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Jenny Grabelsky
How Do the Online Illness
Narratives of People Living with
Advanced-Stage Cancer Inform
Clinical Social Work Practice
with this Population?

ABSTRACT

This exploratory-descriptive study set out to identify the unmet needs of people living with advanced cancer, and how those needs might be addressed by clinical social workers. To this end, the previous literature on this topic was reviewed, and the online illness narratives of ten people living with advanced cancer were examined. The narratives, which portrayed the lived experiences of the population at the heart of this study, were then compared and contrasted with previous research findings to identify areas of need that have not been mentioned in the literature and/or require additional attention and resources.

The existing literature and the blog data from the current study revealed that people with late-stage cancer have many unmet needs that negatively impact their quality of life. This study also found that clinical social workers possess the knowledge, skills, and values to provide effective interventions that can improve quality and continuity of care, and reduce suffering for this population.

**HOW DO THE ONLINE ILLNESS NARRATIVES OF PEOPLE LIVING WITH
ADVANCED-STAGE CANCER INFORM CLINICAL SOCIAL WORK PRACTICE
WITH THIS POPULATION?**

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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2015

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CHAPTER I

Introduction

The purpose of this inductive, qualitative-exploratory, descriptive study is to answer the following question: “How do the online illness narratives of people living with advanced-stage cancer inform clinical social work practice with this population?” Due to advances in cancer research, many people with cancer diagnoses are living longer and surviving. However, there is a group of people living with cancer that will never be survivors: those living with metastatic cancer. *Metastatic cancer*, also known as stage IV or advanced, end, or late-stage cancer, indicates cancer that is not responding to treatment and has spread (metastasized) to distant tissues or organs in the body. With minimal chance of recovery and a sharp limit on expected length of life, treatments at this stage generally aim to control cancer growth or to relieve symptoms caused by it. Most people who die of cancer die of metastatic cancer (National Cancer Institute, n.d.).

Nonetheless, improvements in cancer treatment have also impacted the lives of those with metastatic cancer by extending the length of the palliative care phase (Clausen, Kendall, Murray, Worth, Boyd, & Benton, 2005, p. 277). And although the fields of palliative care and social work are advancing, cancer care delivery has not risen to match the increasing complexity of cancer treatment. With a growing number of treatment options, there is a greater need for trained and knowledgeable clinicians to support this population (Clausen et al., 2005, p. 277).

Social work practice in end of life care has advanced significantly over the past 20 years. Reese (2011) conducted a study on the qualifications and level of involvement of social workers

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in 24 interventions that fall within the role of hospice social workers, including discussing the meaning of life, upholding client preferences regarding their environment and advocacy, civil and legal assistance, and ensuring culturally competent end of life decisions. Self-administered surveys and telephone interviews with hospice directors from around the United States revealed that social workers spent more time and were also considered more qualified than other end of life care workers (such as nurses and spiritual caregivers) to provide 12 of the 24 interventions.

However, social workers who specialize in palliative care are frequently based in hospitals or hospice settings, and thus less accessible to people living with advanced cancer who receive outpatient treatments (Clausen et al., 2005, p. 284). When social work is not an integral part of palliative care within the community, people living with advanced cancer and their families may be deprived of advocacy and therapeutic elements that are so important.

In another study that aimed to identify an optimal model for ambulatory cancer care, Lee, et al. (2012) reviewed the literature on existing models and conducted semi-structured interviews with ten top administrators of comprehensive cancer centers regarding care delivery strategies. Study findings reinforced the importance of inter-professional collaboration, patient-centered care, and continuity of care, and suggested that these elements improve care coordination, patient and provider satisfaction, and clinical outcomes and efficiency for ambulatory cancer patients (Lee et al., 2012, p. 113).

The overarching objective of this study was to complete a content theme analysis of online illness narratives written by people living with chronic cancer to identify the major needs and concerns of this population that can be addressed by social workers. Online illness narratives, also called *blogs*, *Internet blogs*, *web logs*, and *electronic narratives*, are webpages created by individuals who are affected by illness that include unsolicited, first person narratives that are

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published for others to read (Heilferty, 2009).

