make this change in spite of the financial, professional and social risks involved. The change and her innovative practice entailed her taking on the directorship of a new Cancer Counseling Center, the impetus for which had grown out of her clinical work with cancer patients and their families who had pre-morbid behavioral, emotional, social and psychiatric problems prior to their cancer diagnosis and presented unique challenges for psychosocial intervention, requiring more follow up and in-depth psychosocial counseling than patients and families without significant histories of psychosocial distress prior to the diagnosis of cancer.

PF tweaked the system with the support of her director and set up the Cancer Counseling Center. Although her forte was clinical counseling, she had to embark on a public Relations campaign to attract referrals, charge fees for service, take on a number of administrative tasks, write grant proposals, design the space and set up a reporting and accountability system to make this program work. She also had to develop a brochure and a mechanism to promote this center. Although these administrative and program tasks are not innovative in and of themselves, they were novel for PF and the center itself represented an innovative approach to meet the needs of a subset of cancer patients and their families. PF identified the population of cancer patients and their families with pre-existing psychosocial problems and then created a cancer counseling center to meet their needs.

Of all those interviewed, her risks appeared the greatest, both fiscally, in terms of her being the family breadwinner and professionally, stepping outside of a traditional, patriarchal medical delivery system to a free enterprise, fee for service endeavor. PF also ran the risk of no referrals, once she embarked on this course. Nevertheless, she plowed ahead because she felt strongly about this program and also because she had outgrown her current setting and needed to move on.

Her boss helped her to carve out a niche that enabled her to stay in the cancer community where she had built her reputation and in which she was the most likely person to be able to carry off this program, the need for which she had identified and was eminently suited to develop. PF exemplifies the highly trained and experienced clinician who is ready and needs to take that next step, which integrates clinical, program and administrative practice. The culture of the institution in which PF was employed fostered her ability to transform an idea for a program into reality. PF was able to bridge that gap between "professional knowledge and real world needs" to implement a state-of-the-art center for cancer patients (Schon, 1983; Hill, 1991, Schnipper, 2003). PF's innovative center increased her sense of mastery of her work and enabled her to stay in oncology (Christ, 1989; Peteet et al, 1989; Koocher, 1979; Vachon,1987).

Her innovation grew out of demographic changes and new knowledge (Drucker, 1985). Although PF was the ideator, the person with the new idea, and champion, willing to assume professional risk to promote this new idea, her boss was her benefactor, the person willing to grant legitimacy, priority and funding to this new project (Pointer, 1985). PF's boss was critical to her success. He believed in her and had high expectations of her (Livingston, 1988) and provided the necessary support to facilitate her taking on an innovative role (Mars, 1971; Munson, 2002; Zischka & Fox, 1983). Her director recognized her talent and need to move on and helped her carve out a new role for herself so that her professional spirit and talent could soar (Livingston, 1988; Zischka & Fox, 1983). PF started her innovation with a clinical observation and need for novel approach, much like MM, RI, LK and QRT, but PF took her innovation to another level and developed a specialty counseling center, a new program innovation, based on her clinical work. Although many of the steps were similar, PF went beyond the innovations of her preceding colleagues, by creating a center to address the specific clinical needs of the population of cancer patients and their families that she noted required a new system of care.

The Opportunity Grabber

The Opportunity Grabber (OG) is the director of social service at a major cancer center. He has created a culture within his department, which fosters a psychosocial continuum of care for cancer patients and their families at the center and encourages his staff to take a dynamic approach to their work, championing their innovative practice, inviting his staff to participate in psychosocial research and presentations at national oncology social work meetings. He works hard to build into his staff's worklife the concept that clinical work is short term gratification and research, publication and national presentations lend themselves to long term gratification and survival in the field.

He chose to describe his role in the development of a residential housing center for family members, whose loved ones were being treated at the cancer center, as an example of something new and different that he had done. He described this as a situation that presented itself to him by his administrator as something he should take on. Although he has many areas of expertise, the running of a residential facility was not one of his skills. As a result, he was hesitant to take on this new responsibility. He realized that his administrator was eager for this to get started and that he really wanted him to do this. OG began to rethink his hesitancy in taking this on and reframed his perception of this request and novel role for him. He began to immerse himself in gathering information about such projects, and came to realize that this was an opportunity that was being placed in his lap, and he had better take hold of it and run with it. He let his administrator know of his decision and assumed responsibility for this novel undertaking. Although not his idea to begin with, he quickly became involved in the novel implementation of this residential facility and his cultivation of its benefactor. Because it was under the auspice of social work, the facility was designed to be sensitive to the psychosocial needs of families, including the provision of social work services for the residents. One facility quickly led to the construction of another and the administrator became a stronger supporter of oncology social work programs at the center.

OG's initial reluctance to take on this innovative program, quickly was transformed to an enthusiastic embrace of the project once OG recognized the potential for such a program, directed by the oncology social work department. OG's ability to see the potential for this innovative facility is illustrative of "reflection-in-action" and reflective practice (Schon,1983). OG's ability to process the proposed facility illustrates novel problem solving and use of self (Schon, 1987; Klagsbrun, 1983; Holland, 1989; Hill, 1991). To some extent, OG needed to "break the rules" of what he thought were acceptable domains of social work practice (Holland, 1989; Klagsbrun, 1983; Nouwen, 1982; Nouwen, 1979; Kubler - Ross, 1969). Once he had reflected on this project and realized the real world practice demands, he was able to take on this innovative challenge (Schon, 1983).

Like MM,. RI, LK, QRT and PF, OG responded to an external need which required an innovative approach. MM, RI, LK and QRT responded to a clinical stimulus to try something new to assist a patient. PF's stimulus was in part her need to move on to something new, which she had observed previously but needed a champion, her boss, to help steer her move on by implementing a new program. OG's innovation was stimulated by a direct request by his administrator which created the crucible for him to rethink his taking on this residential facility and reframe the request as an opportunity and challenge that he saw merit in taking on. All six respondents were committed to the provision of quality psychosocial support for cancer patients, and their successful innovations are examples of Schon's "reflective practitioners" who, equipped with the requisite training, discipline and knowledge of the field are able to step outside traditional training and perform as an artist to handle "situations of uncertainty, uniqueness and conflict" (Schon, 1987). Each in their own way conducted innovative work, perceived as non-traditional and involving risks that their conventional practice would not have incurred.

The next section will review the risks that the study participants identified as they tried something new or different in their workplace.

Risks

I don't know how inclined we are, as oncology social workers, to take risks. If we do so, it is probably quietly in the service of the needy individual or family. That's probably how it happens. I think oncology social workers tend to be quiet heroes. They do tremendous kinds of things with little need for recognition.

The fifty seven participants interviewed in this study on innovation in oncology social work were able to identify risks that they felt they incurred when they tried something new or different in their workplace. All of the participants worked in workplaces that were structured bureaucratically, with people confronting life threatening illness. Some of the respondents addressed concrete, tangible risks that they experienced in trying something new, including: physical harm to self or client; income and benefits forfeit; and job loss. To quote one of the participants:

> I use a wheelchair, due to my disabilities. My Hispanic outreach work takes me to poor, low literacy communities. Every time I go into these communities at night to run my support groups, there is always a physical risk involved for me. I have gone through a lot of difficulties and risks in reaching out to this population. There are issues of personal safety for me in my work. But the needs of this population for the services I can offer prompt me to do this work. It is safer to sit at my desk all day. But there are two types of professionals: one that just sits down and follows a routine; and the other type of professional is the one who is always looking for a break in the monotony and the routine. I am always looking for new things that give more interest to my work.

In addition to taking physical risks to innovate, another oncology social worker risked her economic well-being because it was time for her to move on and start a new program:

> Deciding to work in the Counseling Center was a huge financial risk for me. My husband was not working, had just gone back to school, so I was the main support of the family. So, I would be leaving my job in the medical center with all of its security and years of built up benefits to start up a new Counseling Center. This whole venture was risky. It's hard for me looking back to know where I got the stamina to do this. I've learned in my life, I like to be in control, so I'm doing change myself, it's much better when it's under my control than when it is forced on me.

