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Gaps in the provision of psychosocial services to cancer patients in a multidisciplinary setting : a social work perspective

Billie Ann Starks

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Billie Ann Starks
Gaps in the Provision of
Psychosocial Services to
Cancer Patients in a
Multidisciplinary Setting: A
Social Work Perspective

ABSTRACT

This qualitative study explored social workers' perceptions of the gaps between the need for and the provision of psychosocial services among cancer patients in a multidisciplinary treatment setting. The participants in the study were social workers from various medical settings in the San Francisco Bay Area. 12 participants, one male and 11 females practicing in the field of medical/oncology social work for an average of nine years, were interviewed. Findings indicated that the most salient gaps are between (a) the number of medical social workers in any given setting and the high volume of cancer patients in need of psychosocial services, (b) the cost of cancer treatment and patients' ability to meet these costs, (c) the roles and duties of social workers and the perception of these roles and duties by their colleagues, and; (d) the complexity of information that patients' must "process" and their ability to do so under the stress of diagnosis. Suggestions for bridging these gaps are included in this paper and relate to restructuring the social work role in a hospital setting, recruiting and training oncology social workers, and providing patients with both titrated diagnostic and prognostic information as well as tools to improve their retention of such knowledge in the face of distress.

GAPS IN THE PROVISION OF PSYCHOSOCIAL SERVICES TO CANCER
PATIENTS IN A MULTIDISCIPLINARY SETTING: A SOCIAL WORK
PERSPECTIVE

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2009

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This thesis project is dedicated first to my Mom and Dad from whom I have inherited character traits that are necessary to become a compassionate and hard working social worker. In addition to that gift, their unconditional love and support have given me the confidence to embark on adventures and accomplish goals that I didn't think were possible.

I must also try to put to words my deep appreciation for my research advisor Elizabeth Kita. This project would not have been possible without her encouragement, availability, and dedication. In a process that was so demanding, it was extremely comforting to know that I could always count on her guidance.

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My thanks also go out to the twelve social workers that I interviewed for this study. All of them seem to put forth a super-human effort towards completing all that is required of a medical social worker and all that they do for cancer patients, their families, and their coworkers. They were kind enough to set aside time for my interviews, without which this project would not have been possible.

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CHAPTER 1

INTRODUCTION

According to the American Cancer Society, one in two men and one in three women in the United States will be diagnosed with some form of cancer in their lifetimes (www.cancer.org, 2007). With prevalence rates as high as this, virtually everyone is affected by cancer whether they are suffering from the illness themselves or have a close relationship with someone who does. There is a tremendous need for psychosocial support services for those who are affected by cancer yet despite health care providers' best efforts, a myriad of patients and their families are not receiving adequate support.

Although the field of psychosocial oncology is relatively young, researchers have been studying the psychological impact of cancer on patients and developing assessment tools and treatment interventions for many years. Psychosocial interventions are implemented to provide emotional support to patients and their families who may be experiencing distress in various aspects of their lives (i.e. financial, social, emotional, occupational, physical etc.) as a result of cancer. Common interventions implemented by social workers include completing psychosocial assessments (Gotay & Lau, 2002), referring clients for services such as individual therapy (Boulton et al., 2001), family (Kuijjer et al., 2004) or group therapy (Davis, Gohen, & Apolinsky, 2005), and providing psychoeducation about the impact of cancer. These developments have led to increases in the quality of support provided to cancer patients; however, there continue to be large numbers of cancer patients who are not receiving support.

The present qualitative study aims to explore this phenomenon by asking medical and oncology social workers the following question: What are the gaps in the provision

of psychosocial services to cancer patients and their families? Participants were asked to discuss their experiences as social workers of cancer patients in a multidisciplinary setting, and account for the gaps between need and intervention that the literature suggests is present in treatment settings. To do so, a semi-structured interview format was employed. As health care settings tend to be complex systems, the interview attempted to mirror that by including questions that also explored the following aspects of the treatment environment: a) multidisciplinary team members, b) the patient, c) the patient's family, d) the managed care system, and e) common ethical dilemmas associated with cancer care.

This paper begins with a presentation of the literature relevant to this topic, establishing both thorough background information and a rationale for the current study. Following the literature review, the qualitative methodology employed will be described. Next, the findings of this study and the various themes that emerged will be reported. Finally this researcher will discuss the findings in relation to the existing body of literature, the implications for social work practice, areas for future research, and the strengths and limitations of this study.

CHAPTER II

LITERATURE REVIEW

The following literature review will explore: (a) the psychosocial impact of cancer on cancer patients; (b) the efficacy of psychosocial interventions; (c) the many roles of psychosocial oncology care, and; (d) research findings that identify gaps in the provision of psychosocial interventions to cancer patients. Each study will be reviewed according to its research design, sample, and findings. Taken as a whole, these topics encompass the body of existing literature related to the subject under examination, that cancer exerts a significant psychosocial impact on patients is well-established, and will be briefly reviewed first.

Psychosocial Impact of Cancer

There is a great deal of literature that substantiates a cause and effect relationship between a cancer diagnosis and psychological distress. In an article by Carlson et al. (2004), the authors present The National Comprehensive Cancer Network's definition of “distress” as:

A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (p. 2297).

Gotay & Lau (2002) demonstrated the significant prevalence of stress amongst a diverse sample of people diagnosed with cancer which included Caucasian, Japanese, Filipino, and Hawaiian participants. Researchers designed a questionnaire and

interviewed 194 cancer patients and found that the majority of the participants (84%) reported experiencing stress at some level. Despite this, only 7% of participants actually participated in support groups. 49% of those who did not participate in a support group endorsed their belief that participation in a support group would be helpful. Furthermore only 5% of participants had received some kind of psychological counseling in the past, and only 25% of those who did not receive counseling endorsed a belief that it would be helpful. With regard to the disparity between stated stress and the provision of psychosocial interventions, Gotay and Lau hypothesized the following:

Lack of information is one reason for low rates of participation because few patients reported receiving information about psychological support. Neither physicians nor patients may be well informed about psychosocial interventions for cancer patients regarding their availability or potential value (Gotay & Lau, 2002, p.33).

This study reflects the high prevalence of distress amongst cancer patients from diverse cultural backgrounds, and points to a clear deficit in the provision of psychosocial support. The authors also found that the subjects' preferences for a specific behavioral intervention such as relaxation therapy, guided imagery, hypnosis, and biofeedback differed across cultures, indicating a need for a range of treatment options in accordance with individuals' psychosocial needs.

Mitchell (2007) used qualitative methods to explore and define distress in cancer patients who received chemotherapy as a part of their treatment regiment. Nineteen cancer patients who received chemotherapy were recruited and interviewed at every appointment, which resulted in the completion of 98 interviews. Interviews were semi-structured and were conversational in nature. Participants were also given the option of

keeping a diary or using a voice-recorder to document their experiences. This may have elicited more in-depth and authentic records of their feelings and reactions due to the privacy and self-determinacy outside of the more formal interview setting. This study examined the social and emotional tolls suffered by the participants, who reported that they “longed to regain some semblance of normality, and felt out of control, frustrated and helpless” (Mitchell, 2007, p.46).

The most common themes that arose among study participants were: their anxiety about cancer, the essentiality of support from multiple social structures (i.e. family, friends, partners, children, and other cancer patients), the stress of cycling through health and wellness, and the stress that arose from the lack of normalcy in their lives. Because the data garnered was from patients themselves, these findings offer oncology treatment providers a more tangible and patient-centered definition of what kinds of support cancer patients need, which may be useful to those who are designing and implementing psychosocial interventions to counteract distress.

Mazur’s (2007) findings augment those of Mitchell (2007). The author conducted a qualitative study in which 12 cancer survivors were interviewed. Mazur aimed to gain insight into how cancer survivors recuperate their bodies, minds, and lives after their cancer was officially "cured." The author noted that the most salient points made by survivors were that physical recovery is lengthy and daunting, and that the fear that their cancer will come back is ever present. Although some cancer patients are fortunate enough to go into remission, the fear of recurrence is continuous, adding a psychologically taxing element to a cancer survivor's life. These two studies point to the

significant stress that cancer patients experience both through the active phase of the disease and in their lives after cancer.

Cancer and cancer treatment takes a tremendous toll on the bodies of cancer patients. Some researchers have explored the connection between physical illness and psychosocial well-being in order to better understand how to treat cancer patients as a whole. Shih & Simon (2008) studied the level of serious psychological distress as it correlates with quality of life in adults with chronic medical conditions. Researchers used data that was collected from a telephone survey conducted in Los Angeles County. Researchers cross examined the following variables: sociodemographics, chronic conditions, health related quality of life, and serious psychological distress. It was found that adults who were young, single, low-income, unemployed or disabled, and/or who had one or more chronic medical conditions had increased levels of serious psychological distress and decreased quality of life. Shih and Simon (2008) concluded with the following statement:

Mental health is an inseparable component of overall health and affects quality of life, health care costs, and medical outcomes. Persons with chronic disease are at higher risk for depression and other mental health disorders and may benefit from targeted screening, outreach, and programs that provide links to mental health and social services (p.526).

In medical settings, it is often the case that a patient's physical well-being overshadows their mental health needs. These findings underline the relevance of psychosocial interventions that attend to both mental health and physical health. Additionally, strength in the methodology of this study is the inclusion of respondents from multiple cultural and ethnic backgrounds as researchers were able to conduct the

survey in seven different languages. The inclusion of participants from various cultural backgrounds increases the generalizability of the results in this study.

Andersen et al., (2007) also explored the relationship between physical and mental health, but did so specifically among people with cancer. The authors examined the efficacy of an intervention program that aimed to decrease psychological distress, and looked at whether or not this intervention resulted in improved physical health among 227 participants who were newly diagnosed with breast cancer. The program consisted of 18 weekly sessions, followed by eight monthly sessions, all of which were facilitated by a male psychologist. Participants were taught coping mechanisms, muscle relaxation, and effective usage of social support. Psychological measures as well as blood tests were utilized to determine psychological and physical health over time. It was demonstrated that a decrease in psychological distress was positively correlated with a decrease in physical symptomatology. The authors concluded that "distress reduction is highlighted as an important mechanism by which health can be improved" (Andersen et al., 2007, p. 959).

The literature discussed above is important for health care providers as well as for cancer patients and their families in raising awareness about the gravity of the physical, psychological and social impact of cancer. The research clearly demonstrates that psychosocial distress can affect a cancer patient in all aspects of his or her life, and that such distress may persist even after a patient's cancer has gone into remission. This research establishes the significance of the psychosocial impact of cancer; the research discussed in the following section will demonstrate ways in which cancer patients can counteract psychosocial distress.

Psychosocial Intervention Efficacy

A number of psychosocial interventions have been found to be effective in counteracting the distress that cancer and its sequelae causes. Boulton et al. (2001) used a mixed-methods survey to evaluate patients' perceptions of a brief counseling service offered by a community cancer center. The counseling service consisted of eight, 50 minute sessions facilitated by counselors who implemented a Humanistic approach in order to focus on the experience of the individual and gain the individual's perspective (Boulton et al., 2001). Of 142 subjects who completed the questionnaire following the intervention, 90% of participants reported feeling as though their overall emotional well-being was improved as a result. The authors also noted that 95% of participants indicated that they would use the service in the future (Boulton et al., 2001, p.127).