Only a fraction of the experience of living with cancer is expressed or observed during a doctor's visit or hospital stay. The increasing popularity of illness narratives offers a unique way to capture the real experiences and needs of this population, which due to experiences of ostracism, isolation, and marginalization may be reluctant to share their highly sensitive, personal experiences with others. Personal narratives about cancer experiences can teach social workers and other health professional a great deal about living with life-limiting illness, suffering, and experiences of care (O'Brien & Clark, 2012).

The analysis of illness blogs is a starting point from which we might obtain valuable information about the experiences and needs of people living with advanced-stage cancer, in their own words. The information gleaned from online emotional support systems and the exchange of information and personal experiences among people living with advanced cancer can provide insight into their emotional and psychosocial needs. By better understanding their perspectives and experiences, social workers may be able to support them more effectively.

People with metastatic cancer are living longer, and with treatment options also increasing in number and complexity, the current lack of support and resources for people with advanced cancer who are not in hospice care can no longer be ignored. The field of social work must carry on its commitment to improvement by learning how to support people with metastatic cancer. People living with advanced-stage cancer have much to teach us about living with life-limiting illness, suffering, and the experiences of care. Addressing this gap in knowledge using thematic analysis may provide new knowledge that is critical to social work policy and practice.

CHAPTER II

Literature Review

People living with advanced-stage cancer are coping with major stressors and need support. Now, due to advances in cancer treatments and research, this population is living longer than ever before. Thus, the demand for helping professionals that work with and advocate for people with incurable cancer is growing. The purpose of this study is to explore how the illness narratives of people living with advanced cancer can inform clinical social work practice with this population.

To address this question, literature on the experiences and needs of people living with metastatic cancer, and the current and potential roles of social workers with this population was reviewed. This chapter begins with a broad description of the population at the heart of this investigation—people living with advanced cancer—and their met needs. The second section will expand upon that foundation by outlining the current state of care coordination for people living with late-stage cancer. The third section will examine the role of social workers with this population. This section opens with an overview of the current roles of social workers with people living with metastatic cancer, and expands upon the topic by highlighting various studies that focused on the current and potential role of social workers to meet the needs of this population. The fourth section describes methods of coping with end-stage cancer, including the use of online illness blogs as an outlet and support. The fifth section addresses the implications, including ethical considerations and researcher bias, of researching personal illness narratives.

The chapter concludes with a comprehensive rationale for the exploratory research findings produced in this study.

Population

Ad campaigns, fundraisers, and survival stories have helped to increase cancer awareness among the general population (Kleban, 2014). Popular images like the pink ribbon emphasize a “culture of cancer” that relates to survivorship and excludes an important group of people who will not survive—“the people we fear and the people we fear we may become”—those living with advanced-stage cancer (Kleban, 2014, p. 7). The following account of a 54-year-old woman with metastatic breast cancer illustrates her sense of alienation once she could no longer call herself a “survivor”:

The month of October, with its emphasis on early detection and celebration of lives saved—with cheery pink everything—felt happy to me. All of this changed in May 2010. All of a sudden I was no longer a happy success story of early detection. The happy pink month of October became a sort of taunt rather than a celebratory time, and I had no idea where I fit in when people were lining up by years of survivorship. Am I a survivor still? ...I am still alive today, almost 4 years later, but incurable cancer with never-ending treatment affects my entire life. My partner and teenage children live with my cancer every day as much as I do and experience its profound effects on their lives. The ups and downs of struggles with receiving news about the cancer and its progression, my variability in being able to be fully present with my family, and the ongoing uncertainty about my prognosis affect the entire family. (Park, E. M., & Rosenstein, D. L., 2014, p. 279)

The resulting emotional isolation from loved ones and community is a “little slice

of...death before it happens” (p.7). Kleban (2014) argues for an open discussion of metastatic cancer and dying:

Perhaps the goal is to learn how to live somewhat differently; to live life fully and not in the future. It has been acknowledged by most mental health workers that while we cannot control the amount of time we live, we can often control the quality of that time. If we cannot control living longer, we can often control living better. (pp. 8-9)

Now, with advances in cancer research and improved treatments, more people with cancer are living longer. For people with metastatic diagnoses, the palliative care phase, which focuses on controlling symptoms to promote comfort, is also lasting longer (Clausen et al., 2005, p. 277). The World Health Organization defines palliative care as the early identification and intervention of patients’ physical and psychosocial problems caused by life-threatening illness (Soelver, Rydahl-Hansen, Oestergaard, & Wagner, 2014, p. 168).