And another thought that her innovative work would place her in a job jeopardy situation. "I worried a lot about the risk to my status and my position. I worried that I could get fired for this." These tangible examples of the risks these practitioners experienced as they proceeded with their successful innovations document some of the barriers to innovation.

In addition to these tangible concerns, the majority worried about institutional sanction of their innovative work. "I was willing to risk the center's reprimand for my client's well-being. I was willing to make the trade off. But the possibility of reprimand did bother me." And another respondent:

> There was always in the back of my mind, the concept that we do not do long term bereavement work here. I'm supposed to transfer this case to somebody in the community. I kept my work with Pam quiet for a long time. I was afraid of the consequences to me if anyone in my department found out what I was doing. On the other hand, I knew somehow that I was doing the right thing in providing bereavement counseling to Pam over the phone.

In spite of the specter of sanction, these clinicians were driven to work creatively with their clients, even though their clinical decisions were at odds with their institution's stated policy.

Another risk that many expressed was their fear of failure. These illustrative quotes capture respondent's expressed fears. "What if you gave a party and no one came and we had involved the whole institution in planning this conference." And another poignantly states:

> The risk of failure, falling completely flat on one's face. I think that is true anytime you try to be new or innovative. There is the risk of failure because you are dealing with too many unknowns. We are committed to innovation. We are constantly asking the question: Can we do it differently, can we do it better. But inherent in that is the risk that you will fail at times. But if we do, we'll learn from that and go on. I think that too many people are not innovative because a fear of failure overwhelms them.

And a final quote from a respondent who eloquently captures the issue of fear of failure and risk to one's reputation:

> Because if this fails, I'm laying myself out. So, there is a certain amount of anxiety about how I would save face if this doesn't work. I feel a bit like a mountain climber tethered by a rope. And I feel perilously close to falling over the edge. I don't think any of us feel really good about heights. I mean I can climb heights. I'm not phobic about it. But I don't think anybody would like to fall off from a high point. I guess that implies failure, because in our culture, you're always striving for high points. So, I carry a lot of fear and insecurities about whether it will really work and the right to do things differently. And shame issues about whether someone will think this is crazy and kind of do this sort of number to put down a new idea.

So, the risks of trying something new for these study participants who successfully innovated are formidable. Working in multidisciplinary settings, with turf wars, these oncology social workers were able to overcome the risks that they experienced by the following supports of innovation.

Supports of Innovation

The administration, the atmosphere is a very open, supportive one in terms of experimenting with new ways of reaching out to patients and their families and helping them.

The majority of those interviewed referenced their workplace safety net as a major source of support to them in their trying something new:

> I had support here from my supervisor. She was very supportive in encouraging me to go ahead and she provided me with a lot of administrative support. I knew that even if I fell on my face that that was OK. The message I got was that the trying it was important enough.

Tolerance for the possibility of failure is an important attribute of innovative work environments (Peters & Waterman, 1984). And another study participant: "This department is wonderful in nurturing, encouraging and supporting ideas."

This oncology social worker is able to speak to the culture of her department and work setting:

> This department is wonderful in nurturing, encouraging and supporting new ideas and especially things that are a little bit unusual or unorthodox. Although our director is conservative, if you have enough enthusiasm and excitement, you can sell her on an idea. And, my sense is that this department is very much in favor of helping people become more creative. And this benefits me not to become stale. One of the great things about working here is that nothing is set in stone. And just because something was done one way for a long period of time doesn't mean it always has to be done that way. I think if we did it the same way all the time, it would become pretty boring.

The work environment and culture are key organizational dimensions to enhance innovation (Peters & Waterman, 1982; Kanter, 1984; Drucker, 1986; Drucker, 1999).

This example contrasts the respondent's experiences in both low and high innovation settings and the impact on her:

> It's interesting because I worked in another setting before I came here. I did oncology work and felt like I had no support to do the kind of work that I felt like I wanted to do. Coming here, I have had tremendous support. There has been tremendous support here from supervisors, colleagues and the medical team to develop novel services and programs. The ideas are mine, but the support is incredible. It's not that someone says why don't you try this. I feel that it's really come from myself, but everyone has been very supportive.

The high innovation workplace provides support and sponsorship to encourage innovation; whereas the low innovation workplace provides no support for new ideas and programs (Delbecq & Mills, 1985; Peters & Waterman, 1982).

The role of the supervisor is poignantly articulated here:

> The support I get in this department through my supervisor has been really crucial about what is going to make me feel more fulfilled, helping me to figure out how to do that and giving me the message that that's an option. That's been really important. Supervision allows me to look at what is good about this work and what's hard. It's like the message that we hope we give our clients. You know, it's

> okay to feel shitty about this and not so great about where you're at or what you're doing. So, to be able to say that, to feel that I'm really struggling here and I'm not sure that this is all that I should be doing. So, someone who can really hear that. So good supervision helps you to think about what your options might be, what you get excited about, and then helps you think how you could make that become a reality. You know if I thought I had to create it all on my own and do it all on my own, I would never have gotten it done because the pressures of this work are just so great. It really makes a difference in terms of being able to develop more new programs.

The critical role of supportive supervision in oncology practice is emphasized here and the parallel process that clinicians experience in supervision in processing the enormity of the pain and issues in their caseloads and their clinical supportive role with clients. Good supervision validates the human struggle here both of the clinician and the oncology population in finding their way.

The importance of good supervision is again echoed by this participant:

> Doing this kind of work is very isolating. There are not a lot of people who are doing this work. So, when I had my own inception of the idea for a new program, I presented it to my supervisor, and getting his support and understanding and then being able to channel it to the proper administration. There was a good line of communication on up and positive feedback all the way. And the impetus and permission from my supervisor to try something new and to be given complete freedom to do it as long as it's appropriate within the hospital's guidelines.

Here we see the "open communication" patterns, an environment of collaboration, easy access to administrative staff. which fosters innovation (Kanter, 1984; Mars, 1971; Munson, 2002; Zischka, 1983). And more explicit guidelines for successful innovation:

> I think it started with my sitting down with my supervisor, explaining my idea to him, being able to tease out where my idea came from, trying to identify certain themes and the needs of the population. Setting up the guidelines for the program, trying as best as you can to anticipate and formulate an agenda and a proposal. I don't think that you can anticipate everything, but it's a good idea to try and get the basics down. And, then when you have something solid, that becomes more of a positive vehicle for you and your supervisor to go to the next administrative level. I think certain things are better when they are formalized. You have to know your

> workplace and how it works. You don't have to have the complete process worked out. So, you discuss the idea with your supervisor. Then the supervisor and the supervisee can then put it together in a more professional way and then take it to the next level when it is more polished.

So, this oncology social worker recognizes the crucial role her supervisor plays in helping to package the innovation for the next administrative level in order to enhance its success (Munson, 2002; Livingston, 1988; Peters & Waterman, 1982; Senn, 1986).

Although most of those interviewed in this study identified supervisory, administrative, departmental and collegial supports for their innovative work, a small, but important subset felt that the support for their innovations came from themselves:

> Quite frankly, it's something I did on my own. I have never shared it with anyone because I know traditionally, what I am doing is not the practice here. I felt that if I shared what I was doing, I would get negative feedback from my colleagues. So I've never shared it. I'm a little nervous now.

This oncology social worker takes full responsibility for her work and feels that she is doing the right thing with these clients, even though it is dissonant from conventional practice. She has adapted what she learned to fit the needs of her client population This practitioner is functioning "out of the box" and is aware that her colleagues would censor her adaptive interventions. She presents the hallmarks of Schon's "reflective practitioner" who adapts and tweaks her work to meet client needs (Schon, 1983; Schon, 1987). And another:

> I pretty much did it on my own. I just did it myself. You know the whole thing about a mentor, well, I never had one. Early in my career I had close friends who worked in oncology, who were great supports to me. But over the years, I have worked for quite a range of characters and I learned to do the opposite of what they recommended. It has not been a star studded cast. I had very good friends in oncology, but let's face it, in terms of somebody above me, there is no one and I make the decisions myself. I have had to do what I have had to do in my position and I did not win any popularity contests as an administrator. I have had a level of

> economic security so I have never had to be afraid that I would not have enough money. I've always gone through life assuming that I would be employable someplace, so I have taken risks on my own without institutional support. My ethics and concerns about the programs and the environment of this setting prompted me to take risks, become a whistle blower, on my own and were based on my decisions without support or sanction from the workplace. I am a leader and have made decisions to make this place better.