Participants indicated that the counseling services helped them by providing a "space" in which they could express their feelings, which served as an intervention in and of itself. Participants also indicated that the service helped them to examine and understand emotional responses, confront their fears of death, and work through powerful thoughts and feelings. For those participants who reported that they did not find the intervention helpful, the treatment modality seemed to be the issue. The authors stated that those subjects found that the Humanistic approach was too non-directive, perhaps reflecting the findings of Gotay & Lau (2002) which emphasized the need for a range in the types of interventions offered.

Kuijer, Buunk, Majella de Jong, Ybema, and Sanderman (2004) also investigated the efficacy of a brief counseling intervention program designed to assist cancer patients and their partners. The intervention program was aimed to aid couples in identifying and discussing shifts in their relationships as a result of one partner's cancer, as well as helping them to adjust to the consequent change in caretaker dynamics. Couples in the experimental group attended five 90 minute discussions sessions which were facilitated by a psychologist. The cancer patients and their partners reported that the five counseling sessions improved their relationship satisfaction overall, allowed for adequate adjustment to shifts in relationship dynamics, and lowered levels of distress. The authors also reported that:

Patients reported lower levels of psychological distress after the intervention. An important finding in the present study is that the intervention not only elicited short term effects, but that the effects were generally preserved until three months after completion of the intervention (Kuijer et al., 2004, p.330).

The long-term efficacy of this intervention is notable, and adds value to the findings of this study. The limitations to this study, however, should also be considered. The sample was small and limited to 59 couples who were all from one region of the Netherlands, rendering the findings less generalizable.

While Boulton et al. (2001) and Kuijer et al. (2004) demonstrated the efficacy of counseling services, a study by Davis, Gohen, and Apolinsky (2005) underscores the importance of providing psychosocial interventions other than counseling. Although the sample size in this study is small (N=30), the authors collected thorough data from subjects, and provided a detailed analysis of patients' experiences. The authors recruited cancer patients who were in their first year of membership at a community cancer support

center. The participant's member profiles provided information regarding their diagnosis, medical treatment, psychological history, support networks, coping tools, and an interest survey of the various program offerings of the community center. The participants completed a short interview that included qualitative and quantitative questions that evaluated any changes in their treatment, emotional state, coping strategies, feelings about the community center, and participation in specific activities.

Participants reported attending support groups (37%) as well as social events (40%). Other activities that were found to be popular amongst participants were: relaxation groups (57%), healthy cooking groups (53%), laughter groups (50%), and managing anxiety (43%). The authors noted that a common theme arose among patients' reports, which was their appreciation of the feeling of community membership that the various activities afforded them, and the inclusion of their family and friends in their activities. Researchers also suggested that 57% of participants who did not utilize formal counseling services may have benefited just by virtue of their membership in a community of cancer patients where support services were available. These findings affirm those of previously discussed studies that emphasize that although cancer patients' preferences for types of interventions may differ, the vast majority of them will have some similar need for services.

These studies demonstrate how efficacious psychosocial services can be. How these psychosocial services are made *available* cancer patients and their families however continues to be a complex problem. A cancer patient encounters many health care providers throughout the duration of their treatment, and providers from different

professions may vary in their conceptualizations of (a) how to assess for the psychosocial impact of cancer and (b) how to best treat the psychosocial impact of cancer.

The Many Roles of Psychosocial Oncology

In addition to studying both the prevalence and treatment of psychological distress, researchers have also examined the roles of different health care providers in cancer care treatment and how it effects the provision of psychosocial interventions. The settings in which cancer patients receive their diagnoses are often hospitals which, by nature, are fast-paced, busy and complex systems. One element of this complexity is the fact that care is provided by a team of people, all of whom have different professional identities. Definitions of cancer diagnoses, psychosocial distress, and psychosocial intervention may deviate from each other according to provider, creating gaps between the recognition and assessment of psychological distress in cancer patients and the process of referring a cancer patient to the appropriate psychosocial services.

A physician's role is extremely important to consider include when analyzing the interactions between patients and health care providers. Typically, a patient will receive a visit from a physical therapist or a social worker only after the physician has submitted a referral for such services. Cuisinier, Van Eijk, Jonkers, and Dokter (1986) were some of the first authors to discuss the need for strengthening the physician's role in psychosocial care with a specialization in patient education. In this study, the authors reviewed literature to "investigate the question of which problems occur in the psychosocial support and education of cancer patients by his doctors, and how these

might be resolved" (Cuisinier et al. p. 6). The authors identified interesting and relevant phenomena that occur between the physician and the patient, and how it can create barriers to achieving optimal psychosocial support.

First, Cuisinier et al. (1986) indicated that physicians tend to withhold information or avoid a direct discussion with their patients about their condition because they expect that the patient will have an adverse emotional reaction to the information. The authors suggested that physicians aren't necessarily prepared for these difficult conversations in their trainings, and will choose what they say to patients according to what might be least provocative.

Also, the authors indicated that quite often, patients are only capable of recalling 40% of the discussion that follows their diagnosis, as their strong emotional reaction may inhibit their ability to concentrate. While some patients are afraid to ask for psychosocial support due to the stigma that comes along with mental health issues, other patients will need more time to process the information before they are able to formulate questions. The authors stated that "physicians also often lack the experience to analyze the patient's life situation intensively and often lack the knowledge and ability to approach patient education in a systematic manner," (Cuisinier et al., 1986, p.12).

Merckaert et al. (2008) published an article which specifically evaluated physician's detection of cancer patient's and their relatives' distress (Merckaert et al., 2008.) Researchers worked with physicians by providing them with either a basic communication skills training or a consolidated version of the training. Concurrently, cancer patients completed a questionnaire to measure their anxiety and depression as well as their use of coping mechanisms. After the training was completed, physicians

interviewed patients and their relatives while also providing them with information (good, bad, or neutral) regarding their cancer care.

Several important findings resulted from this study. First, physicians have the tendency of underestimating the distress of their patients. Merckaert et al. (2008) posited that the reason for this is that the physicians are protecting themselves from strong emotional responses. Second, the authors identified that a physician's perception of emotional distress may be distorted due to their frequent contact with patients who are suffering physically and emotionally. Finally, authors pointed out that it is possible that patients may minimize their distress levels in order to appear strong in the presence of their physician (Merckaert et al., 2008, p.266). There was no statistically significant difference in either of the communication training programs.

In addition to physicians, there are other health care providers with whom cancer patients work closely and their roles are important to consider when thinking about the complex system that comprises cancer care. Vitek, Rosenzweig, and Stollings (2007) discussed the role of oncology nurses suggest the use of specific assessment tools, and recommend that oncology nurses administer these assessments. The Distress Thermometer (DT) (Vitek, Rosenzweig, & Stollings, 2007) is a global 0-10 rating scale on how much distress the patient is currently experiencing, and the Problems Checklist (Vitek, Rosenzweig, & Stollings, 2007) which allows patients to specify in what areas (i.e. practical, family, emotional) they are experiencing the most distress.

The authors suggested that oncology nurses complete these assessments with patients as they have the most frequent patient contact. The authors then pointed out that oncology nurses typically work in a very busy multidisciplinary setting and will have to

go through a referral procedure after reading the results of these measures to ensure that the patients are receiving the psychosocial support they need. The authors failed to mention however, how this practice might be implemented in every day nursing practice. The change to the nursing service that this would require may be prohibitive, as some literature points out that change within macro systems like hospitals or cancer care settings is extremely complicated, time consuming, and expensive (Bunston & Mings, 2007).

Numerous studies have been conducted in order to determine the reliability and validity of this measure, as well as to determine a protocol to be implemented upon reading the results of the Distress Thermometer (DT) (Jacobsen et al. 2005; Ransom et al. 2006; Graves et al. 2006; Ozalp et al. 2007; Shim et al. 2008; Gessler et al. 2008; & Hegel et al. 2008). While the DT has been found almost unanimously to be an effective tool to screen for psychosocial distress in cancer patients from various cultural and ethnic backgrounds, there are differences throughout study findings in identifying a universal scoring method. Also, in the studies listed above clinical psychologists were designated to administer the DT which is contradictory to the originally prescribed implementation of this tool. None of the studies designated a specific discipline to administer the DT in their findings.

While health care providers may determine the course of a cancer patient's treatment regimen, the patient's role is also important to consider when looking at the complexity of oncology care. Research demonstrates that while cancer patients are encouraged to be active participants their oncology treatment, they are sometimes incapable of doing so due to the psychosocial distress that is a result of the experience of

having cancer. A study by Servaes, Vingerhoets, Vreugdenhil, Keuning, and Broekhuijsen (1999) examined the emotional expression in women with breast cancer in comparison to emotional expression in healthy women. The researchers recruited 48 breast cancer patients, and 49 non-cancer patients to complete a battery of measures that included: an emotion self disclosure scale, alexithymia scale, emotional expressiveness questionnaire, interpersonal behavior scale, and an adjustment inventory. The authors concluded that:

[A woman with breast cancer] has conflicting feelings about expression her emotions, is reserved and anxious, effaces herself, and represses aggression and impulsiveness. However, we feel that the present data better fit the hypothesis that the cancer-prone characteristics are a consequence of confronting a life-threatening disease rather than reflecting premorbid personality features (Servaes, 1999, Comment section, ¶ 9).

Communication on the side of the patient may be further complicated by the employment of psychological defense mechanisms which cancer patients utilize to cope with the distress of their cancer diagnosis. A study by Wool & Goldberg (1986) provides a thorough presentation on the employment of denial by cancer patients, present the potential for deficits in the provision of psychosocial services as a result of the patient's denial, and suggests treatment methodologies for mental health professionals in the assessment and treatment of denial. The authors interviewed 15 cancer patients who exhibited the following four types of denial: (a) denial of the physical manifestations of the illness, (b) denial of the diagnosis, (c) denial of the implications of the illness, (d) denial of affect associated with the illness (p.6).

The authors point out that denial is not necessarily an adaptive or maladaptive way of coping with a cancer diagnosis, but emphasized the importance of paying

attention to a cancer patient's denial to be sure it doesn't interfere with the process by which the patient recognizes their need for treatment. The authors reported that "denial helps modulate emotional reactions to the stress of life-threatening illness and ease the patient's course during treatment. "Often initial denial is replaced by integration of knowledge about the illness and the adoption of more flexible coping strategies" (Wool & Goldberg, 1986, p. 9). Therefore, the hope is that psychosocial interventions will lessen the need for denial among cancer patients by helping them to develop coping mechanisms that empower them to face their diagnosis and seek the appropriate treatment.

The authors suggest supporting patients through their initial denial by normalizing strong emotional reactions, and arranging for concrete services over which the patient has control. However if a patient is in extreme denial, additional support is needed for the patient, the patient's family, and the multidisciplinary team (Wool & Goldberg, 1986).