Given today’s emphasis on cancer survivorship, more attention needs to be paid to the people who will not survive (Kleban, 2014). Thus, the research question for this study is: What are the experiences of people living with advanced-stage cancer? and, What supports do they need so they can live better? The experiences of people with metastatic cancer have significant implications for the practice of social work with this population. Given the valuable role of social workers in hospice care, it is important that the needs of those with cancer who are receiving palliative care no longer remain hidden.

Needs

As cancer treatments have improved, more patients with advanced cancer are living longer. The challenges of living with incurable cancer are significant and uniquely different from those faced by people with non-recurrent cancers; however, this population’s needs are a

neglected aspect of cancer survivorship. Clarifying goals of care, improving advocacy efforts, and prioritizing the management of active symptoms are necessary to ensure proper care for people living with advanced-stage cancer (Park & Rosenstein, 2014, p. 279).

Symptom burden. “Advanced cancer is associated with increased physical symptoms and more invasive and burdensome treatment” (Ng, Verkooijen, Ooi, & Koh, 2012, p. 1055). Profound physiological, psychological and economic issues are associated with the diagnosis, treatment, and symptoms of incurable cancer (Cui, 2014, p. 562). The substantial burden of physical and psychological symptoms can profoundly affect their quality of life (Park & Rosenstein, 2014, p. 280). The significant symptom burden experienced by advanced cancer patients can lead to multiple unmet needs, which are defined as “the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being” (Sanson-Fisher et al., 2000, p. 227). Identifying this population’s unmet needs can help to shed light on the types of services that need improvement and prioritization and ultimately lead to more appropriate interventions for people living with advanced cancer.

Many patients living with advanced disease experience undertreated somatic symptoms. A systemic review conducted in 2007 that assessed symptom prevalence in more than 25,000 people living with late-stage cancer, found fatigue (74%), pain (71%), lack of energy (69%), weakness (60%), and appetite loss (53%) to be the most commonly reported symptoms (Park & Rosenstein, 2014, p. 280). Cancer-related fatigue is not only a physical symptom. It is also a subjective and multidimensional symptom with physical, emotional, and mental components (Park & Rosenstein, 2014, p. 280).

Hwang, Chang, Cogswell, Alejandro, Osenenko, Morales, Srinivas, and Kasimis (2004) aimed to identify the prevalence of significant symptom burdens and unmet needs of 296 male

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United States veterans with advanced cancer. In this cross-sectional survey study, participants completed various questionnaires, assessment scales, and other validated measurements of function, depression, health, and social support. The areas of unmet need reported most frequently by study participants were physical (80.0%), activities of daily living (53.3%), nutrition (46.1%), and emotional (32.5%) (Hwang et al., 2004, p. 428). Psychological symptom distress was also frequently reported, and was associated with unmet needs in the emotional/social, economic, medical, and community domains (Hwang et al., 2004, p. 428).

This study has several limitations. Participants were all male veterans who may have presented with unique physical and psychological needs that are independent of their advanced cancer diagnoses. Moreover, a low prevalence of reported unmet needs in the economic, medical, and community domains might be attributable to veterans' ability to obtain comprehensive cancer care within VA health care systems regardless of financial and insurance status (Hwang et al., 2004, p. 430).

Psychosocial stressors. Advanced cancer is associated with high level of unmet psychological needs (Ng et al., 2012, p. 1055). "For many individuals with incurable illness, the specter of their own mortality becomes increasingly powerful and unavoidable" (Park & Rosenstein, 2014, p. 279). This terminal population, which symbolizes the antithesis of hope, is often disregarded even within the larger cancer community (Kleban, 2014). Kleban argues that the fear of death deepens the separation between people living with advanced-stage cancer and the rest of society, and that for people living with life-limiting cancer, this distance reinforces feelings of shame and withdrawal from life's activities.