This respondent has been able to step outside the norms of the institution and take directive action based on organizational conflict and need for leadership. He epitomizes Schon's "reflective practitioner," who accessed novel problem solving and use of self to transform a workplace (Schon, 1983; Schon, 1987).

For the majority of the respondents, the support of the workplace environment and supervisor was critical for innovation:

> I have immense support from my supervisor. I get support and encouragement. I really can't do this on my own. I feel that the motivation is here to begin with, and then with the support I really feel very good about pursuing these new methods of helping.

However, a smaller subset of the study population felt strongly that they innovated on their own, without support:

> I thought of it on my own. I'm a much more independent type of person. I don't feel I need to run to someone to say: Well, I'm thinking of trying this; what do you think? I'll just try it, okay, let's do this and see how it goes. But I wouldn't describe myself as trying things that blow up. Hardly, I've never had that happen. I guess maybe because of where I am in my career, where I am as a clinician, that I am more mature.

And another participant addressing this issue.

> I think the thing that's been the most supportive of this work has been my commitment, my own practice and my own belief in how important it is. And so I keep doing it because I feel that this is the way. For me, anyway.

These practitioners cite their own belief system, their commitment and their inner well spring as all the support they need. to innovate. "I've always been interested in doing things a little differently."

Others acknowledge that the combination of their own internal motivation and external acknowledgment make all the difference in the world in their sustained creativity.

> A lot of the work that I do is behind-the-scenes work, where I'll work for months and months for a paper to come to fruition. And it's really very difficult sometimes to keep the motivation coming from within. So, when I get this external support, I find it very reinforcing. It helps to get reinforcement and recognition, because the outcome of our work in an oncology social work department is difficult to measure. There's little profit incentive. I used to like it when we got financial reward and recognition in terms of increments. The fact that there wasn't one this year, after a very, very productive year, was the most difficult thing I've ever had to deal with in a job situation. In the absence of that, I've really had to reach for it from within myself and it's been quite difficult.

This participant echoes the need for support, money and time to foster innovation (Peters & Waterman, 1982) and a "culture of pride" and recognition of employees by management (Kanter, 1984; Munson, 2002; Zischka & Fox, 1983). These supports are critical for all employees, including highly self motivated individuals as exemplified by this worker.

Barriers to Innovation

I think trying new things is scary. You have to step outside your comfort zone to try new things. And sometimes we get very comfortable in what we do and it becomes almost a routine. We tend to get comfortable, at least I get comfortable in my ways. So any change is difficult.

There are a number of barriers and obstacles to innovative practice which the participants described. Fear of failure was a repetitive theme:

> Fear of failure, criticism, disapproval from peers or people in superior positions, fear of disappointing myself or others and them finding out that I am the imposter I

> think I am. And fear of being judged and evaluated. And I suppose the bottom line would be in a job that the performance would be so poor that you wouldn't have a job someday.

Another spoke of "getting your ego damaged and fear of rejection by your colleagues, other disciplines or getting shot down by a patient." So, genuine concern that a novel intervention might " not be receptive to clients or could possibly cause harm or damage." Concerns about lack of confidence in oneself surfaced: "Some people have more chutzpah than other people, more security in the interface between their professional and personal lives." The role of the setting in evoking these fears is expressed here: "Fear of whether or not it is going to be successful. Are people going to think it's a good idea? Are they going to help or are they going to support or discourage it?"

Other critical obstacles for participants involves colleague or institutional induced shame. "I know I have the right to do things differently. But I feel shame about whether someone will think this is crazy and kind of do this number to put down a new idea. So, it was hard." And another addresses professional barriers in social work which get in the way of innovation.

> My experience in social work is that we are not real supportive of ourselves. It is painful to say that, but I think that is true. I see that particularly in teaching hospitals, where there is an atmosphere of competition. Instead of each of us saying: Oh, isn't that wonderful; it's let me see how I can tear this down in order for me to be okay. I see this in social work, nursing and other ancillary health care programs, where women are the majority of the profession. I don't think we know how to support each other very well. I think we would try more new things, but that message pervades. Everyone knows it at some level, whether it is conscious or not. I think it keeps people from trying.

These powerful thoughts are consonant with the body of literature describing the general impediments to innovation in organizations (Peters & Waterman, 1982; Pointer, 1985;

Senn, 1986; Munson, 2002; Zischka & Fox, 1983; Delbecq & Mills, 1985; Drucker, 1999). However, these respondents bring a fresh look at the challenges to innovation in oncology social work, which have not been chronicled in the literature thus far.

The struggle between the traditional stance in providing service and a new approach to helping a patient is expressed here:

> The struggle in our profession between the traditional social work role of who we are, our identity per se. It keeps us down. You're supposed to do it a certain way and if you do it differently, there is not a lot of support for doing it differently. So either one has to have already faced the demons and risked before, and is in a safe place, so it's okay to do it. Some of us, our whole life is in a safe enough place to take that jump and try something new. But others are not able to take that risk because they are uncomfortable with it.

The theme of traditional approach vs. novel approach and the safety of staying with what is known as opposed to moving in a different direction to intervene clearly obstructs innovation.

The disposition to move from the safe to the unknown is a common theme implicit in this study:

> It's been very hard, very painful for me this past year with some of the responses from social work. I've had to struggle with that because there is in me that wanting everybody to support and say: I'm wonderful. Having to go against everyone has been very hard. It's been lonely and that's the other side whether people want to deal with that. I went into social work in a hospital because I am a social person. I made the decision to not go solely into private practice and stay here and create a whole new program because I am a social person. Yet by definition of doing this differently, I'm isolated and have had to deal with that. For me it came down to I can't sell out. There's too much of a push in me, a whole aspect of me that I'd be ignoring if I did not do this. So, the cost would be too high for me if I did not do this new project.

In spite of the tremendous obstacles, including isolation from peers, the cost to this participant would have been higher had she not innovated. This drive, heroic spirit and courage is exemplified in most of the study participants in the face of all odds.

Another obstacle is the fear of being disloyal to the group:

> In my previous job, the department was at war. And I remember when the director came back from vacation, she brought all of us back little pill boxes exactly the same so that no one would be jealous of the other. I don't think that was by chance. I think that's some of how we were. I don't think that kind of thing supports individual growth. It's like we're all supposed to stay the same glom and if you leave, you are disloyal. And I don't mean literally leave. I mean some way professionally move on.

An example of the rigidity that sometimes exists in departments which can stifle innovation and reflective practice. Lack of respect and trust by the institution can interfere with innovation:

> A lot of my colleagues throughout the country don't always have the respect and trust of their institution and their department's sanction to go ahead and try something new. So, a lot has to do with where you are. And if you are not in the right place at the right time, I don't think it is always possible.

The culture of the workplace, systemic lack of respect for the practitioner, precarious status and position and administrative disapproval can be major constraints to innovation. An insightful interviewee acknowledged the developmental stage of the institution as a barrier to innovation:

> Where the institution is can sometimes get in the way. We have had so much turnover in terms of physicians, staff and this whole program has been turned inside out so that the psychosocial things are not as forefront as ought to be and once were. There is so much catching up that we have had to do because we've gotten so big so quickly. That can be problematic and get in the way. They have spent a tremendous amount of money on a huge biotechnology program, it doesn't leave a lot in the pot. If you had all the money to go along with all the developments it would be dynamite, but you have to do it in stages.

This example of too much growth at one time, not planned incrementally, with over expenditure in one area, illustrates the deleterious effect of organizational dissonance on the oncology social work department's ability to innovate in a major medical center. Too rapid growth, with divergent institutional needs and priorities impose fiscal limitations on oncology social work in host settings.