As the psychological distress itself impacts a cancer patient's ability recognize and express their emotions, the inability to communicate is exacerbated by a general apprehension around emotional disclosure. A study by Okuyama et al. (2008) aimed to explore the concerns around emotional disclosure of Japanese cancer patients to their physicians. Participants were asked to complete self-administered questionnaires that measured: their reluctance to disclose emotions, their psychological distress, and relevant sociodemographic/biomedical factors. The authors found that the majority of participants reported that they would be hesitant to report emotional distress to their physician because (a) a physician doesn't have the time, (b) a physician doesn't ask, or (c) they did not want to bother the physician. Additionally authors present the following:

About half of the patients had a 'Negative attitude to emotional disclosure'. The result that older patients were more likely to endorse this attitude may indicate some relation to Japanese traditions which place much value on being modest and reserved. Many other beliefs may underlie this attitude such as cultural background and stigma attached to psychological problems... (Okuyama et al., 2008, p.464).

The authors also discussed further findings in which participants endorsed a fear of disclosure, as they believed it may negatively impact their relationship with the physician. The authors indicated that establishment of a safe relationship that fosters emotional disclosure is important on the part of the physician. Combined with the physicians' reluctance to address these concerns in their patients, as demonstrated in the aforementioned studies by Cuisinier et al. (1986) and Merckaert et al. (2008), this may lead a communication breakdown between providers and patients that precludes the linkage of interventions with treatment needs.

With these gaps in communication, and a lack of specificity about exactly who should be assessing for psychosocial distress in cancer patients, the literature points to a need for medical/oncology social workers to bridge the gaps. In a study by Gadalla (2007), the demographics of cancer patients who were receiving support services from social workers were collected and analyzed. Authors utilized information that was collected by biannual surveys in 2001 and 2003 conducted by a federal statistics analysis organization in Canada. It was found that over that two year period, the number of cancer patients that social workers were serving increased by 5,422 patients. Also, the demographics of this population demonstrated that social workers were servicing vulnerable populations such as single-parent families, low-income families, patients with

depression, and patients with physical limitations. These findings represent the increasingly important role of medical and oncology social workers.

A study by Miller et al. (2007) directly addressed how medical social workers should be involved in psychosocial support for cancer patients. The researchers designed five, 90 minute structured meeting sessions facilitated by a social worker and other health care providers such as nurses or physical therapists. Participants (N=115) were patients who had been newly diagnosed with advanced cancer and receiving radiation therapy. The interventions included relaxation training, written materials on financial matters, community resource referrals and revision of legal issues, and provided additional counseling for emotional support as needed. It was found that the sessions were effective in obtaining the goal of improving patients' quality of life through interventions that attended to emotional, spiritual, physical, psychological, and social domains. The findings suggested that patients who participated in this intervention program had an improved quality of life in comparison to patients receiving standard care.

Anecdotally, the authors noted that their study was the first to be published – in 2007 - indicating that there is a dearth of literature on the topic. Furthermore, the authors noted the following:

A limitation perceived by the social worker during this study is that the intervention was delivered in a manner which is different from standard social work clinical practice... It was instead delivered as part of a structured educational process where personal and sensitive information were provided without any knowledge of the participant's position in dealing with their situation, medically, socially, emotionally, or financially (Miller et al., 2007, p.116).

Miller goes on to explain the limitations of this research, as there seems to be a lack of empirical literature that includes practical interventions that social workers can apply to

their every day clinical practice. While researchers have designed interventions that are helpful only within the context of their study design, the next article is more directive as to how a social worker can use their skills to best suit the needs of cancer patients.

A theoretical article was written by Davis (2004) which examined current literature in an effort to identify practice methods specifically for medical social workers. Davis (2004) points out that there is still a great deal of research to be conducted in order to identify the most effective methods for screening breast cancer patients for their need for psychosocial services, as well as the most effective strategy by which to treat them. Based on her research, the author identifies medical social workers as the primary health care provider to fulfill this role, as well as the importance of educating other oncology treatment team members of the importance of the provision of psychosocial services.

Davis (2004) states:

The hospital is an ideal setting for social workers to assess the needs of women with breast cancer, provide needed services and appropriate referrals, and educate other members of the treatment team on the psychosocial needs of those women (p. 331).

Clearly, in a complex system in which many people are working together to determine the best course of treatment, discrepancies between interdisciplinary communication, assessment of patient's needs, and referral for interventions are inevitable. The next section will contemplate some of the gaps that have been discovered, as well as the limitations of the existing literature.

Gaps and Limitations

While there is a great deal of literature that pertains to the psychosocial impact and treatment of cancer, this inclusive review of the literature acknowledges the existence

of gaps and limitations between the identification of psychosocial distress in cancer patients, the assessment of this distress in order to identify psychosocial supports that would be helpful, and making referrals to such services. A study by Carlson et al. (2004) identified a need for raising awareness about psychosocial services that are available to cancer patients who endorse experiencing psychosocial distress. The authors administered a demographic measure, the Brief Symptom Inventory, a problem checklist, and a psychosocial questionnaire to 2,776 cancer patients. The results indicated that close to one-third of the participants endorsed experiencing distress in the domains of somatisation, depression, and anxiety while only about seven percent of participants were currently in psychosocial treatment, and 20% of participants reported that they were unaware of the psychosocial services available (Carlson et al., 2004). It is important to ask why such a small percentage of cancer patients were utilizing psychosocial support, and just as important to ask why such a large percentage of patients were unaware of the services available to them.

In an effort to create a working model that addressed the gaps in communication, assessment, and referral to services, Bunston and Mings (1998) attempted to design an intake and referral service that would call for hospital wide change to address the psychosocial stressors in cancer patients. The gaps in psychosocial support services were identified in their qualitative study that included patients, nurses, social workers, physicians, and community organizers. “The need for better coordination of care, the lack of standardized psychosocial assessment instruments, and the absence of formalized mechanisms for referral were common themes” (Bunston & Mings, 2007, p.70). The

solution to this problem was to create a multidisciplinary intake referral service team that would allow for more comprehensive screening and service provision.

As noted above, change in a macro system like a hospital or cancer care setting can be prohibitively complicated, time consuming, and expensive. This study helps to demonstrate how cancer care settings are often nested within a larger medical system, and how the larger system may inadvertently create a greater disconnection between the needs of cancer patients and psychosocial services. Despite much support from the hospital administration and much preparation, Bunston and Mings' (2007) plan for change was denied. There were many obstacles in the way of change, the most important of which included: the lack of research that supported the authors' suggestions for multidisciplinary action; the resistance to change as hospital staff across disciplines would have to adhere to new policies and procedures; and a lack of funding by insurance companies. The authors contributed valuable lessons in utilizing their research to identify the gaps in the assessment of the psychosocial impact of cancer, the provision of psychosocial interventions, as well as for advocates in the future who are aiming for change in order to fill the gaps in psychosocial intervention in health care settings.

Inasmuch as there seems to be an abundance of literature that endorses many variations on psychosocial service provision, social workers should consider the important limitations identified by Cwikel and Behar (1999). Their aim was to identify inconsistencies in the prescriptions for how to translate the findings of the literature into clinical practice. The authors first addressed the issues of identifying cancer patients who are in need of psychosocial services, and the discrepancies in methodologies employed to do so. The existing literature does not identify the most effective model for a

multidisciplinary team to identify a cancer patient in need of psychosocial support.

First, the authors pointed out the varying needs of the minute number of cancer patients who have participated in empirical studies. Second, they reported that there is an undeniable gap in the literature that is representative of communities of color. Finally, authors recognized that because cancer affects all people from all racial and ethnic backgrounds, this gap prevents psychosocial intervention providers from practicing in a way that is culturally appropriate for each individual that they are serving.

Lillquist and Abramson (2002) support the above stated findings and highlight the limitations of research that has been conducted on psychosocial intervention efficacy. The authors point out that the most widely researched population is women, and more specifically, women with breast cancer. The authors also reported that “substantial differences may exist between individuals choosing to participate in a study and those who decline” (Lillquist & Abramson, 2002, p.70). Therefore, it is important to take into consideration the demographics of the participants in the studies and determine whether or not the results are generalizable.

Finally, a careful review of this body of literature reveals that there are no studies that directly ask medical and oncology social workers for their perspectives on why there are gaps in the provision of psychosocial services for cancer patients. As noted above, it seems that oncology and medical social workers are increasingly held responsible by the social work profession as well as other disciplines to be the experts on how to assess for and treat the psychosocial impact of cancer. The present research study will aim to contribute to this body of literature by conducting in-depth interviews of medical and

oncology social workers in order to gain insight into the perspective about these why these gaps exist, and how bridges might be built.

Summary

This review of the literature has endorsed the psychosocial impact of cancer, and has identified the different ways psychosocial distress manifests itself in the lives of cancer patients. Also, this review has identified some of the many approaches to psychosocial intervention to counteract distress, and the importance of assessing each individual to understand which intervention will be most helpful for them. This review has identified the complex system in which cancer patients receive their medical treatment, and how a multidisciplinary team approach can complicate communication with cancer patients, and the assessment and treatment of psychosocial distress. Finally this review of the literature has defined the gaps of psychosocial intervention provision, as well as the limitations of the existing literature. The aim of the present research study is to contribute to filling the gaps by asking medical/oncology social workers specifically about the identified gaps in psychosocial intervention provision.

CHAPTER III

METHODOLOGY

This qualitative study was designed to explore the provision of psychosocial services to cancer patients from a clinical social work perspective. The literature demonstrates that gaps exist in the provision of psychosocial services to cancer patients; however, there is not much research that specifies how these gaps are defined by social workers who are often the primary liaisons between cancer patients and psychosocial services. This chapter presents the methodology utilized in this study and describes the sample selection, data collection, and data analysis procedures.

This study was conducted utilizing flexible methods. A semi-structured interview was utilized in order for social workers to reflect on their experiences so as to understand the phenomenon under study from their perspective (Anastas, 1999). Social workers were asked to expound on their role in providing support to cancer patients, and also describe the role of multidisciplinary team members, patients, family members, managed care, and ethics.

Sample

Participants in this study were Master's level social workers, who work or have worked in the last five years as a part of a multidisciplinary team to liaise and provide cancer patients with psychosocial support in the San Francisco Bay Area. Clinicians providing support to cancer patients in a private setting only were excluded from this study.

Participants were recruited by way of a "snowball" sampling procedure (Anastas, 1999). A recruitment flier was circulated via email, and a Smith Alumna, who is

currently an oncology social worker, assisted this researcher with distribution of recruitment materials. Also, this researcher visited social work departments in hospitals and cancer care centers to drop off recruitment fliers in social work departments. In addition to these networking methods, this researcher also contacted social workers by phone, and requested that participants encourage their colleagues to participate as well.

Participants in this study were one male, and eleven females, 10 identifying as their racial identity as Caucasian, one identified as Latina, and one identified as Asian. The average number of years practicing as a medical social worker was nine years, and the average number of settings participants worked as a medical social worker was 2.75. Eight participants were affiliated with a teaching hospital, three of which worked as an inpatient social worker, two as an outpatient social worker, and two as both inpatient and outpatient social workers. The remaining four participants worked in non-teaching hospital settings, two inpatient, one in a skilled nursing facility, and one both inpatient and outpatient.