In addition to the psychological toll of impending death and length of life remaining, patients with advanced disease often feel marginalized or isolated (Park & Rosenstein, 2014, p.

280). Qualitative studies indicate that patients with advanced cancer feel cast off and perceive a loss of social status within the healthcare system (Soelver et al., 2014, p. 168). “Approximately 20% of all patients with advanced cancer have symptoms consistent with a depressive disorder, and nearly 14% meet diagnostic criteria for an anxiety disorder” (Park & Rosenstein, 2014, p. 280).

Physical, social, and psychological stress can result in unique psychosocial needs in cancer patients. Ng, Verkooijen, Ooi, and Koh (2012) investigated the prevalence of unmet psychosocial needs among 535 cancer patients undergoing ambulatory care. *Psychosocial needs* were defined as “needs arising in the physical, informational, emotional, psychological, social, spiritual and practical domains as part of a patient's experience of cancer and its treatment” (Ng et al., 2012, p. 1049). Seventy-five per cent of participants reported unmet needs. The most prevalent was disease information needs (61.5%). Financial (40.2%), social support (39.7%), psychological (27.3%) and physical needs (26.1%) were also commonly reported by participants (Ng et al., 2012, p. 1049).

Healthcare providers play an important role in providing information and education to clarify the barrage of confusing and often unverified information that may be available online or in print material (Ng et al., 2012, p. 1055).

Culture and context-specific needs. Unmet needs have also been found to vary among different cultural groups. A cross-sectional study conducted by Effendy, Vissers, Osse, Tejawinata, Vernooij-Dassen, and Engels in 2014 used surveys to collect self-reported data from 180 Indonesian and 94 Dutch patients with advanced cancer receiving outpatient treatment at oncology clinics. Participants were asked to complete the Problems and Needs in Palliative Care (PNPC)-short version questionnaire to describe their problems and unmet needs relating to daily

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activity, physical symptoms, autonomy, psychological issues, spiritual issues, and financial problems.

Over 75% of the participants reported suffering from fatigue, and two out of three from pain. Although the researchers hypothesized that differences in economic resources between both countries would lead to differences in unmet needs, the prevalence of most physical problems, including pain, was similar in both countries (Effendy et al., 2014, p. 2). Still, the comparison between both countries did reveal some noteworthy differences.

Indonesian patients reported more financial problems and unmet needs for professional medical attention than their counterparts in the Netherlands, where there are more economic resources and treatment facilities, and where most nationals have free health insurance (Effendy et al., 2014, p. 5). Dutch patients, however, reported more problems related to issues of autonomy than Indonesian patients, where it is more culturally accepted to be dependent on family during illness, and less emphasis is placed on the value of independence (Effendy et al., 2014, p. 5). In the Netherlands, many patients mentioned that they have spiritual problems. Unmet spiritual needs are associated with a reduced sense of spiritual meaning and peacefulness. Significantly fewer Indonesian study participants, who live in a culture that is strongly influenced by spirituality, had difficulties with accepting their disease (Effendy et al., 2014, p. 5).

Although this study offers insight into problems and unmet needs of patients with advanced cancer in a European and an Asian country, the generalizability of its results to the United States population is unknown. Nevertheless, findings indicate that culture-specific differences in the supportive care needs of people living with advanced cancer exist.

A study by Lam, Au, Wong, Lehmann, Koch, Fielding, and Mehnert (2011) also compared groups of people from an Asian and European country to compare psychosocial needs

across different cultural settings. In this study, completed questionnaires were collected from 348 Chinese and 292 German women with advanced breast cancer about their unmet psychosocial needs, psychological distress, and physical and psychological symptoms. Altogether, the most prevalent unmet needs among study participants fell within the Health System and Information and Psychological need domains (“fear about the cancer spreading”). When considered separately, however, there were significant differences in the prevalence and patterns of reported unmet psychosocial needs between Chinese and German women. Chinese women prioritized needs for information about their disease and treatment, whereas German women prioritized physical and psychological support (Lam, 2010, p. 531).