Cited by many of the study participants was lack of time as a barrier to innovation.

> There is not a whole lot of time to think about things, to formulate ideas and to consider trying new things. The work is so unpredictable, overwhelming and draining. There is not a whole lot of time to say: Oh gee, let me think about this case for awhile and figure out something new to try. It is so frustrating that there is not a lot of time to think about things thoroughly and think about what might be different and formulate a plan.

Relating time to the nature of oncology work, one participant said:

> Clients already have the illness so they feel an emergency to act. They feel their time is limited and they feel the clock ticking away and so are more willing to consider change, something new. Their fear is the motivating force. My colleagues don't have that. They don't hear that clock ticking away. It's very difficult for them to consider change, doing something creatively different They are consumed with their everyday lives, work demands and time constraints.

The exquisite sense of urgency for the patient population and the lack of time to innovate for the oncology social workers, who do not have the time to reflect on their practice, to be "reflective practitioners" (Schon, 1983). And another:

> I just don't have enough time to put into developing new interventions. That's the biggest obstacle and the size of our caseloads. Some days it seems like you're just putting psychosocial Band-Aids on so many people. You need time to develop a new intervention and to research new skills, as well as having the time to put these into practice. And that just doesn't always become available.

This example depicts the trajectory of time and the processes to develop and implement new interventions.

The workload is considered by many a significant obstacle to innovation:

> Sometimes I get tunnel vision because I feel pretty overwhelmed by the demands that are placed upon me by my workload. I can get so focused and wrapped up that it is hard for me to step back and think that there might be a better, easier or more

> creative way to manage this, because that takes more time and energy. If you don't have the time to even let yourself think about it than how are you ever going to try something new. So, I think the demands of the work interfere with taking more risk.

Large workloads and lack of time for reflection are perceived as major hurdles to innovative practice.

The following poignant statements about the nature of the workload express additional obstacles to innovation:

> The sheer numbers of people that I work with. I speak for myself and looking at my colleagues, I feel that everybody feels like they are spread very thin. And the numbers keep you from innovating. The numbers keep you running so much that you feel that you are so busy, you don't have the time to think about trying new things. Not finding the time to think about what might be different.

And another:

> Oncology social workers have too many cases. That's probably the biggest stumbling block. Because how can you do something fresh. Usually creative things are somewhat time consuming. You might have to get some materials together, go out of your way physically. And when you have things stacked up, sometimes all you can do is the bare minimum. I often feel that I have not even done an adequate bare minimum for patients and families. So to go the extra mile is a real problem. Because of our administrative duties, it's hard for our host settings to permit us. It is not that they are stodgy. But I had to respond to my beeper. There were times I had to cover the emergency room and I could not be gone when that was my duty. You can't foist your intakes on someone else or be doing something else. So, our caseloads, administrative duties and responsibilities get in the way.

Clearly the press of the ongoing work distracts practitioners from focusing on a particular new area of practice innovation. The self discipline required to do so in these settings is extraordinary. The environment, daily routine and pressures described by these respondents makes it difficult for workers to think reflectively on their practice.

The concluding barrier is the education and training of social workers:

> We have become overeducated as social workers. I think we have become too theory based and have lost our edge as social workers. We've become too much clinicians and not social workers. I think we are too focused on trying to label and categorize people now, as opposed to taking the interactions and just dealing with the set of circumstances that are presented to us. We do too much book learning now and not enough experiential stuff. I think we should spend more time out in the field as opposed to classes.

And another perspective which addresses the training of social workers:

> I hope the structure that is imparted in school will change. These are the sort of ways you do things and this is how you introduce yourself to a client, this is how you make a contract. All of those things that get tucked away in the back of your mind. I feel that sometimes here in an oncology setting I sort of toss those aside. I say it doesn't matter what the books say about you're not supposed to touch a client. Those things are ridiculous. I mean to not touch someone in certain situations would feel completely wrong to me. But those kind of things, I don't know if they actually fully inhibit me from being creative, but they make me stop and think about it and question it, which maybe is not such a bad thing.

Trained to maintain professional distance and boundaries, oncology social workers learn that to be effective they need to struggle with the ongoing challenge of achieving "the right balance between professional distance, human connection and closeness" so needed by patients and their families (Hill,1991). The skill and art of oncology social work includes the capacity to bridge the gap between "professional knowledge and the demands of real-world practice (Schon, 1983; Schon, 1987). It is notable that practitioners are aware that their traditional training may pose an obstacle to them in their practice. To circumvent this obstacle, Schon poses the model "reflection-in-action" to identify the professional equipped with the requisite training, discipline and knowledge of the field who is able to step outside of traditional training and perform as an artist to handle "situations of uncertainty, uniqueness and conflict" (Schon, 1987). These practitioners exemplify an awareness of the need to conduct themselves in this manner to adapt to the needs of the population served and to overcome the impediments of their training. As the last respondent commented that her training causes her to stop and think, which is a good thing in her work.

Typology of Innovators

People usually have good ideas, but they don't know how to go about getting them into reality.

An unexpected discovery in reviewing, coding and organizing the data was the emergence of a typology of innovators. A surprising finding was that the participants self described themselves in such a way that they logically, redundantly began to fall into three categories of innovators: The Reactor; The Academic; and The Initiator. These three categories of innovators are perhaps the most significant finding of this study and provide a fresh look at innovation in oncology social work. In the tradition of grounded theory, these categories emanated from immersion in the data and leaped out at the researcher in the repeated review of this data (Strauss & Corbin, 1990; Miles & Huberman, 1994; Patton, 1998).

The Reactor

The majority of oncology social work participants in this study who try something new do so in response to a compelling and poignant situation that is not solvable by traditional tactics. For example: "There is so much helplessness and hopelessness in my caseload, that I would try anything new to try to alleviate the suffering." And to quote another: "When things are so bad, why not try something new, some new intervention to try to help, especially when the conventional ways are not working." And another:

> With cancer patients, their level of misery is so great that if you are nervous that you might make things worse, you realize that things can't be any worse for them. This maybe gives you the confidence to try something new.

This quote captures the spirit of The Reactor:

> Sometimes I get into a niche. It's worked for me in the past. It's comfortable and I stay there. It's not that the patients are mundane or anything like that, it's just the day-to-day gets mundane. The reality of the day-to-day, where all you have is papers on your desk and phone calls to make, and there's nothing more challenging than moving that stuff along. I'm in an energy lull, just going about my paces and suddenly this is driving me nuts. This usually happens when I am working with a patient and have tried my old bag of tricks that feel comfortable for me, and it doesn't seem to work. And the patient keeps saying the same thing over and over again to me, and it's clear that I haven't heard them because my interventions haven't worked. It is then that I am willing to try something a teeny bit innovative and that's usually how I present it to patients. I've been working with you and we've been going in this direction, a little bit if that doesn't work, and then we'll come back. More or less reluctant, but willing to give it a shot.

And this candid quote strikes at the essence of The Reactor:

> I think because my own self image is not of myself as an innovator, that all my innovation has always come about by situations calling for it. So, it is more rising to the occasion that presents itself, rather than sitting back in my chair, which you never have the luxury to do, and thinking of ways to innovate. I think it is always a reactive phenomenon, a responsive phenomenon. I think with our caseloads, a lot of what we do is reactive instead of proactive. I think it is good to be resourceful. And it would be nice if we would have more luxury to sit back and innovate in a programmatic way, but it ends up always being whatever is needed at the time.

This concluding quote emphasizes the heroic aspect of these innovators:

> It is hard for me to generalize, but as a profession, oncology social workers are not inclined to take risks. If they do so, it is probably quietly in the service of the needy individual or family. That is probably how it happens, identifying resources that weren't known anywhere else, those kind of things. I think oncology social workers tend to be quiet heroes. They do tremendous kinds of things with little need for recognition.

In summary, The Reactor represents the majority of study participants' approach to innovation.