Data Collection

Procedures to protect the rights and privacy of participants were outlined in a proposal of this study and presented to the Human Subject Review Board (HSRB) at Smith College School for Social Work before data collection began. Approval of the proposal (see Appendix A) indicated that the study was in concordance with the NASW *Code of Ethics* and the Federal regulations for the Protection of Human Research Subjects. Data collection was gathered via semi-structured interviews conducted at mutually convenient and private locations. Prior to each interview participants were given an informed consent document describing their participation in the study and their

rights as human subjects, as well as any potential risks or benefits of participation (see Appendix C). The participant and researcher each kept a signed copy of the informed consent document, and the researcher will keep these documents in a secured environment separate from the data for three years after the conclusion of the study as mandated by Federal regulations.

In order to ensure participant confidentiality, demographic information, researcher notes, transcripts, and audio files have been kept separate from informed consent documents and are identified by number codes rather than names or other identifiable information. Any names or other identifiable information from participants or clients that were recorded during the interviews was removed or disguised during transcription and for use in the final thesis project.

After participants provided their informed consent, they were asked four demographic questions to identify their gender, race, number of settings in which they've practiced as a medical/oncology social worker, and number of years practicing as a medical/oncology social worker. After demographic information was collected, this researcher utilized an interview guide (see Appendix D) to learn more about the roles of: social work, other disciplines, the patient, the family, managed care, and ethics as it impacts the provision of psychosocial support to cancer patients. The interview process sometimes called for clarification, or additional questions in order for the participant to elaborate. The length of the interviews ranged from 30 minutes to 75 minutes. All interviews took place between January 20, 2009 and April 20, 2009.

Data Analysis

This researcher began data analysis by transferring the interviews from the recording device to the computer by converting the files to mp3s. This researcher then transcribed each interview verbatim using the transcription software program Express Scribe which is compatible with a foot pedal. This process allowed this researcher to listen to the interviews a second time in order to clean the data.

After transcription was completed, this researcher went through each transcript to identify which questions were being asked and answered and numbered the questions as they appeared in the margins of the transcript. The process of the interviews was very open, and at times this researcher would change the order of the questions to accommodate the flow of the interview, or the participant would answer more than one question in the context of the original leading question. Numbering the questions in the margins made it easier to locate the questions later on in analysis.

This researcher then went over the interview guide and identified the questions that were omitted during the interview process because they were redundant/irrelevant. (see Appendix E). The researcher then color coded questions in order to apply the corresponding color to the questions as they were found in the transcripts. Using designated colors, this researcher starting with the first question and went through each transcript one by one looking for answers to that question, and repeated for the following 18 questions. After this process was completed this researcher then went through each transcript as a whole to recheck the first application of color coding, and applied colors to the other answers that emerged.

After the color coding process was complete, this researcher began to go through the transcripts to underline significant statements that either were directly related the question that was asked, as well as significant statements that were mentioned that were not related the questions. This was a technique applied to be sure to account for all relevant data, take note of powerful quotes, and maintain neutrality to minimize researcher bias.

A constant comparison method (Anastas, 1999) was utilized in which first the researcher identifies important indicators or statements, implements axial coding in which themes and categories are developed, keeps field notes in order to reflect back on ideas and concepts as they emerged from the data, and further develop themes and categories. This researcher formulated themes continuously throughout the above listed processes of color coding and underlining. This researcher transferred data from transcripts to a written document in order to group indicators by question, compared the answers in each group, and took note of the frequency of similarities and differences. This researcher then identified the main themes that emerged as a result of the richness of the data and the following chapter will discuss each theme.

CHAPTER IV

FINDINGS

As reported in the Methodology section, data was analyzed thematically. The following 4 major themes emerged in response to the interview questions, each of which will be discussed in more depth in this chapter: (a) Psychosocial service gaps identified by social workers, (b) Confusion and diffusion of the social work role by multidisciplinary team members, (c) Managed care and its impact on the provision of psychosocial services to cancer patients, and (d) Patient's difficulty in posing questions to medical professionals.

Theme A: Psychosocial Service Gaps Identified by Social Workers

The first theme that emerged from the comparison of the interviews demonstrated that social workers do perceive gaps in the provision of psychosocial services to cancer patients. Only one out of 12 participants reported that there are no gaps in the provision of psychosocial services to cancer patients, however this participant works in a skilled nursing facility which is different from all other participants who worked in an acute hospital setting. The average length of stay in an acute setting is 2-5 days, whereas this participant's work with cancer patients lasted over weeks or as long as a month. Additionally, medical providers in a skilled nursing facility do not rotate, and all staff members work as a part of an integrated treatment team.

The following four "gaps" were most commonly listed by the social workers who participated in this study:

1. An inadequate number of social workers in the multidisciplinary setting to attend to the high volume of cancer patients, a disparity that is exacerbated by a lack of medical social work training specific to oncology issues;
2. The glairing financial strain of cancer treatment on patients;
3. The nature of oncology social work services to be crisis driven and prescriptive;
4. The obstacles that arise between social work and other health care providers in a multidisciplinary setting.

The following four sections will contain a description of each of these gap in greater detail.

1. Lack of Medical Social Work Presence and Training

"I think just sheer numbers, there's just not enough people, there are not enough of us social workers to provide the needed services... there's a couple hundred [patients] that I'm supposedly following."

Eight of 12 participants reported that there are not enough social workers on staff to adequately support the high volume of cancer patients that need psychosocial services. At one large city run hospital in the Bay Area there are only two oncology social workers for 700 oncology patients who are both inpatient *and* outpatient consumers of oncology social work services. At another hospital there is one inpatient social worker who is responsible for patients on oncology *and* neurology units. At yet another large hospital in the Bay Area, there aren't any social workers who specialize in oncology, and the medical social workers pick up as many cases as they possible can to attend to the high volume of oncology patients. One participant made an important observation and reported, "Providers don't want to refer for a service that they can't promise." He went on to explain that due to the lack of social work presence in the hospital, health care providers

sometimes felt as though they couldn't refer a social worker in fear that the social worker may not be able to take on the case and set the patient up for disappointment.

When asked about how they've informed their practice with oncology patients, social workers also reported that there is a lack of education specific to medical and oncology social work. One participant stated, "I don't think there's adequate training in school for medical social work." Participants reported that they did not have oncology-specific classes to focus on in their graduate programs, and also added that they often were unable to attend seminars for continuing education either because they are too overloaded with work, or they are unable to pay for the expense of the training cost and travel. A lack of time and social work resources is compounded by the fact that social workers may not feel adequately equipped to take on oncology patients in the first place.

2. Financial Strain on Cancer Patients

Another gap in the provision of psychosocial services to cancer patients is the fact that cancer care is so costly that it sometimes bankrupts a cancer patient and their family, and places financial concerns at the forefront and moves psychological ones to the background. One participant reported, "Half of my patients are in the 40-50 age range...they get cancer, then they lose their insurance, bills start to pile up, they can't send their kids to college, it is an enormous impact." The psychological distress that compounds financial difficulties only makes it more difficult for cancer patients to cope with their illness, and also how their illness is affecting their loved ones.

Another participant stated: "I can't tell you how many patients ask me if their MediCare will cover a 24 hour caregiver at home and I have to tell them 'No.' Nothing covers a 24 hour caregiver at home." It is likely that if a cancer patient is in need of 24

hour care at home, then they will either have to pay for the professional service privately, or someone in their social support system will have to try to help with caretaking responsibilities. One participant pointed out that "San Francisco is a city where people escape their family for whatever the reason, and they're kind of a lone." Unfortunately, if a person moved away from their family to lead an independent life, and happened to be diagnosed with cancer they may not have the resources to pay for the care that they need.

Another financial hardship that social workers identified is that patients often times have to meet requirements based on their income and insurance company to be eligible to receive specific treatments. If the patient does not meet requirements, treatment can be held up or withheld completely. If the cancer patients are not going to hospitals or treatment centers for their medical treatment, then they will likely not have contact with a social worker because they are discharged into the community and low priority on even the outpatient social worker's list of patients to check in with. Most outpatient social workers do not make home visits, and rather will make phone calls if they feel as though the patient is in need of support. After the medical system has failed them, it is probable that the cancer patient who has lost his medical treatments will not want anything to do with the hospital, social worker or otherwise. Although social workers did not specifically identify the managed care system as a gap that exists in the provision of psychosocial services, the role of managed care and how it contributes to the gaps will be discussed later.

3. Social Work Services are Prescriptive and Crisis Driven

Another significant gap that participants reported was the fact that social work services in cancer care seem to be crisis driven and prescriptive, rather than an early

preventative intervention. When asked about how cancer patients are referred to their services one social worker reported that patients have to get to a "really intense place of having a problem before they get seen, and it doesn't need to be that dramatic." Another participant reported that in her experience of working with cancer patients it is the "top 20% of people who are so distressed that everyone on the team is getting calls about the patient," meaning that the doctors and the nurses and the social workers are receiving frantic phone calls from the patient or family members because their distress has reached a peak. Most participants reported that although they do see some patients who are newly diagnosed with cancer, patients who are in crisis or patients who are at the end stage of life are prioritized and require much more of their time and dedication.

Social workers indicated that it is not uncommon for a cancer patient to "make it through their entire oncology 'life' without ever having spoken with a social worker." It seems that if a patient is not in a crisis situation, or does not get referred to a social worker by medical providers they can make it to an end of life stage without ever having had a psychosocial assessment by a social worker. A psychosocial assessment is a systematic interview conducted by social workers to gain information about the cancer patient's social supports, cultural background, past and present mental, emotional, and physical health, and gain information as to how the patient is currently functioning. Without this social work specific assessment, multidisciplinary team members will not have pertinent information regarding the patient's biopsychosocial functioning to assist them in formulating an individualized medical treatment plan.

Social workers also observed that for some cancer patients the psychosocial distress "starts when there's the suspicion of cancer," suggesting that it would be most

helpful to have social work support immediately upon the first suspicion. Ideally this would require enough social workers to meet with every cancer patient that receives a possible new diagnosis of cancer. While social workers are doing the best they can to care for cancer patients who are in extreme distress, there is likely a large number of cancer patients who are not being assessed because they have not explicitly stated that they are in need of psychosocial support. (The difficulty that cancer patients face in openly discussing such issues will be discussed later in this chapter.)

4. Lack of Clarity about Social Work Service

Seven out of 12 participants reported that their role is not fully understood by multidisciplinary team members. One participant reported that there was a survey conducted in her hospital to assess health care provider's understanding of a social workers role in a hospital setting, and the survey demonstrated that medical providers believe that social workers only have associates degrees. The lack of clarity about social work services creates miscommunications among treatment team members which inhibit the provision of comprehensive cancer treatment, and negatively impacts cancer patients and team members alike.

Due to the misunderstanding of social work role, social workers are regarded as the "catch-all service" meaning multidisciplinary team members will refer a patient to social worker for any problem that they themselves do not have a solution for. One participant stated: "I do see that they don't very often offer the option to patients of not having treatment ... It creates this illusion and mythology that the doctor can always offer something." Clearly, this referral process covers a broad range of issues and social

workers are expected by team members to have solutions to the countless issues that arise.