This study is limited in that it did not address the needs of patients with advanced cancer in the United States. However, significant differences in the unmet needs of women with metastatic cancer in different countries reinforces the notion that consideration of cultural and health service contexts is imperative for the identification and implementation of cancer supportive care services and interventions to reduce unmet needs.

These studies indicate that the perceived unmet needs of people living with advanced cancer may be context and culture-specific, and thus can vary according to geographic location and cultural values. In order to improve the quality of care provided to this population, medical professionals must understand the unmet needs their patients experience and communication among medical providers and between providers and their patients must be improved.

Coordination of Care for People with Advanced Cancer

Continuity and coordination of care for people living with advanced cancer still need improvement.

Coordination of care (e.g., between the patient's oncologist and his or her primary care provider) is one of the most important and problematic aspects of cancer survivorship. Several studies have suggested that survivors often fail to receive recommended post-treatment care. Improved coordination of care holds the promise of decreasing survivors' exposure to medically unnecessary or duplicate testing. The possibility of participating in a clinical trial is another unique aspect of care coordination for patients with advanced cancer (and those for whom standard care approaches have failed). Here the challenge is to balance current treatment options and outcomes with optimal timing of and eligibility for investigational treatment opportunities. (Park & Rosenstein, 2014, p. 280)

Differences in perceived needs

For people living with advanced cancer, symptoms, health problems, and unmet needs are subjective, culturally influenced and oftentimes not understood or prioritized adequately by their doctors. Issues that cause the most discomfort or are perceived to be the most threatening for the patients with advanced cancer are frequently assessed as unimportant by their medical providers, which makes the task of setting care priorities more challenging (Konstantinidis & Philalithis, 2014, pp. 419-420). "There is... a certain discrepancy between the health-related physical and emotional issues that are identified by patients with advanced cancer, and those identified in patients by professionals on medical, surgical, and oncology hospital wards" (Soelver et al., 2014, p. 168).

To obtain a patient perspective on continuity in palliative care in relation to interactions with their medical providers, Soelver et al. (2014) conducted semi-structured interviews of 11 adult patients with cancer who were at home in Denmark following hospitalization. Patients were asked to describe interactions with their medical professionals that had been effective in

identifying and alleviating their significant physical and emotional problems. The interviews revealed four issues in patient-provider interactions that acted as barriers to the identification and resolution of patients' physical and emotional problems and needs. These barriers to continuity in palliative care were "falling outside the professional framework", "not being regarded as a person", "unidentified/unmet needs for guidance and involvement", and "patient strategy—minimizing conflict" (Soelver et al., 2014, p. 167).

Falling outside the professional framework. Patients generally did not feel that their medical professionals were proactive or informative in helping to identify their problems, and described the challenge of communicating problems to their doctors in busy hospital environments. Moreover, patients reported that they did their best to adapt by hiding their problems, or even blaming themselves for the problems, when they had difficulty finding the opportunity to talk about their problems or if nothing could be done medically to address them. As a result, some of the patients' problems were never identified or addressed by their providers (Soelver et al., 2014, p. 177).

Not being regarded as a person. Patients reported that their clinicians did not have time to talk with them about their perceived problems, and that the lack of time to discuss these issues was an obstacle in their identification and assessment of issues relating to lifestyle, habits, and relationships. Some of the participants reported that not having the time to converse with their doctors made them feel neglected or uncertain of whether or not they belonged. Participants emphasized the sense of security in seeing the same doctor who knew about their medical history. Those patients who were not on a fixed treatment course and came in contact with many providers in different wards described a sense of anonymity and lack of belonging (Soelver et al., 2014, p. 178).

Unidentified unmet needs for guidance and involvement. Participants reported that their medical providers rarely talked to them about their needs for guidance. Consequently, they had to find solutions to alleviate problems on their own, but were not sure of their needs or were not aware of existing opportunities and resources for help (Soelver et al., 2014, p. 179).

Patient strategy—minimizing conflict. A fourth issue that emerged in the interviews was participants' concealment or suppression of their short and long term problems in efforts to avoid or minimize conflicts with medical professionals. These patients did not think anyone could help, blamed themselves for not being able to find a solution on their own, rationalized that their providers had other patients to tend to, or hoped that the issue or problem would be better the following day (Soelver et al., 2014, pp. 179-180). Despite the small sample of advanced cancer patients represented by this study, the findings nonetheless revealed a discrepancy between the patients' problems and the assessments and interventions provided by the professional palliative team.