The Academic

The Academic is a smaller subset of study participants who innovate as a result of attending a workshop, seminar or conference, reading a journal article, taking a course or being exposed to a new way of doing things in a training or staff development/ in service meeting or group or peer supervision. The feeling of being exposed to novelty and its impact on practice is expressed in this quote: "When I attend conferences, I feel inspired to try something new." In this example, the participant cites the specific area of innovative practice and links it to her formal training:

> I am experimenting with the use of Pain Diaries. This is much more intellectually based and more focused than any other type of work that I have ever done. I started doing this after reading a book on cancer pain management and subsequently attending further seminars in this area of practice. All this gave me the idea of what a pain diary is and I have been able to sort out for myself that this is something I would like to experimentwith. It's really neat and I am having a lot of fun with it.

The impact of extensive training on innovative clinical work with an oncology population is echoed by this respondent:

> I just finished a three year Post-Master's Clinical Training Program, and I would say that has really helped me look at my clients somewhat differently in terms of being able to better appreciate all the many psychodynamic issues that might impact on how they deal with the diagnosis. It has broadened my perspective and given me a better basis to provide creative counseling to patients and also in terms of providing perspective to staff about who these people are and what their struggle might be about. I have organized weekly case consultations on floor rounds and never would have had the confidence to set up these rounds, without my extensive training.

Another powerful example of the impact of education on innovation:

> Last year I did a fellowship in oncology social work, studying working in metaphors, being much more aware of the symbolic ways in which people are able to talk about what is going on. My being willing to join with them in that - not always having to pull it back into reality, but knowing that that's where sometimes people are able to talk. So, that has become a new approach for me, which has really helped in my work here. I am thinking about a case that I did a lot of work with last year. Charlotte, who was getting a bone marrow transplant and was so fearful of the transplant. She had decided to go ahead with it, but with lots of trepidation. It turned out that she loved gardening and was an avid gardener. She would talk a lot about having plants and putting seeds into the ground and watching them grow. She would describe what you have to do to take care of them and a lot of that talking was around the time she was getting her bone marrow transplant. My being willing to work within that with her, using metaphors and helping her make those connections, was powerful for both of us. I saw her throughout the seasons. It was good to have an experience like that - it was really useful for Charlotte. I know I helped her get through her transplant and it was worth the risk. And I think that part of that knowing wasn't something that my training in graduate school had prepared me for. It helped me to have had the fellowship training in working in metaphors.

Clearly, these examples cite the significant role of educational instruction as a stimulus for some oncology social workers to try something new in their work.

The Initiator

The Initiator category applied to only a very few participants in this study. These oncology social workers were by their very self proclaimed nature on the lookout for innovative opportunities. They did not wait for a training or a dire clinical situation to propel them to try something new. On the other hand, they lived to innovate. It was as much a part of their persona as eating, breathing and sleeping. No matter where they are, they find situations in which to innovate. For example:

> I like to keep it new and fresh because that's what keeps me stimulated too, I think if it starts to sound like a canned speech, which someone once accused me of doing, a very angry patient, said that it sounded like a canned speech. I had to stop and think. Is that what it's coming across like – even though that's not what I feel. So I try to keep it fresh and really work hard to approach each new case with no preconceived notions as to how I'm going to do it, but really find out what they need and proceed from there. So, I expand my job description to suit my needs, also in terms of what I want to do as a professional and a clinician.

The commitment to try new things as a lifestyle is expressed by this respondent:

> I am an adventurer. I've always been that way. I mean, I go mountain climbing and hiking and I've gone on vacations where I haven't made any reservations for my housing. I just wing it. And I like to do things that way. I guess I really believe that life is an adventure. And that's the way I live my life. And I feel that the one thing that's true, more than anything in the whole world, is that things are constantly changing. And that if we get fixed and rigid in any one particular thing, I think that's death. And so I think we need to always be learning new things, trying new things. Because otherwise you get tired of what you're doing. You get bored with what you're doing, and that's what you reflect to your clients. So, I always like to do new things. You know, and the people who come in to do these things, like imagery and meditation, are very excited by it, because it enables them to see how they're open to new things, new learning.

And additional comments from another respondent who likes to initiate change as a philosophical approach to life:

> I have learned a lot since I have been here, from patients and families. Change happens to us whether we want it or not is my personal philosophy that I have come to through all this. And it isn't because people are good or bad or whatever, the saying in the street, shit happens, well it does. Change in one way or the other I think happens and so it's adapting. My particular philosophy is that our task in life is to adapt and how we are going to handle that change. I'm somebody I've learned in my life that I like to be in control. So I'm doing change myself and it's much better when it's under my control than when it's forced on me. I think it's a mastery thing as I have come to do it and found that it can work and really can be fun.

There were only a few Initiators in this study cohort, but they are an important group of oncology professionals who bring a particular perspective to innovation in oncology social work.

Summation of Typology of Innovators

In this exploratory study, oncology social workers cited a variety of factors which . stimulate them to innovate in their practice. Their responses were categorized into a Typology of Innovators. The Reactor, who innovates in response to situational need; The Academic, who innovates in response to new learning/training and workload applicability; and The Initiator, who innovates in response to an inner drive, their own personal philosophy and need to try new things. Many respondents noted the tragic and crisis nature of the work as stimuli to try something new in an effort to ameliorate the situation. Out of the depths of despair, some practitioners were moved to innovate. This unanticipated discovery of a typology of innovators merits further study and exploration, since it is not documented in the literature.

Chapter VI

Quiet Heroes: Recommendations and Implications for Practice

Introduction

This study was conducted to explicate the critical factors that impact oncology social workers to innovate in their daily practice. The preceding chapter highlights the following factors as contributory to innovation: organizational culture; supervisory/ institutional support; client need; staff development opportunities; continuing education; conference/ workshop attendance; collegial exchange; networking; role models of excellence; and practical supports. In addition, Chapter V also summarized the factors that participants perceived as inhibiting innovation, including: personal demons; fear of failure; competing demands, such as time, workload, energy, other priorities, everyday life; resources; money; traditional training; other staff; institutional/ systemic/ administrative barriers. A poignant refrain was: "People usually have good ideas, but they don't know how to go about the process of getting them into reality." In this concluding chapter, the focus will be on participant recommendations to foster innovation; innovation as an antidote to the stresses of oncology social work; and implications for practice.

Recommendations for Practice

There has to be an institutional mandate to take care of the people that do a high risk job. If there is not a mandate, then you are going to have problems. People will not be as creative and will not have the energy to take on new things.

The participants identified three areas of focus as recommendations to foster innovative practice in oncology social work: administrative and supervisory underpinning of support; staff development; and time set aside to think. Leadership of the department was seen as impacting staff's potential. "If you have good leadership and the department is well respected, then it is easier to try new things. But if you have an ineffective leader, your department is not going to be seen as well." The need for top management to commit to innovation is echoed by this respondent.

> I first think that they have to make a commitment at the top administrative level to support new, innovative programs. And they also need to advocate through the system for these programs. Administrative staff have to be cognizant of what the clinical staff is doing so they know where time is being spent and where corners may be cut so that new things can be developed. I think administration hasto be willing to give up trying to be all things to all people. We also need to include the people on the front lines doing the service in the planning. And that people feel recognized and valued for what they do

The recommendation by the respondents of the need for strong leadership, which builds well respected departments and involves front line staff in decision making is critically important.

"Staff need to know that the administration has confidence and believes in them, gives them recognition, treats them as professionals, encourages them and provides a safe environment to think in another way and to try new things." A culture of pride in the workforce is a frequently repeated theme by respondents as well as the literature on innovation in organizations (Kanter, 1984; Drucker, 1999; Livingston, 1988; Peters &

Waterman, 1982). Another comment:

> Be open to new suggestions. You have to always allow your social workers to grow. I think that you do that by allowing them to try new techniques, sending them to conferences, allowing them to network with other people an providing enough in-service education. Encourage people to be flexible and grow. I think that is one of the reasons we are able to hold onto staff.

So, this administrative attitude of support also helps to retain staff:

> What is really wonderful about being here is that we are encouraged to find our niche, to do one's own thing. There's no sense of being held to a rigid role and administration appreciates and cultivates each of us.