Conversely, social workers are sometimes *not* referred for something that they *can* help with, due to the misunderstanding of the social work role. There seems to be a disconnect between the conceptualizations of treatment and what is best for the patient seems to create barriers between social workers and other health care providers. One social worker described, "The culture of medicine is that if there is a problem, there is a solution to it. Either you're a problem to be fixed or you're a problem patient." Another social worker pointed out: "A surgeon thinks 'Okay, I can operate I can get this cancer out;,' [but] what the person's going to look like after and how they're going to deal with it is not the surgeon's problem." This demonstrates a difference amongst multidisciplinary team members in the recognition, definition, and means of finding a solution for a "problem."

The misunderstanding of the social work role, plus the different styles of conceptualizing cases for each team member is complicated even further when there are multiple health care providers working with one patient. As mentioned above social workers are the designated team coordinators for patients who often require specialty treatment from many different doctors. One participant reported that a patient once said, "One doctor told me I had a month and another doctor told me I have a year [to live]... which is it?" Communication is difficult despite the multiple modalities that social workers listed for communication such as: medical charts, multidisciplinary rounds, in person communication, telephone/pager communication, and emails chains. Social workers who reported that communication efforts were ineffective observed the

following: (a) email chains are not included in the medical chart, so important information may never reach key multidisciplinary team members, and (b) not all medical providers attend multidisciplinary rounds and critical decisions are sometimes made without key team members, and (c) sometimes psychosocial stressors are regarded as obstacles in the way of decision making processes and presents conflicting messages to the social workers role which will be discussed later in detail.

Theme B: Undefined Role of Social Work

"Back to the beginning question, there is no one role that we do, we have multiple... multiple roles."

Although participants did not identify their myriad roles and the role diffusion as contributing to gaps in services, a summary of such roles will be provided to further contextualize gaps that participants did identify. When participants were asked about their "primary role when working with cancer patients," none of them identified themselves as performing a singularly defined role. Instead, all participants spoke to a wide range of roles or of role diffusion as a major characteristic of oncology work. The time that social workers have to focus on any one of the following roles is further limited due to the unclear prioritization of these roles in their work with cancer patients and demanding caseloads.

The eight most common roles that were described by participants are to:

1. Provide emotional support.
2. Provide resources to attend to "practical needs."
3. Complete a psychosocial assessment.
4. Act as the multidisciplinary team coordinator.

5. Assist with discharge planning.
6. Clarify the role of social work for multidisciplinary team members.
7. Act as an educator for cancer patients and their families.
8. Act as an as an advocate for the patient in the managed care system.

One participant summed it up nicely by saying that she attends to "whatever is not medical that comes up for people." Depending on the individual social worker, this was either a point of personal and professional pride or of potential burn-out. In the following eight sections, each of these roles will be explicated in greater detail.

1. Emotional Support

Eleven out of 12 participants reported that their role is to provide emotional support primarily to cancer patients and their families, and secondarily to multidisciplinary team members.

Social workers stressed the importance of orienting cancer patients to the social work role by emphasizing their availability for emotional support. Emotional support to cancer patients directly includes validating and normalizing the psychological distress they experience, as well as screening the patient for symptoms of depression, anxiety, or other signs of severe psychological impact. One participant reported that she informs the patient about the services that she can offer to support them if they are experiencing distress and added, "I have to just really check in with them and try to make them feel like they're not crazy, and that there are things that we can do to help them."

Secondly, participants reported that providing support to family members is an essential part of their work. One participant reported, "we rely on the family members a lot to support the patient, and we also provide a tremendous amount of support to the

family member." Social workers stressed the importance of caregiver support, as caregivers are often so consumed by the patient's medical condition that they forget to attend to their own psychosocial well being. "Giving the care giver permission to talk about their own distress" was an intervention that was often identified as a large component of emotional support to family members.

The provision of grief and loss counseling to patients and families when a diagnosis has progressed to a terminal stage seemed to be a category of emotional support that is distinctive from the rest. Most participants reported that they are more concentrated on their work with cancer patients and their families who are in the end of life stage of treatment due to the intensity of the transition. Some participants also reported that emotional support isn't really warranted by cancer patients and their families until this time, because during active medical treatment patients and families are more focused on the practical and concrete needs (which will be explained in greater detail later in this chapter). Social workers also emphasized the importance of continuing education around issues of death and dying, as this seems to be one of the most difficult issues that social workers provide support around.

Finally, providing emotional support to the medical team was something that social workers identified as a role for themselves. In most cases social workers are mindful of the distress that medical providers can sometimes face in their work with cancer patients. If these participants realized that a doctor was having a difficult time talking with a patient about the transition to end of life care as evidence by their lack of interaction with the patient, or a doctor was merely having a strong emotional reaction to the difficult conversations that take place in cancer care, the social worker would take

action. Most often they would either try to act as a liaison between the patient and the doctor to ease tension and act as a mediator if need be, or they would approach the health care provider directly to initiate a discussion to provide them with an opportunity to discuss any emotional distress that they are experiencing.

2. Provision of Resources

A close second to emotional support was the role of resource provision which 10 out of 12 participants reported they provide for the cancer patients and their families. The role of resource provision encompasses a myriad of "practical" or "concrete" needs.

The following is a list of "practical" needs as defined by participants:

1. Referrals to emotional support such as: outpatient therapy programs, support groups.
2. Referrals to health service agencies outside of the hospital such as home health programs that provide nursing care, meals on wheels, end of life care agencies.
3. Assistance with arranging and/or paying for transportation, assistance with lodging,
4. Assistance with navigating the health care system such as: completing insurance applications, collaborating with insurance companies regarding treatment criteria.

One participant stated: "Don't just throw concrete at somebody, soften that concrete a little bit embedded in something that is palatable." This statement exemplifies the complexity with which social workers contend in terms of providing *both* psychosocial support *and* concrete provisions. Another participant also spoke to this point as she described a development in her relationship with patients beyond just

providing something concrete, such as arranging transportation or providing a referral to a mental health service in the community. She stated that "they kind of see that I can help them with something so they start talking about other stuff." In other words, when a cancer patient is facing a number of psychosocial stressors and is in the hospital where they are unable to tend to those stressors because of their illness, their greatest concern is creating a plan to move forward after their hospitalization. The social worker has to validate the patient's need for concrete, action-oriented interventions, but in the course of providing them also tries to build a relationship that then serves as a source of emotional support. One participant reported that "practical support ends up being emotional support," as it is likely that once a medical social worker takes care of a practical need such as setting up transportation from one hospital to another, the cancer patient has a reason to accept the social worker as someone who is helpful and reliable as an alliance in the hospital setting, which could later develop into a relationship that allows for a therapeutic alliance as well.

3. Psychosocial Assessment

A psychosocial assessment is one of the most central aspects of a medical social worker's job. By establishing a historical and cultural context, it helps the social worker understand how this patient will function in relation to their cancer diagnosis, and how the patient will experience being in the medical setting during their hospitalization. Participants reported that the psychosocial assessment helps them to understand important aspects of the patient's functioning such as coping mechanisms, social support systems, and most importantly their understanding of their cancer diagnosis.

It is likely that the other health care providers who are caring for a cancer patient aren't aware of the stressors that impact the patient's functioning. As one participant stated, "every discipline approaches a patient from the point of view of what they can work with... they're not going to do a whole psychosocial assessment, they're not going to see well is this person sleeping well." Because the social worker is the only team member who conducts a comprehensive biopsychosocial assessment, it is the social worker who ends up knowing the most about the patient and, as a result, is positioned on the treatment team as the coordinator of services. Social workers also utilize their clinical skills to helping other health care providers work with the patient in a sensitive and appropriate way. This leads to the social worker's role as a team coordinator.

4. Team Coordination

Participants described their role as a team coordinator in many different ways. It seems that majority of participants are held responsible for coordinating and facilitating meetings between multidisciplinary team members, patients, and their families. Many participants reported that patients have a great deal of difficulty posing questions to doctors for various reasons; this will be discussed in greater detail later on. Conversely, participants reported that doctors sometimes have a difficult time with emotional conversations and sometimes may experience something similar to "countertransference" in their work with patients and families. One participant reported that "for oncologists it's hard, unable to give it to them straight." As a result, patients are sometimes confused about the extent of their diagnoses. Participants also noted how this may lead to an ethical dilemma for them, as they are not equipped to explain and discuss

medical information with cancer patients; however they also feel that the cancer patient should be as informed as possible.

Social workers also coordinate communication among team members directly, especially if there are multiple providers that in most cases are only focusing on their specialty area, i.e. pulmonologist and nephrologists. Some participants also said that certain forms of communication such as mass email chains are ineffective both because they are not included in the patient record and because essential team members may accidentally be left out of the information exchange.

Finally, participants reported that they are often involved in the difficult discussions around end of life care and the transition from aggressive medical intervention to comfort measures only. Social work support is needed during this time for patients and providers alike for the reasons listed above, and participants reported that they also struggle with the ethics of end of life care. Participants reported that at times some family members will push for continued treatment against medical advice, while other times the medical provider will be "holding out for that 2% chance" that an intensive treatment will make a difference. The ethics involved in these difficult times require the collaboration between all team members, the patient if they are able, the patient's family, and if need be an ethics committee to ensure that decisions are being made in an ethically sound way.

5. Discharge Planning

As mentioned above, participants reported that they were often identified as a resource provider and a team coordinator in cancer care. This responsibility is extended even further when a social worker is responsible for the daunting task of discharge

planning from the hospital into the community. Participants reported that they need to collaborate with other facilities, agencies in the community, the patient's family, and assess the patient's biopsychosocial needs once again to ensure that the patient has everything they need before they are sent out of the hospital.

Half of participants reported that although they coordinate care for patients, they do not have time to follow up with patients in the hospital, and often don't know how the patient is doing once they've left the hospital. One participant simply shrugged her shoulders in response to a question about what happens to the patients after they are discharged from the hospital, and another participant reported, "I don't have much follow up... but we do have outpatient social workers for our oncology patients." This might pose problems for patients in terms of having to form new working relationships with providers while in the midst of their cancer treatment.

The other half of participants reported that there is a thorough continuum of care with cancer patients and that they may work with the patient until they have gone into remission, transitioned to a health care agency outside of the hospital, or until the patient has passed on from their disease. For some participants this continuity is essential for the patient, as they are the "constant" caretaker in the hospital setting (as teaching hospitals require that doctors rotate every so often, or nurses rotate their shifts on a daily basis.) One participant reported, "One of my biggest roles is being a constant... you know in a year I'll still be in clinic...I think trying to give them that level of consistence." However other participants also said that the continuum of care extends their role too far, and that it is difficult to dedicate an adequate amount of time to all of their patients. For example when asked about how much of a continuum of care takes place in her work one

respondent reported, "more than I want." She continued, "again, because the diagnosis is what keeps in involved in their care... The only time I ever end involvement is when they go into hospice and the hospice social worker will pick it up, but again, the door is always open." This participant went on to explain how she is a sounding board for patients who might be unsatisfied with their hospice service.

An additional important finding regarding the continuum of care is that some of the participants who reported that there was a continuum of care noted that the continuum is focused on those patients who are at the end of life stage. They simultaneously expressed their concern for those patients who have completed treatment, as they aren't necessarily in "need" of continued emotional support however may have moved to a place psychologically that would allow them to process their experience of cancer in a different way.