Communication

In some cases there was a lack of common understanding between patients with advanced cancer and their doctors. Schenker, Park, Maciasz, and Arnold (2014) conducted a cross-sectional telephone survey of 169 patients with advanced cancer to assess their palliative care needs. The participants were read a description of palliative care and were subsequently asked three questions about their current interest in subspecialty palliative care services, which addressed their perceived need, likelihood of requesting, and willingness to see a palliative care specialist if it was recommended by their oncologist.

Although most participants who reported unmet symptom and emotional/psychological needs desired or perceived a need for subspecialty palliative care services, the findings showed

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that desire or perceived need for palliative care services was not associated with increased likelihood of requesting them. However, most participants reported that they would probably see a palliative care specialist if their oncologist recommended it (Schenker, Park, Maciasz, & Arnold, 2014, p. 670).

Studies indicate that patients with advanced cancer feel that they lose social status in the healthcare system, feel cast off, or may have difficulty getting in touch with medical staff. This experience of powerlessness restricts patients' ability to cope with their issues" and may also be a barrier to requesting palliative care services. (Soelver et al., 2014, p. 168)

Clinical social workers are qualified to assist patients with advanced cancer in thinking about their needs, the services they might benefit from, and facilitate the communication necessary to access those resources.

Still, there are a number of unmet needs among patients who are receiving palliative care (Soelver et al., 2014). Seriously ill patients tend to "avoid difficult conversations by talking optimistically about difficult subjects. This patient avoidance could mean that the need for help remains overlooked, unidentified, or breached if the professional does not take this into account in communication with the patient" (Soelver et al., 2014, p. 182). A 2010 study by Stajduhar, Thorne, McGuinness, and Kim-Sing identified important ways in which professionals can communicate with their advanced cancer patients "from a patient perspective," including making time to talk with patients about their issues and fears in order to identify their perceived needs for help, and providing honest and supportive information regarding progression of their disease (Soelver et al., 2014, pp. 181-182). Generally, there are not enough trained, multi-professional

teams in hospices, on palliative care teams and palliative hospital wards, which could provide specialist palliative care (Soelver et al., 2014, p. 168).

Palliative care

“In 2010 a randomized controlled trial of early palliative care for patients with metastatic non–small-cell lung cancer demonstrated clinically meaningful improvements in quality of life, mood, and survival compared with patients who received standard care” (Park & Rosenstein, 2014, pp. 280-281). Additional studies have also shown improvements in quality of life with the early introduction of palliative care. Consequently, in 2012 the American Society of Clinical Oncology recommended that palliative care be incorporated into standard oncologic care from the time a person receives a metastatic or advanced cancer diagnosis (Park & Rosenstein, 2014, pp. 280-281).

Ambulatory cancer care

“Cancer is a huge problem throughout the world. The World Health Organization (WHO) estimates that by 2020, over 15 million people worldwide will have cancer, and about 10 million people will die of this disease every year” (Effendy et al., 2014, p. 2). More and more people are living longer with advanced cancer due to advances in life-extending treatments. Cancer incidences rise with age. As the population grows, so does the likelihood that people with advanced cancer will present to hospital emergency departments (Jelinek et al., 2013, p. 159). “The prevalence of unmet psychosocial needs among cancer patients in ambulatory care is generally high.” (Ng, et al., 2012, p. 1049).

Jelinek, Marck, Weiland, Philip, Boughey, Weil, and Lane (2013) conducted semi-structured interviews with Australian clinicians working in emergency medicine, palliative care, and oncology clinics in order to identify the issues they considered to be most important for

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managing people with advanced cancer who present at hospital emergency departments. Jelinek, et al's (2013) qualitative study revealed several limitations of emergency room settings that participating clinicians believed were barriers to providing optimal care for patients with advanced cancer. Obstacles identified included the physical environment of emergency departments such as busyness, noise, lack of privacy and information and wait times. Lack of available resources was another impediment, which included issues such as time pressure, competition with other patients presenting with medical emergencies for the limited space available, overcrowding, and insufficient space for families to visit. A third barrier that clinicians identified related to managing patients with advanced cancer who present in hospital emergency rooms had to do with unclear roles and expectations of the staff providing care for this population. This category included issues such as seniority and comfort with dying, a range of expertise and comfort in providing care for patients with end-stage cancer, and contradicting views about dying in the emergency department as either life-saving or for providing palliative and end-of-life care (Jelinek et al., 2013, p. 156).