This comment speaks to the importance of a culture that develops the potential of staff as fully as possible.

The powerful context of oncology social work practice and the special need for administrative support is reflected by this respondent:

> We're working in somewhat of a depressing field. You're surrounded by a lot of terminal illness, a lot of death. I mean there are success stories but it seems to me that the folks that are referred to us are primarily the sicker ones. Certainly, more people on your caseloads die than live. So, I think that continued and extensive support from the department and the hospital helps you recognize that your work is valuable and that sometimes is enough to make you feel enthusiastic about your job and try novel approaches with clients.

Administrators and supervisors are a major source of replenishment and support to staff in carrying on with the daily work (Blum & Fisher, 1983; Holland, 1989; Lederberg, 1998; Reese & Sontag, 1999).

The need for administrative backing and assessment of some of the pitfalls of innovation are expressed here:

> It is important to convey a respect for the work that people do and also convey a respect for their need to branch out. Also, to just be very honest about the constraints that do exist, and not leave it at that. It is very easy to say no that will not fly. But I would rather reframe that as to there are these constraints and how can we work around them or modify them. I don't take no for an answer real easily from institutions. I think if there are pitfalls, helping them articulate what they need to do and pointing them in the right direction. I guess being a conductor. That's how I kind of see this role, that's exciting. Being willing to take some risks and letting people do things in a way that's different from how I would do it. There's a real delicate balance in conveying that without squashing somebody.

This exemplifies the role of the manager in helping staff to make their innovations successful, by helping them with small, feasible, incremental change (Delbecq & Mills, 1985; Peters & Waterman, 1982; Drucker, 1999).

The morale of the department impacts innovative practice.

> The attitude of our director is very encouraging about having us grow, learn and take on new things. She seems to have confidence that we can do it. She encourages us to submit abstracts to national oncology social work meetings. The encouragement works better than guilt. It's great to work with colleagues who are into it too, because we feed on each other's ideas. Enthusiasm is contagious, not only from higher up but from colleagues, all around morale. It helps to have a secretary who is energized and willing to be helpful.

The culture of the workplace emanates from the shadow of the leadership impacting on all levels of staff (Senn, 1986).

In addition to the departmental director, the pivotal role of the supervisor is expressed by many of the respondents as fostering innovation.

> Supervisors need to encourage their supervisees to experiment, probably by case study methods, meeting around specific cases and looking at different approaches. Reviewing both traditional and new approaches to helping somebody cope is important and playing that out. And then the supervisor needs to support and encourage those who actually do try.

The role of the middle manager in buffering the negative impact of the organization hierarchy and supporting innovation is critical for front line workers (Mars, 1971; Livingston, 1988; Munson, 2002; Weissman, 1990).

> Good supervisors are role models and instill confidence in their staff that they value them, their ideas and their trying creative things. They create an atmosphere where supervisees feel safe, being listened to and having some sense of autonomy. The supervisor needs to be open to creative thinking and projects and to listening to the supervisees ideas. I feel that a lot of what we are trained in is the path to do it and not so much the ways to find what is your own style. My supervisor has helped me to look at my developing my own style.

As these respondents listen to their clients, they need a feedback system in which they are listened to and given the opportunity for reflection on their own experiences and style of helping clients.

The study participants recommend strongly the importance of staff development and continuing education, given the complexity of oncology social work and the many new scientific developments of which they have to keep abreast.

> I think our staff development meetings are excellent. Many of them are stimulating and we are encouraged to take whatever we can get, even if it's just one little technique, and try it in our individual or group practice. I would recommend using a similar model that we use, monthly in service trainings on topics that staff members feel that they need to learn more about. We invite people who can educate on specific topics. Our topics have included: different interviewing techniques, working with cancer patients and families with alcoholism; therapeutic touch; clients with a history of incest; and working with families. So the in-service is not to make us the experts, but if we can recognize those issues in our caseloads so we know what to do. How you might deal with the situation then might stimulate you to learn more about the topic. That's what I did. I just thought I see a lot of families and family approach is very different than seeing someone individually, so I thought I should learn more about how to work with families. I went and took the course because I thought that was important in my work here.

Not only is the staff development seen as important, but the opportunity for dialogue amongst staff that occurs in these trainings was discussed:

> Not just staff development with an expert speaker, but the forum to talk about what it is that we are trying and the support around that. I think the seminar I took was a goldmine with all of us talking about what we do and then learning from each other. I think that we all have such good insight that it was really exciting to learn from each other as well.

Particularly, with the many stresses inherent in oncology work, the opportunity for staff to talk about their work and experiences is critical to their learning, coping and growth. Sharing their work with each other can be very inspiring for oncology social workers and stimulate creative thinking.

The practical reimbursement by the institution for taking courses is highly recommended by study participants.

> Give any kind of educational tuition benefits to people who want to take courses, study or go to conferences. The financial reimbursement really makes taking courses feasible. Fortunately for us, we do have tuition reimbursement as long as the course relates to your work here, they will pay for it.

The moderate salaries of most oncology social workers might preclude their taking courses without tuition reimbursement. "I probably would not have been able to afford the courses I took; but because of the tuition program, I was able to take the training and to use the skills in my work. "And another views the tuition program as a bonus:

> We have a reimbursement for any education that we do so we can continue to take courses. That money is like a bonus or a perk for us. Of course, the ideal would be to be able to take time off to take courses.

Another feature recommended is "the Department having discretionary funds, set aside to send staff to national conferences and regional meetings. Also, the institution identifying relevant training opportunities and workshops so that staff is made aware of them." The importance of communication with oncology social work staff about the range of training options available to them and keeping them informed of these along with funding for attendance is advised by this study cohort.

Time set aside to think came up in a number of different ways during these interviews. The idea of a sabbatical was discussed by this respondent:

> I think the world of education is good in that way. I think the idea of a sabbatical is very appealing - to have a structured opportunity to devote a significant amount of time to at least the exploration of a different area. So often, the utilization of social workers is such that there seems to be little opportunity for expenditure of much energy beyond what the day-to-day delivery of service permits. Something in the realm of that sabbatical or a variation of that could be very useful. I think what happens now is that some departments will organize a retreat, an annual retreat, but my concern about that is that the expectations become so high that it can never meet them.

The need for time to think and reflect about the work is a dynamic theme in the literature (Schon, 1983; Hill, 1991; Klagbrun,1983; Weissman, 1990). The study participants in addition to recommending a sabbatical, also recommended the implementation of sanctioned time off for reflection. For example:

> I think in terms of the time issue that there should be some time set aside to do that kind of work in much the same way that the docs in this department and the nurses set aside time. We are a research institution and have a certain amount of time set aside that is considered research time. I think that it would be helpful for us to also have time set aside to work on other projects, whether it would be strictly research oriented or not. The way it works for docs is that every doctor and every attending has a research day and basically their schedules are set up for that. It's a day when they do not see patients, where they may or may not be in their offices and they may be off anywhere, so that's really supported. I would like to really feel that that was not only something that you are supposed to do, but here's the time to do it. This would provide more time for my own professional development.

An interesting recommendation and one that appreciates the need for time to think, read and do research to stay abreast of the field and continue to grow.

Regarding time to further develop one's interests, this respondent has much to suggest:

> I think if people had a couple of hours a week or a day a month to do some research, to do some reading, to have a pet project that really was their own, that had their name on it, that creates a feeling of ambition, drive and eagerness to innovate. When your host setting gives you a message that we value this, go ahead and write a paper if you want to or do such and such if you are interested, it means more if they say: it's so important and valuable for you to come up with ways to keep your work fresh and exciting, that we're going to give you time to do that. And I think letting people specialize in having babies of their own, that's wonderful. Because when people have an investment in something, they are more likely to be creative and fresh rather than feeling that they're working on an assembly line. Let people have time, their own interests and their name on something that's really their own and they'll take pride in that.