6. Role Clarification

Another role described by participants seems to be one that is grounded in the need to advocate for themselves, and discuss with other health care professionals the role of medical social workers in a hospital setting. As described above, eight of 12 participants reported that multidisciplinary team members did not fully understand their role as a social worker. One participant reported "[It's a] constant process of educating people and having strong limits or boundaries around, you know, 'that's not something I do,'" as she reported that she is referred to work with patient's around a myriad of issues that come up for which she doesn't necessarily have a solution, i.e. bankruptcy.

Another participant reported that when a new rotation of training doctors reports to the hospital, there is a brief one-time meeting entitled "Psycho-oncology Rounds" in

order to introduce criteria for social work referral. Other participants reported that they provide the multidisciplinary team with a list that contains examples of psychosocial issues that would be addressed by social work. While some participants seemed to view this as just another part of their job, other social workers seemed to feel devalued and frustrated by the process.

7. Education

Education of cancer patients and their families about the multiple psychosocial stressors that come up when experiencing cancer, and about the managed care and hospital systems was also identified as a role by participants in this study. First, social workers will work with patients around their understanding of their cancer diagnosis and seem to serve as translators for medical professionals after collaborative meetings have taken place. For example, one participant said, "I'll say 'doctor. do you mean to tell the patient this?', or, conversely, translate for the patient." This is an opportunity to address any confusion that is being experienced, and any questions that may come up for the patient and their family as they are typically taking in a lot of information in a short amount of time.

Second, participants reported that they are responsible for educating cancer patients and their families about the psychological impact of cancer by reviewing the symptoms of depression and anxiety. Participants emphasized the importance of normalizing a patient's reaction to his or her cancer diagnosis by discussing the importance of recognizing a natural reaction to a life threatening illness and when the illness has elicited a more severe psychological reaction such as chronic depression. In addition, social workers typically will educate patients and families about the benefits of

psychosocial support services as patients and families may have never encountered a mental health professional before. Again, normalizing the need for some extra support around the psychological impact of cancer is something that participants identified as an important aspect of their teaching.

Finally, social workers reported that they often find themselves educating patients and their families about the managed care system which, according to participants, is extremely confusing and takes a lot of time and effort to figure out. The degree to which managed care impacts the provision of psychosocial services to cancer patients will be discussed in greater detail later in this study. This overall process of education may also develop into something that is more geared towards advocacy that will be discussed next, as patients are often overwhelmed by the aforementioned stressors.

8. Patient Advocate

A common phrase mentioned when talking about their role in working with cancer patients was "to help the patient navigate the system." Some participants stressed the importance of their role as a mediator between the patient and the managed care systems (i.e. the specific hospital system, and the larger health care system governed by insurance companies) that are incredibly difficult for the average consumer of health care to understand. For example, some participants reported that they identify themselves as an advocate against the patient's doctor who is facing pressure from the hospital administration to discharge the patient as quickly as possible. Hospital administration faces pressure from the patient's insurance company that is threatening to stop paying for the patient's health care because their hospital stay has extended the time allotted in their insurance plan. Social workers advocate against the managed care system when a patient

is not ready to be discharged for psychosocial reasons. For example a social worker recounted:

The insurance keeps saying 'Why aren't they going?' and I just kind of made a decision, so the hospital may not get paid for the day but I don't really care in this case, because the family is so fragile and they need so much warning. So sometimes I have to forget about managed care.

This particular social worker assessed that the patient who was going to be discharged by the hospital would only fail at home due to the psychosocial stressors the patient and his family were facing, and to prevent re-hospitalization and a great deal of psychological stress for the patient and the family. In keeping with her role as patient advocate, she advocated against the hospital's discharge date.

This role of advocate impacts multidisciplinary relationships as participants described the stress that arises during a discharge discussion. One participant reported that "psychosocial issues are seen as barriers to discharge," and added that in multidisciplinary rounds it is important for social workers to speak up and advocate for their clients despite how psychosocial issues are viewed by other health care providers. Another participant reported "One doctor, when he sees me coming towards him he goes 'Oh no what's going on now?' To him I have this reputation like there's something going on with the patient." Inherent in the role as an advocate are the conflicting messages of advocacy for the patient and allegiance to the managed care system in which the social worker is practicing. While social workers are the only providers who are responsible for conducting a psychosocial assessment, recognizing psychosocial stressors, and providing services to care for those stressors, social workers are also covertly asked by the system to stop recognizing such stressors when it is time for the patient to be discharged.

Theme C: Managed Care

"I think that an enormous amount of the stress for patients is in trying to navigate the insurance system. I mean that is, I think it's for many people it's actually harder than having cancer."

Ten of 12 participants reported that managed care, (the macro system in which the cancer patient's treatment is dictated by their insurance carrier and the hospital's negotiation with insurance carriers) negatively impacts their ability to provide adequate psychosocial services making this another central theme in the findings of this research study. Participants reported that when complications with the managed care system arise it requires an increase in support from social work to attend to practical needs due to the fact that managed care and the systems of the hospital automatically expect and rely on social workers to be the ones to get cancer patients back on track with their treatment plans.

The practical needs to which participants attend include filling out forms and making phone calls to insurance companies, as well as attending to patients' emotional needs. Patients experience a great deal of stress when there is pressure from the hospital to be discharged or if there is a delay in their treatment because they aren't meeting criteria for the appropriate treatment. Also, some participants reported that their patients suffered a great deal of stress when they were under the impression that their insurance plan would provide a good amount of coverage, when in actuality the cost of their weekly medication regimen wasn't even covered. The extra time dedicated to resolving managed care complications distracts social workers and their patient's from focusing on

the medical treatment, other psychosocial stressors, and leads to less time spent with the other patients on participant's caseloads.

As described above, managed care companies can put social workers in the position of advocating against the system in which they work. This produces a competing relationship, as the social worker is allied with both the multidisciplinary team and the patient. One participant reported that there is usually "intense pressure" from insurance companies and presidents of hospitals to discharge the patient. Another participant reported that this pressure to move patients out of the hospital sometimes "leads to re-hospitalizations which isn't good for anybody, especially the patient." Social workers are ethically responsible for advocating on behalf of the patient, and at the same time doing so may create tension among the multidisciplinary team.

Participants reported an additional need for advocacy when working with a patient who does not speak English as their primary language. The language barrier makes it difficult for the patient to understand their diagnosis, never mind the complications of the managed care system. One participant recounted a story of a patient that she was working with who received a letter in the mail informing her of changes to her insurance plan. This patient happened to understand English, however the description of the change was confusing and it wasn't long before she was no longer qualified to be receiving treatments that she had been receiving for years. She stated, "The number of hours I spent on the phone last week with HealthNet was ridiculous, and how much runaround I got, and how many...I mean I talked to five different people and was told five different things." Another participant referred to managed care systems as

"malignant capitalism," and was nothing less than disgusted with the way manage care impacts the patients with whom she works.

Theme D: Patients' Difficulty Posing Questions to Medical Providers

"I'm amazed at how articulate physicians are at broaching topics, and how skilled patients are at keeping that reality away."

Finally, an extremely important theme that presented throughout the twelve interviews is that medical social workers have observed that cancer patients experience difficulty posing questions to medical providers for a variety of reasons. The inability to openly communicate with medical professionals may contribute to the gaps in provision of psychosocial services to cancer patients.

First, it is likely that patients are not feeling as though they have enough time with their doctor to think of the questions to ask. One participant reported "There's not an atmosphere created that encourages them to ask a lot of questions... the whole system tells them there's a lot of pressure on the doctors here to see a lot of patients, and it's not uncommon for a patient to wait two to three hours [to see the doctor]." Another participant reported that patients are also feeling vulnerable due to their illness and the power dynamic that exists between the patient and the doctor, and that patients are also feeling shock and are overwhelmed by the medical information they are receiving. If a cancer patient is not comfortable posing questions directly to a medical provider about their psychosocial stressors, and a medical provider is not trained to screen for psychosocial stressors, the patient may never complete a psychosocial assessment which is only conducted by social workers. Also, a patient may not be aware that what they are experiencing is categorized as a psychosocial stressor, and may for example credit their

inability to sleep with their medical condition, when lack of sleep could point to signs of anxiety or depression for example.

Aside from the limited amount of time spent with doctors and the psychological limitations of the illness and environment, participants also reported that oftentimes patients don't know what kinds of questions they should be asking their physician. One participant pointed out that patients are seeing several different doctors and other health care providers who are taking care of specific aspects of their illness and this may be difficult for the average patient to understand. One participant suggested, "As basic as it may sound I think it's a good tool for people and their families to write down things, and to take notes," as doctors are often covering a lot of information about the medical complications and the treatment regimen all at one time.

Participants also seemed to observe that the difficulties listed above are exacerbated with the patient is a new immigrant, does not speak English, or has strong cultural beliefs that differ from that of the dominant health care culture. One participant reported that due to the fact that the hospital she worked for served underinsured and uninsured patients, many of whom live in poverty. She went on to explain that such patients often suffer from a lack of resources to access information, and may also suffer institutional racism as health care providers may assume that a patient is fully informed. This participant also reported that she worked with a Latino patient didn't know what the word "cancer" meant and in his culture, a doctor is someone to be respected and not someone to pose questions to.

Another participant described her work with a Chinese patient who's culture strongly believes that cancer is contagious, which lead the patient to experience a great

deal of fear around being abandoned by his family or, even worse, transmitting his disease to one of his loved ones. Yet another participant recounted a story of an Asian-American patient of hers who was believed to be contagious by his family. He was only 35 years old and was sent to a skilled nursing facility for hospice treatment because his sister rented out his room. Participant reported that one of the most important roles is to supplement the communication between the patient and the health care providers to avoid the gaps listed above.

Summary

The major findings of this chapter outlined a social work perspective regarding the gaps in the provision of psychosocial services to cancer patients. This chapter also outlined gaps that were not explicitly identified by social workers as gaps, but were contributing factors to the gaps that exist. The following chapter will discuss these findings in relation to the relevant body of existing literature, as well as discuss implications for social work practice and future areas of research.

CHAPTER V

DISCUSSION

This chapter will integrate the findings of this research study with the relevant literature previously reviewed. The implications for social work practice will also be discussed, as well as areas for future research regarding gaps in the provision of psychosocial services to cancer patients in a multidisciplinary setting. Finally, the strengths and limitations of this study's design and methodology will be discussed.

The literature reviewed in this study established the following:

1. That the psychosocial impact of cancer and the different ways psychosocial distress manifests itself in the lives of cancer patients is significant.
2. That the “fit” between a particular modality and any given individual is important in considering the merits of the varied types of psychosocial interventions.
3. That the system in which cancer patients receive their medical treatment is complex and a multidisciplinary team approach can complicate communication with cancer patients as well as the assessment and treatment of psychosocial distress.
4. That there is a lack of research on this topic and the research that does exist has significant limitations.