Although the emergency room is not an ideal environment for people with advanced stage cancer, the reality is that hospital emergency departments play an important role in caring for patients living with advanced cancer. This population is frequently directed to hospital emergency departments because other options such as being seen by their outpatient physicians on short notice or direct inpatient admission were not possible. Moreover, "given the complex nature of advanced cancer, sudden and unexpected changes in the condition of a patient might occur, and the ED might well be the ideal place for rapid assessment and management of such events" (Jelinek et al., 2013, p. 159). Moreover, insufficient "palliative care at home as the disease progresses increases the need for emergency hospital admission. Similarly, there is a risk

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of acute readmission if patients are discharged too early and are not sufficiently prepared to cope at home.” (Soelver et al., 2014, p. 168). A noteworthy advantage of receiving treatment in hospital emergency departments for this population is that they are “often...the only place that can provide immediate access to diagnostic tests and medical interventions” (Jelinek et al., 2013, p. 155).

Similar tensions, including time pressures, lack of communication with other services, lack of expertise, and tensions around extending the lives of people with advanced illness have also been found among clinicians in the United States who work with this population. Smith, Fisher, Schonberg, Pallin, Block, Forrow, Phillips, and McCarthy (2009) conducted a qualitative study to explore the perceptions, experiences, and beliefs held by emergency department clinicians regarding palliative care in the emergency department. A total of 26 emergency department providers (including 14 physicians, six nurses, two social workers, and four technicians) working at two academic hospitals in Boston participated in three focus groups.

The focus groups revealed conflicting attitudes about the feasibility and desirability of providing palliative care in the emergency department. Other issues identified in the focus groups included: frequent conflict around withholding life-prolonging treatment (e.g., between patients’ families and written advance directives), inadequate training in pain management, communication and documentation around end-of-life treatment decisions is poor and lack of communication between outpatient and emergency department providers leads to undesirable outcomes (e.g., resuscitation of patients with a do-not-resuscitate order). Also significant, the focus groups revealed that patients who have been established as needing a palliative approach often visit the emergency department because their family members are distressed by end-of-life symptoms.

Overall, the emergency department providers expressed significant discomfort, conflict, and gaps in knowledge with issues concerning palliative care in the emergency department and were almost unanimous in their belief that improved communication and documentation from outpatient providers should be a major focus of future (Smith et al., 2009, p. 92). These findings are limited because of the study's small sample size and may not be representative of the views of emergency department clinicians at other hospitals in Boston or other parts of the United States. Still, they indicate that improved communication between continuing care physicians and providers in hospital emergency departments is needed, and that emergency physicians' understanding and management of patients requiring palliative care must also be developed.

Proper training, and clear roles and expectations of all care providers for people living with advanced cancer, and improved communication between them, are necessary for improving the quality of care for this population. The valuable role of emergency department providers in caring for patients with advanced cancer should be understood. However frequent emergency visits among this population may also indicate something is missing from standard care, and steps should also be taken to develop and expand community and outpatient services for this population.

Support for family caregivers

A cancer diagnosis as well as the treatment of cancer and its symptoms is associated with profound physiological, psychological and economic issues. With patients living longer, "cancer has developed into a continuous care problem...[and] family caregivers of cancer patients experience increased responsibilities and a variety of problems that arise from the various demands of their caregiving role" (Cui, Song, Zhou, Meng, & Zhao, 2014, p. 562).