Time to think, do research, write a paper or prepare for a presentation represent reflective time that busy oncology social workers have too little of: "I recommend an administratively approved , sanctioned, maybe an hour a month of creative time. It could be for brainstorming with colleagues with sanction and encouragement from administration." The perception of many participants is that this acknowledgment of the role of structured, real time in their work schedule to share ideas and current work with colleagues, read and do research would enhance innovation in organizations. The need for time to reflect and process the work of oncology social work is a consistent theme of this study cohort and also mirrored in their recommendations for thoughtful supervision and continuing education:

> It. is in those periods of reflection that you really learn and if there is some way to structure in those periods of reflection, then our learning would be so increased. That's why I went back to school for my doctorate, to have more time to think, read and be creative.

Innovation: An Antidote to the Stresses of Oncology Social Work

Trying new things makes the work less stressful. All of us here have been involved developing new groups for family members and patient survivors. We have found that to be a wonderful balance, almost antidote, for the stresses of working with a sick and dying population.

The majority of those interviewed felt that trying new things was essential to their being able to do oncology work. Many spoke to the life affirming nature of innovation in the face of illness and death and felt that their trying new things provided more options and tools in their work.

> I think for sure trying new things makes it less stressful. There has to be a balance. Nobody can just see patients all the time or else it's really going to do you in, particularly if you are in a place like this. I think doing new things is a way to keep yourself alive. It's a way you test out what you know clinically. Does this really work? Is my thesis about this kind of patient accurate or not? Is this group a better way to serve this bunch of people than seeing them individually? I think that is essential to helping people in the field survive. And if they don't have the time or the mandate to experiment, then you're gunning your own program. If you don't allow for that, build it in. Otherwise, you can only do the same thing so many times and then you just run out of any kind of inclination to keep doing it. So, I think it is essential to keep people committed.

This respondent describes the need for oncology social workers to cope with the stresses of oncology to have a diverse clinical repertoire to draw upon and one that is dynamic and responsive to new approaches to care. Although the oncology healthcare literature cites the need for a repertoire of coping strategies, it has not included trying new things and innovating as one of them to counteract the stresses of the work.

A number of participants spoke of the stimulation and life force that trying something new offers:

> On balance it makes it less stressful. There is a mental stimulation that is gratifying. There is an intrinsic pleasure to learning something new, seeing something in a new light, that I think lessens stress. Creativity mitigates and works against the fear of death. I have tried to steer my patients toward the more creative parts of their lives, because I really do think they do get some release from that. And I think it's true for us as well. Our creativity lessens fear and anxiety. If you want to get philosophical about it, it's the life force as opposed to the death forces. And for me the learning and doing new things make things lighter. It has a lot to do with lessening the feelings of helplessness and increasing feelings of control.

The multidimensional components of creative practice in facilitating the work and coping of oncology social workers are exemplified in this quotation.

The impact of the work on practitioners and it's motivating them to innovate to counteract the subtle erosion of spirit from the daily assault of patient contact is poignantly discussed by this worker:

> I have an enormous respect for the people who have the capacity to look at things a bit differently or find a unique way of framing it. So, on those occasions when I can do that, I feel renewed motivation and energy. There are so many factors that come into play. I think where one is literally chronologically vis a vis an organization and one's profession. There are moments when I find myself still thinking, when am I going to discover what I want to do with my life. I wonder if there is that moment where you fully give up that mask. The time for that has passed. This is one of the things that this profession has done for me. I experienced this most powerfully when I was working on the palliative care unit. The experiences of being with terminally ill patients, some of whom had profound regrets at not having done what they may have wanted. I think that on some subliminal level that became such an incredibly powerful message. Don't postpone, don't delay, don't assume you have forever. It's interesting to see how that impacts in various ways on oncology social workers. These are truly tragic events to be filled with regret with no opportunity to do anything about it. So, I think this is the crucible for wanting to innovate, to try out something new and to energize my work.

Many felt that their new interventions increased their options to help and kept the work fresh and not stale:

> The more options you have the less helpless you feel and the more avenues there are to explore something. So, trying new things is really just saying there is another way of doing something. With patients, you are giving them another option, a sense of some more control. It gives me more flexibility in my practice and different ways to help and deal with the things I struggle with, rather than choosing one particular narrow way. When I am faced with a dilemma with a client or am at an impasse, I can step back and get a chance to look at it and then try something new. And in those moments trying something else does relieve stress.

Impressive in many of these quotes is the practitioners' commitment to help against all odds, to make a difference, to come up with something that might in some small way alleviate suffering and distress.

The life affirming component to innovation was mentioned by many of the study participants:

> Doing new things is very life affirming. And being stuck in a groove with all the sadness, feeling burned out and stale and doing the same thing over and over again is not life affirming. It really is death. So, I think any kind of creative endeavor promotes life. Promotes creativity, new things and new possibilities and of course, reduces stress.

So, the metaphor of life and death, "when there is life, there is hope" is inherent in the perception of creativity as affirming life promoting, novel interventions.

That the creative helping role is an uplifting one is powerfully stated in this quotation:

> Any time that you can use your spontaneity, creativity and flexibility, almost in an artistic kind of way, can only help. And, after all, social work is an art. It's not a science. The more flexibility you have in creating, the more gratifying the work is. You're constantly creating: an atmosphere in your session; safety; and a new perception. You're helping the patient and family to create a new perception of their situation. You're helping the client to create a new coping style or to look at an old one. Through the words you use, the images you use and the kindness you show, basically you're creating for the family a new way of looking at their crisis. And when you help someone or feel that you have helped, it is uplifting. And the more uplifting and creative things you do, the better you feel about your work. So stress

> is still there. I don't think anything takes it away really. But for the moment in time you feel a sense of fulfillment, helpfulness and competency.

So the art of oncology social workers helping others, offering best practice with creative and kind interventions may assist workers in coping with the stresses of this work. There is considerable consensus amongst those interviewed that trying new things is recommended as an antidote to the stresses of oncology work.

Caveats to Innovation

Nevertheless, there are some caveats, which are important to review. A subset of those interviewed felt that trying new things could increase stress on the short run, but decrease over the long haul, and was contingent on the success of the innovation and the setting:

> The success of the innovation matters. The cost/benefit ratio has to be taken into consideration. The cost of taking the time to develop the program, think up the program and conceptualize it has to be taken into account. If you try something new and it comes out positively, then it's worth it. As long as what you do is not a bust, then it's worth it. Also, if you're in a setting where there is sanction and encouragement, then the risk taking or the innovation-trying can be stress reducing.

For some participants trying something new alone is not the antidote to stress, but the outcome of success and institutional recognition are powerful antidotes. Whereas, for others cited previously, trying something new with the time involved reflecting on the innovation and the process of thinking about it provides the needed antidote to the stress of the work. Schon's reflection-in-action is payback enough (Schon, 1983).

Others addressed the organizational context in which the innovation occurred, which could increase stress. Was the innovation the participant's idea or was it forced upon them? Was the institution conservative?

> Trying new things in a conservative, hidebound system makes the job more stressful. Trying to swim upstream in a system that does not permit it, adds to your stress. But being in a place that says innovate and do things differently is a wonderful, supportive message to get.

The following example demonstrates the inventiveness of social workers in difficult systems:

> If the environment where you are working is supportive, then doing new things is a natural outgrowth and you feel good. If it is a hostile system, then trying new things can be stressful because you either are not going to get support, you're going to be reprimanded or you are doing something new because you are trying to thwart a hostile system. I can give you an example: When I was a hospital social worker, we used to always have to apply to five nursing homes. So, we would think of all sorts of ingenious ways to pick ones they would never get into so they could get into their first choice. There were all these types of things we would do to appease a system that was hostile and at the same time we would meet what was good for the clients. So, that was a situation where the needs of the institution and the needs of the clients were at odds. And all our creativity was geared at helping the clients humanely through a hostile system.

Here the caveat is that the worker's innovations were stressful due to the institution's mandate that was at cross purposes with their professional goals and their innovations were all directed at helping clients through a hostile system. Although they had the gratification of helping, they had the stress of potential institutional sanction and reprimand.