(Unmet) Psychosocial Needs

The likelihood of cancer patient's experiencing psychosocial distress in some form is as high as 84% (Gotay & Lau, 2002). Additionally, psychosocial support services such as brief counseling programs or support groups have been found to improve

cancer patient's psychosocial functioning (Boulton, 2001; Kujer et al., 2004), as well as other treatment modalities such as social groups and cancer community centers (Davis, Gohen, Apolinsky, 2005). The findings of this research study demonstrate that social workers believe that psychosocial support is warranted when there is the first suspicion of cancer, and this need extends throughout the stages of cancer, confirming the findings of Mazur (2007) who pointed out that patients who are in remission often live in fear of cancer's return. The findings of this research study also suggest that the provision of resources or meeting the "practical needs" of cancer patients is in and of itself a form of psychosocial support, which may speak to a similar effect discussed by Davis, Gohen and Apolinsky (2005) who suggested that some cancer patients benefited just by virtue of their membership in a community of cancer patients.

The combination of the psychosocial impact of cancer and the benefit of psychosocial support services throughout the progression of a cancer patient's treatment demonstrates the important role that social workers fulfill within the hospital setting. Unfortunately, the findings of the present study also demonstrate that the social worker's role in a hospital setting is embedded within a complex system that contains barriers to providing psychosocial support throughout the duration of a cancer patient's treatment.

Social Work Role

A contribution of the present study to the existing body of literature is the description participants offered regarding their role as social workers in a hospital setting as a part of a multidisciplinary team. The fact that no research that identifies and explains the role of a social worker in a hospital setting was found in an inclusive review of the literature reflects the lived experience of the social workers interviewed in the

present study as having ill-defined, diffuse and vague roles and duties. Although the complicated nature of the field in which oncology social workers practice makes it difficult to research, it is possible that continued empirical research will inform training and education needed to properly train oncology social workers.

In this study, social workers identified several obstacles that stand in the way of providing cancer patients with psychosocial support within a complex system like a hospital, one of which was a lack of specific educational training. Due to the fact that there aren't specialization courses in graduate studies, a social worker learns according to the practices of their colleagues, meaning that practices can be inherited without necessarily being efficient, or based on research or theory. The literature suggests that screening tools such as the Distress Thermometer and the Problems Check List (Vitek, Rosenzweig, and Stollins, 2007) be implemented (although not specifically by social workers).

Without graduate education specialization and a universal protocol for identifying patients who are in need of psychosocial support, it is likely that social workers are not able to define an empirically supported or theoretically grounded area of expertise within their role. This can add to the sense that social workers are not necessarily “experts” and instead that their role is to carry out the tasks of other experts on the treatment team (i.e. doctors, nurses, physical therapists, etc.) The findings of this study demonstrate that neither social workers nor the multidisciplinary team members with whom they work can explicitly define their primary duties as a medical social worker. Social workers either aspire or feel obligated to provide support around "everything non-medical," which is categorized into the eight self-selected roles that social workers identified. Because these

roles are not explicitly outlined and instead are roles that social workers perform implicitly, other providers do not necessarily identify them as having the expertise that they do to provide psychosocial interventions.

As social workers are feeling ill-prepared to enter into this specialty area and their role is not clearly defined, they are further challenged by the extremely high number of cancer patients for whom they are responsible. The most commonly listed gap by participants in this study is between the small number of social workers and the high numbers of patients. In short, their cases are absolutely overwhelming. For example, a social worker may be one of two oncology social workers who are assigned a caseload of 25 patients or more, all of whom have varied, dynamic, and ever-changing needs that do not relent in accordance with the social worker's availability. Do the patient and family who are struggling with end of life decision-making take precedence over the cancer patient who has just lost her job, insurance, and financial security? Furthermore, what happens to a patient who is not in such crisis, like a patient who is being introspective during his time in the hospital and is thinking about how he is going to tell his family members the news that the doctor just shared with him before the doctor rushed off to see his next patient? Is he or she necessarily in *less* need of social work services? Or will he or she simply not get them because of the quiet nature of his or her crisis?

While social workers are struggling to prioritize and make the best use of themselves as a limited resource, their role is further complicated as they often become triangulated with both the patient and the team members. For instance, if the patient is deemed medically clear for discharge by the rest of the team but the social worker believes that it is crucial for that patient to remain in the hospital due to the psychosocial

issues that are threatening to their success at home, how does the social worker balance his or her role as team member with that of patient advocate? Team morale suffers as medical providers sometimes view such psychosocial issues as merely a barrier to discharge, and the pressure from hospital administrators and managed care companies to get patients out of the hospital as soon as possible is ever present.

This role as an advocate can be further complicated if a social worker has been working with a patient cleared for discharge and the social worker cannot guarantee continuity of care. Because social workers are so consumed by the caseload that exists in the hospital, there isn't time for them to extend themselves to the cancer patient as a support after they've left the hospital. For instance, if a social worker had been providing support to a cancer patient who has been medically cleared for discharge but after completing an assessment identifies that patient's need for additional support in the community, she may have referred that patient to a support group, or an individual therapist. Unfortunately, without the continuum of care, the social worker will never know if that patient followed through with the services in the community and her ties to that patient as an advocate and a therapeutic ally will be lost.

Patients may not follow through with services in the community merely because they don't have the time or money to spend on support services. A patient may be employing defense mechanisms, and may not feel as though he is in need of support after he has left the hospital (Wool & Goldberg, 1986). Research also shows that a variety of psychosocial intervention should be made available to cancer patients (Gotay and Lau, 2002), as different treatment modalities work best for different people. For whatever the reason, it may be too difficult for the cancer patient to follow through with the initial

referral for services, and without follow up it is even less likely that he will pursue support services in the future.

Multidisciplinary Role

The literature suggested that medical providers of cancer patients have difficulty with or even avoid discussions that may include a strong emotional reaction (Cuisinier et al., 1986). For example, a doctor may have difficulty delivering the news that a patient's cancer has progressed to a stage that is no longer treatable. Findings of this study provided mixed support for this in that participants reported that while most doctors handle emotional conversations well, there are some doctors who experience a "countertransference" that gets in the way of their ability to have conversations with patients.

A compounding issue is the tendency of doctors to underestimate the levels of distress that patients are feeling (Merckaert et al., 2008). The findings of this study suggest that team members are conceptualizing distress differently according to their profession, and that the identification of distress and how to address it might be discipline-specific. As mentioned above, multidisciplinary team members do not have a thorough understanding of the social work role. Theoretically, if a doctor does notice that a patient becomes tearful during her hospitalization, but the doctor neither feels comfortable with the emotional response that the patient is having nor understands that a social worker could evaluate that patient to better identify their needs, he may not refer that patient to social work for an assessment and emotional support. Conversely, this misunderstanding of the social work role and countertransference during emotional reactions could lead to over-referral of patients to social work services.

Patient Role

Patients struggle to communicate the psychosocial stressors that they are experiencing whether it is due to the fact that often cancer patients are only capable of recalling 40% of the discussion that follows their diagnosis (Cuisinier et al., 1986), their desire to conceal emotional reactions because of the stigma attached to psychosocial distress (Servaes et al., 1999), or the inherent power dynamic that exists between a doctor and a patient (Okuyama et al., 2008), the psyche's employment of defense mechanisms such as denial, or because the cancer patient has not had adequate time to come to terms with their experience as a cancer patient (Wool & Goldberg, 1986). The findings of this research study indicate that it is extremely difficult for cancer patients to pose questions to medical providers, as participants reported that patients often do not have the time or wherewithal to think of questions to ask the doctors. It seems that social workers have automatically assumed the role of "interpreter" between the cancer patient and the doctor, however it does not seem as though this disconnection has been explicitly identified as a gap in the provision of psychosocial services to cancer patients.

If a physician is experiencing some difficulty in conducting an emotionally-laden discussion with his patient (which is likely a normal experience to have) and a cancer patient is under distress while taking in information about the medical diagnosis, the level at which the patient and the physician are able to communicate can be severely compromised. It may be possible that neither the cancer patient nor the physician will have the capacity to step outside of his individual emotional reactions to objectively and comprehensively discuss the matter at hand. Social workers themselves have identified this as an important dynamic, however it does not seem as though it is known by other

medical professionals that it is something in which social workers specialize. Thus, they do not think to enlist the aid of a social worker.

A major contribution of the present study to the existing literature involves what participants revealed about the financial impact of cancer. Previous research did not address the financial strain that devastates cancer patients as a competing psychosocial need. Instead, it is included in the overall psychosocial impact the disease itself. The findings of this research study demonstrate that cancer patients are sometimes consumed by the financial demands of having cancer to the point where they're unable to afford basic housing never mind the costly medical treatment regiment that bankrupts them in the first place. When cancer patients are under financial strain it seems as though they are not capable of participating in psychosocial support interventions that have a counseling component because their efforts are being put towards finding the resources that will keep them afloat. It may be that cancer patients are not aware of the psychosocial support services (Gotay & Lau, 2002) because they are not seeking information about that kind of support.

Implications for Social Work Practice

Any recommendations one can make about bridging the gaps between cancer patients' psychosocial needs and the services that they receive are contextualized by the nature of the treatment setting. The very structure in which cancer patients receive their treatment, medical and otherwise, is an environment that is complex and intricate. The nature of a hospital setting is fast-paced and crisis oriented, which propels all of the many multidisciplinary providers into frenzy while they do their best to attend to each individual patient while still acting as a comprehensive treatment team. This

environment is further complicated by the managed care system, which puts an actual price on each hospital bed and generates even more pressure to treat a patient as quickly and efficiently as possible. System wide change in a hospital setting requires a plethora of time, money, and resources (Bunston & Mings, 2007) making the implementation of change extremely difficult. After a thorough comparison of the existing body of literature and the findings of this research study, there are some recommendations as to how the field of social work could take action to bridge some of the gaps that inhibit in the provision of comprehensive psychosocial support services to cancer patients within the constraints of a hospital setting.

First and foremost, it would be helpful if there was an increase in the number of medical social workers employed in hospital settings. It is very clear from the results of this study that social workers are overwhelmed by the large caseloads they are responsible for and as a result, cancer patients are not receiving the support that they might need. One social worker captured this well by stating, "If there were two of me, it wouldn't be too bad." It may be reasonable to propose that for every medical social worker who specializes in oncology care, another position be created. An increase in the number of social workers would enable them to focus much more on each of their patients, rather than try to prioritize their patients based on the severity of their situation.

To go a step further, it would be recommended that two social workers work as team to have a stronger focus on less "roles." One social worker, for example, could focus her efforts exclusively emotional support. This would include conducting a psychosocial evaluation for each new cancer patient to identify any psychosocial stressors that may exist including "concrete needs" with reevaluation after 1 month of the

initial evaluation whether psychosocial stressors were found or not. Social workers would then focus their efforts on providing emotional support to the cancer patient and family as needed with an emphasis on support in times of miscommunication between the patient and their medical providers, during end of life decision making, and death and dying.

The other social worker would assume the role as resource provider and would address the concrete/practical needs of the patient. This social worker would be a case manager and logistical crew director by arranging transportation, helping to direct patients and families when managed care questions arise, assisting with coordination of services at multiple treatment agencies and the paper work involved, and coordinating the discharge plan. Both social workers could be introduced to the cancer patient and their family as a as a treatment team, with little overlap so that one can assist the other in the provision comprehensive treatment for all cancer patients.

This division and focus will not only assist social workers in being able concentrate their efforts more efficiently for more patients, but it would also help to create a more defined role for social work in a multidisciplinary setting. It is just as important for social workers to specialize their roles, as it is for multidisciplinary team members to be able to define the social work role and refer accordingly.

Another recommendation that would not require such a dramatic change would be to provide cancer patients with a tape recorder. It would be beneficial for cancer patients to get the message that there is an overwhelming amount of information to be taking in throughout their treatment, especially if they are being treated by multiple specialists, and it may empower patients to be more actively involved in their treatment. A tape recorder

would be a simple tool that would help the cancer patient review and reflect on what he has heard from the doctor, and would likely give more time and space to think of any questions that he might have. This would also encourage patients to make more informed decisions regarding their medical care, and would help patients feel as though they are an inclusive part of the treatment team.

Other suggestions would include those that would require social work graduate schools to provide courses in which students can specialize in medical social work. It would be helpful for graduate students to have the option to take specialization courses that emphasize the benefit of joining with a client as a case manager by helping to meet a concrete need of theirs to establish a therapeutic alliance. Also, a thorough introduction to the managed care system and the many ways in which patients that have chronic illness face postponement or loss of their treatment all together due to managed care complications. As of right now, social workers are learning about the managed care system as they go, and it would likely be beneficial to both the social worker and the patient if the social worker had knowledge of managed care going into their work.

Finally, it is clear that cancer patients are under an incredible amount of financial strain due to the extreme costs of their medical care. While the funding for cancer research is invaluable to the future of cancer treatment, it would be helpful if cancer research foundations allocated some of their funds to cancer patients who are struggling in the midst of their disease.

Implications for Future Research

Future research that explores the experience of cancer patients during their hospitalization and their interactions with a multidisciplinary team would be beneficial to

the field of social work. A more in depth understanding of what cancer patients need and want during their hospitalization will assist social workers in tailoring their services to the needs of the patients. Research that explores the financial strain that cancer patients experience related to the managed care system would also be helpful to understand what resources can be designed to assist these cancer patients. Also, future research that measures the benefit of concrete service provision to cancer patients and the emotional support that is inherent in that work would benefit social work practice in hospitals.

Further research should be conducted regarding the gaps that exist in the provision of psychosocial services to cancer patients in a multidisciplinary setting that has a larger sample size and more diversity in race and geographical region. It is important for social workers to continuously evaluate their role in a hospital environment and anticipate the barriers to providing cancer patients with comprehensive psychosocial support services. Future research would also be helpful to learn more about how multidisciplinary treatment providers describe their working relationship with social workers, and how they understand the social work role.

Strengths and Limitations

Given the restricted amount of time and resources available to the researcher, there are limitations to be considered. First, this study only called for a small sample of 12 participants all of whom were practicing in the San Francisco Bay Area. The results cannot necessarily be generalized to a larger population of medical/oncology social workers. Also, the small number of participants limited the diversity of participants in culture, gender, and the diversity of the settings in which they practice. Another limitation of this study was that the exploratory methodology allowed for deviation from

the interview guide in order to clarify answers and gain more information. Each of the twelve interviews was not exactly the same.

Despite these limitations, the qualitative nature of this study lent itself to a more in-depth data analysis of testimonials by social workers currently practicing in the field, and gave the researcher freedom to ask questions specific to each participant's experience. The findings may also augment the existing literature, as it has generated recommendations for social work practice, and areas of future research.

Summary

In conclusion, social workers did identify "gaps" between the need for psychosocial support services in cancer patients and what is being provided to them in multidisciplinary settings by medical social workers. While more research is needed in this area, it is likely that an increase in the number of social workers will help tremendously in bridging the gaps that participants articulated. It is likely that social workers will benefit from continuing to define their role as medical social workers, and develop an area of expertise rather than fulfill a variety of roles. Also, future research regarding the financial strain on cancer patients would contribute to the literature, as financial strain was shown to be a difficult psychosocial stressor that competes with other stressors in the lives of cancer patients and their families

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Appendix A

December 19, 2008

Billie Ann Starks
1515 Funston Ave.
San Francisco, CA 94122

Dear Billie,

Your revised materials have been reviewed and all is now in order. We are happy to give final approval to this very useful study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

It should be most interesting to get some information on why these valuable services appear to be under-used. Good luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Beth Kita, Research Advisor

Appendix B

WANTED:
Medical and/or Oncology Social Workers for Study

Gaps in Provision of Psychosocial Services to Cancer Patients in a Multidisciplinary Setting: A Social Work Perspective.

Purpose of this study: To explore a social work perspective of why there are gaps in the provision of psychosocial services to cancer patients by defining: their role as a social worker, the role of multidisciplinary involvement, patient and family involvement, and the role of managed care.

Procedures: Participants will be asked to complete an in person interview that will take approximately 45 minutes to complete and will be tape recorded.

Eligibility criteria: Master's level oncology or medical/surgical social workers who work (or have worked in the last 5 years) in a hospital or cancer care center as a part of a multidisciplinary team, and provide support to cancer patients.

(Social workers who serve cancer patients in a private setting *ONLY* will be excluded from this study.)

Each participant can choose a \$5 gift card to Starbucks™ or Jamba Juice™ as a token of the researcher's appreciation for their participation!

To learn more about this research, call or email:

Billie Ann Starks

2nd year Master's student, Smith College, SSW

Phone: 857-998-2590, Email: Billie.Starks@gmail.com

Address: 1515 Funston Ave, San Francisco, CA 94122

(Please use "RESEARCH" as a subject heading in emails. Thank You!)

This research is advised and supervised by: Smith College School for Social Work, Lilly Hall, Northampton, MA 01063

If you are not interested in this study but you know someone who might be, please pass along this information!

Appendix C

Informed Consent Form

Dear Participant,

My name is Billie Starks, and I am a second year graduate student at the Smith College School for Social Work. The study that you have expressed interest in participating in is a research project that I will be working on throughout the duration of the next several months. The purpose of this research study is to learn more about a medical/oncology social worker's perceptions of why there are gaps in the provision of psychosocial interventions in a multidisciplinary setting. This research study will be submitted to the Smith College School for Social Work as a Master's Thesis, and may be used for presentation and/or publication.

Your participation in this study will require you to meet with me, Billie Starks, to complete a one time interview that will be tape recorded. Participants in this study must be a Master's level social worker who is currently working, or within the last 5 years has worked, in a multidisciplinary setting providing psychosocial support to cancer patients. Those social workers who work or have worked in private practice *only* with cancer patients will be excluded from this study. The interview will be scheduled at your convenience, and will have to be completed in a location that will allow for clear audio recording (i.e. a small office space at your place of employment, etc). The interview will take approximately 30 minutes to complete, however it would be appreciated if you were able to spend some additional time with me to allow for a more extensive interview. I will be asking you a series of open ended questions to stimulate an in-depth discussion. The tape recording of the interview will be transcribed verbatim by me, Billie Starks for analysis.

Possible risks of participation in this study are emotional reactions or feelings of stress that may arise as a result of the conversation elicited by interview questions.

Benefits to participating in this research may include a positive experience in which you are willing to process your experience as a social worker in a multidisciplinary cancer care setting. Also, the information gained from this study may potentially contribute to the field of social work in raising awareness around social work needs and experiences in a multidisciplinary cancer care setting, and contributing to the current body of literature that has not yet implemented extensive research on this topic. Additionally, awareness around the needs of cancer patients and their families will be raised and developed. This may help social workers and other health care providers better serve the needs of their patients! Finally, you can choose either a \$5 gift card to Starbucks™ or \$5 gift card to Jamba Juice™ as a token of my appreciation for your participation in this study.

Maintaining confidentiality is an important component to the protection of participants in this research study. It is important for you to know that I will be conducting this research under the supervision of a research advisor, and that she will also be viewing the data that is collected. In order to protect your confidentiality, the tapes that are used to record the interview will be labeled with a code number so that all information that could identify you will be stored separately. Also, when presenting the information that is gained from this research study, all data that is used to demonstrate findings will be carefully disguised in order to assure that no identifying information is revealed. All materials utilized in eligibility screening and during the interview, (i.e. consent forms, audio tapes, and notes) will be stored in a *locked* case file. Also, any and all electronic materials will be saved in a file that is password protected. According to Federal guidelines, all materials utilized for the purposes of this research will be protected and stored for three years, and should the materials be needed beyond this three year period, the materials will continuously be stored in a secure location.

I would like for you to keep in mind that your participation in this research study is completely voluntary, and you have the right to withdraw from this study, or refuse to answer any question without penalty. If you do choose to withdraw from this study before we meet for the interview, please contact me and I will immediately destroy eligibility screen tools that contain your information. You can reach me via email: Billie.starks@gmail.com or telephone: (857) 998-2590 with any questions or wishes to withdraw. If any other concerns arise pertaining to your rights as a participant in this study, you may also contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (415) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY. Thank you for your valuable time!

Signature: _____

Printed Name: _____

Date: _____

Appendix D

Sample Questions for Semi Structured Interview

Gender: ____

Racial Identity: _____

Number of years practicing as medical/oncology social worker: ____

Number of settings in which you worked as a medical/oncology social worker: ____

Social work role

How are patients referred? Who is referring them? What is the most common reason for referral?

What is your primary role when working with cancer patients?

What are most commonly used interventions?

When you have found that cancer has had a psychological impact on a patient, when and how do you broach this topic with a) the patient, b) their families, and c) with the multidisciplinary team?

Do you believe there are gaps in the provision of psychosocial interventions?

If so, what obstacles seem to contribute to these gaps?

Is there follow up with a patient?

How do you inform your practice?

Multidisciplinary role

How do you work/ communicate with other disciplines primarily?

How does this enhance/hinder your work?

How do other disciplines understand your role?

Literature demonstrates avoidance of difficult discussions, have you observed this?

Patient's role

How are patients oriented to social work's role in their multidisciplinary treatment?

What opportunities are patients given to voice their needs/concerns?

Is there a continuum of care or follow up with all patients?

Literature demonstrates patients have difficulty speaking up with Dr's have you observed this?

Family role

How/when/why are family members involved?

What opportunities are families given to voice their needs/concerns?

How are needs followed up on?

Managed care role

How does managed care influence your role?

Ethical role

What are common ethical implications you face in your practice?

Appendix E

Sample Questions for Semi Structured Interview

Gender: ____

Racial Identity: _____

Number of years practicing as medical/oncology social worker: ____

Number of settings in which you worked as a medical/oncology social worker: ____

Social work role

How are patients referred? Who is referring them? What is the most common reason for referral?

What is your primary role when working with cancer patients?

When you have found that cancer has had a psychological impact on a patient, when and how do you broach this topic with a) the patient, b) their families, and c) with the multidisciplinary team?

Do you believe there are gaps in the provision of psychosocial interventions? If so, what obstacles seem to contribute to these gaps?

How do you inform your practice?

Multidisciplinary role

How do you work/ communicate with other disciplines primarily? How does this enhance/hinder your work?

How do other disciplines understand your role?

Literature demonstrates avoidance of difficult discussions, have you observed this?

Patient's role

How are patients oriented to social work's role in their multidisciplinary treatment?

Is there a continuum of care or follow up with all patients?

Literature demonstrates patients have difficulty speaking up with Dr's have you observed this?

Family role

How/when/why are family members involved?

How are needs followed up on?

Managed care role

How does managed care influence your role?

Ethical role

What are common ethical implications you face in your practice?