Trying new things that causes one to step out of your comfort zone to do something new could be stressful, depending on who one is and where one is in their career path:

> For the direct practice worker, one of the things that sustains them is a core structure that they will come to depend on. The introduction of new things might become more stressful. I think it depends on where one is at. There seems to be that elusive point between being able to do what one knows and do it well, but at some hard to define moment, to stop and check out: is my equipment still in good working order? I often use the metaphor of a car. Now a car, however finely made, it can't go forever without needing a bit of an overhaul. We have some people on

> our staff who have remarkable capacity to keep functioning. If one person stops and does the self inventory and realizes I need a break, the world is not always able to respect that. The organization can't always say in response to I need to take a break, yes, take one. It would be a logistical nightmare to try to figure out how to do that.

The car overhaul analogy and the readiness to try something new represent another way of recognizing the caveats to someone trying something new with respect to where they are in their career life cycle.

Discussion and Implications for Practice

In this exploratory study, oncology social workers cited a variety of factors which stimulate them to innovate in their practice. An unanticipated finding was the discovery of a typology of innovators: The Reactor, who innovates in response to situational need; The Academic, who innovates in response to new learning/training; and The Initiator, who innovates in response to their own personal philosophy and need to try new things. Many respondents noted the tragic and crisis nature of the work as stimuli to try something new in an effort to ameliorate the situation. Out of the depths of despair, some practitioners were moved to innovate. This merits further study and exploration.

When asked what inhibits their capacity to innovate, all respondents cited a non-supportive bureaucratic structure as a hindrance to innovation. They also noted fear of failure; volume of work; practitioner's personal style; traditional social work training coupled with constricted view of the profession as obstacles to innovation. When asked to make specific recommendations to organizations, all of the respondents recommend an institutional environment or culture which support innovation. To quote one respondent:

“There has to be an institutional mandate to take care of the people that do a high risk job, and if there isn’t, people will be too depleted to be creative and will act out.” Other recommendations identify specific organizational policies and behaviors which include: increase educational opportunities for staff; encourage professional exchange/ teamwork among colleagues; encourage staff to develop special interests; support workers in the difficult nature of the work; and set realistic goals for staff.

All of the respondents felt that their job satisfaction was enhanced as a result of their innovative practice. Caveats included the need to consider individual variations among staff; and the importance of recognizing that administrative or external pressure to innovate could be stress provoking to staff.

Although industry recognizes the importance of corporate culture in promoting innovation, social work has been slow to focus attention on the internal organizational supports and obstacles to innovation. Oncology social workers are constantly confronted with complex and profound human problems which require creative problem solving and innovative interventions. The respondents in this exploratory study repeatedly cite the role of internal organizational structure in either promoting or inhibiting innovation. The findings point to the subtlety of innovation in organizations and the need to support most staff who innovate. Organizations need to assess their need for and the value they place on innovation as they develop personnel practices and hire new staff. Further research on the typology of innovators may assist organizations select, train and hire new staff appropriate to the organization’s values and vision.

This study suggests that practitioners who innovate report that they feel more satisfied in their work. This study also suggests that the nature of oncology social work, which deals with life threatening, chronic illness and existential despair, serves as a catalyst to mobilize some staff to innovate to find new ways to meet the needs of cancer patients and their families. In some instances, innovative practice serves as an antidote to the stressful nature of the work. These areas would provide fruitful areas for future research.

The data in this exploratory study have implications for supervisors and administrators in oncology social work, as well as schools of social work. Although the findings must be approached with some caution due to the limited sample size and sampling methods employed, the study identifies the role of the culture of the setting in promoting and inhibiting innovation in oncology social work. The study suggests that training programs for middle managers and administrators in oncology social work need to be developed to foster the growth of work cultures which promote innovation. Given the changing needs of cancer patients, it is the innovative social work staff, department, institution and schools of social work that will be able to meet the future needs of cancer patients, their families, caregivers and healthcare professionals.

Appendix A
Letter

Dear ________:

I am writing to you to request your permission to visit your department and interview some of your staff. For my doctoral dissertation at Hunter College School of Social Work, City University of New York, I am conducting a research study to learn more about what influences practitioner innovation in oncology social work practice. The definition of innovation in the study is: trying something new or different in your oncology social work practice.

I would like to interview you and your staff because you and your department are known nationally for your state-of-the-art, innovative programs and services for patients and families. Each interview will last approximately 15-25 minutes. All responses are confidential (i.e. will not be shared outside the interview) and the data will be handled anonymously. No one's name will appear on any of the material.

This is a promising area of research which may hopefully add to all our knowledge about the components that influence innovative work in oncology social work.

I thank you in advance for your time in considering this request. I would like to discuss this further with you, and I shall call you next week.

Sincerely,
Carolyn Messner, A.C.S.W.
Director of Education & Training
Cancer Care,Inc.

Appendix B
Memorandum

To: Social Work Staff
From: Carolyn Messner **Re: Doctoral Dissertation Study**

For my doctoral dissertation at Hunter College School of Social Work, City University of New York, I am conducting a research study to learn more about what influences practitioner innovation in oncology social work practice. The definition of innovation in the study is : trying something new or different in your oncology social work practice.

I would like to interview each of you to hear what you think of this subject. The interview will last approximately 15-25 minutes. All responses are confidential (i.e. will not be shared outside the interview) and the data will be handled anonymously. Your name will not appear on any of the material.

I would like to interview each of you because of your work in this major cancer center.

This is a promising area of research which may hopefully add to all our knowledge about the components that influence innovative work in oncology social work.

If you wish to participate in the study or would like additional information before you decide, please call me during this week. Participation in the study is voluntary.

Please feel free to call me collect at (212) 302-2400.

I thank you in advance for your time in considering this request.

Appendix C
Interview Guide

1. Explain the purpose of the study.
2. Review confidentiality and anonymity of data analysis and use.
3. Request permission to tape the interview. Explain the use of tapes to assist in data analysis. Explain that tapes will be destroyed after doctoral study in this area is completed.
4. Obtain demographic data.

   How long have you been at ----------(site) ?

   How long have you been a social worker?

   How long have you been an oncology social worker?

   Age___; Gender__; Race ___; Marital status___.
5. Interview Questions:
   - A. Please tell me about the work you do at ___(site)? i.e. What is your specific assignment & job responsibilities? What service do you cover? What services do you offer?
   - B. Describe in your own words something different or new that you tried in your practice. Tell me as much as you can about this.
   - C. How did you happen to try this? What prompted or stimulated you to try this?
   - D. Did anything or anyone help you to do this?
   - E. Did you feel you were taking a risk in trying this? If yes, what prompted you to take the risk?
   - F. Do you often try new things? Do you like to try new things?
   - G. What inhibits your ability to try new things?
   - H. What would you recommend that agencies do to stimulate practitioners to try new or different things in their oncology social work practice?

6. Thank the study participant!

Appendix D - Table 1
Background Characteristics
(N=57)

* Numbers will not always equal 100% due to rounding.

Item	Frequency	Percentage *
Gender		
Male	6	11
Female	51	89
Marital Status		
Single	14	25
Married	39	68
Divorced	3	5
Widowed	1	2
Age - Years		
25-29	6	11
30-34	9	16
35-39	11	19
40-44	7	12
45-49	12	21
50-54	8	14
55-59	3	5
60-64	1	2
Race		
Black	1	2
Hispanic	2	4
White	54	95

Appendix E – Table 2
Participant's Work Experience
(N = 57)

* Numbers will not always equal 100% due to rounding.

Item	Frequency	Percentage *
Years of MSW Experience		
1-4	9	16
5-9	15	26
10-14	17	30
15-19	8	14
20-24	6	11
25-29	1	2
Over 30	1	2
Years in Oncology		
Less than 1	1	2
1-4	16	28
5-9	19	33
10-14	12	21
15-19	7	12
20-24	1	2
25-29	1	2
Years at Site		
Less than 1	4	7
1-4	24	42
5-9	18	32
10-14	8	14
15-19	3	5

Summary: Five Years or More	Percentage
MSW Experience -	85
In Oncology-	70
At Site -	51

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