"The caregiving experience places immense emotional, social, physical and financial

burden on family caregivers, which could impact their well-beings and quality of life” (Cui et al., 2014, p. 562). Cui et al. (2014) surveyed 649 family caregivers of advanced cancer patients at 15 hospitals in Shanghai, China to identify their unmet needs, which were categorized into seven spheres: maintaining health, support from healthcare professionals, knowledge about the disease and treatment, support on funeral, information on hospice care, psychological support for patients, and symptoms control for patient (Cui et al., 2014, p. 562). Factors associated with family caregivers’ needs included the burden of paying for treatments, former caregiving experience, and length of caregiving time (Cui et al., 2014, p. 562).

Participants identified several complex care activities for which they did not always have the skills and knowledge to carry out, including making decisions about the type of cancer care to provide as well as where and how to provide it, deciding whether or not to seek professional care, problem solving, and negotiating the healthcare system and accessing its resources (Cui et al., 2014, pp. 562-563).

Although a limitation of this study is its sole focus on Chinese family caregivers, whose cultural values may be quite different and thus not generalizable to those of caregivers in the United States, the findings do provide useful insight into the responsibilities and needs of family caregivers of advanced cancer patients.

Family caregivers of people living with advanced cancer also experience unmet needs, which may influence their capacity to provide quality care for their chronically ill loved ones. Cancer services need to develop and tailor resources, services, and interventions to meet the needs of family caregivers so that they do not become healthcare issues as well (Cui et al., 2014, p. 563). Meeting the needs of family caregivers would enable them to provide better care for their loved with advanced cancer. Clinical social workers can address family caregivers’ unmet

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needs by providing emotional support and financial guidance, and making appropriate healthcare service referrals, as well as by assisting family members with their caregiving activities.

Role of Social Workers

Reese (2011) conducted a study on the qualifications and level of involvement of social workers in 24 interventions identified by hospice social workers that fit within their role, including discussing the meaning of life, upholding client preferences regarding their environment and advocacy, civil and legal assistance, and ensuring culturally competent end of life decisions. Self-administered surveys and telephone interviews of 43 hospice directors in 34 states and Washington, D.C. asked respondents to select which discipline—nurse, social worker, spiritual caregiver, or other—spent the most time providing each intervention. The results showed that, of the 24 areas, social workers were considered most qualified to address the following 12 interventions: financial counseling, referrals, assessment of emotional and social problems, counseling about suicide, facilitating social support, counseling about denial, promoting cultural competence, community outreach, counseling about anticipatory grief, crisis intervention, bereavement counseling, and counseling about death anxiety (Reese, 2011, p. 391).

Although a limitation of this study is its small sample size, the responses show that social workers play an important role in improving quality of life for hospice clients. The findings of Reese's study marks measured progress in hospice social work since 1994, when the field initiated efforts to advance its practice through improving education, more clearly defining standards for social work in end of life care, documenting hospice social work outcomes, increasing hospice research, and providing social workers with continuing education. These initiatives greatly contributed to the advancement of social work expertise in end of life care (Reese, 2011).

Cancer care delivery has not risen to match the complexity of cancer treatment. With a growing number of options for treatment, the need for knowledgeable and trained cancer care workers is also increasing (as is the need for bridging communication gaps between clinics, medical professionals, and patients receiving ambulatory cancer care). Lee, Fitzgerald, Downey, and Moore (2012) conducted a study that aimed to identify an optimal model for ambulatory cancer care by way of a literature review of existing models and semi-structured interviews with ten top administrators of comprehensive cancer centers regarding care delivery strategies. The study defined *model of care* as “a multidimensional concept that defines how health care services are delivered, determines what roles are needed, who has decision authority and what kind, and establishes role relationships with the patient or family within the team” (Lee, et al., 2012, p. 108). All cancer care models reinforced the importance of inter-professional collaboration, patient-centered care, and continuity of care and suggested that these elements improve quality of care, clinical outcomes and efficiency, and patient satisfaction for ambulatory cancer patients (Lee, et al., 2012, p. 113).

The fields of palliative care and social work are advancing. A study by Clausen, Kendall, Murray, Worth, Boyd, and Benton (2005) explored the role of social workers in palliative care for people living with advanced cancer. The researchers conducted semi-structured interviews with cancer patients, their caretakers, and their key medical professionals over the course of one year. This qualitative, longitudinal method, which enabled investigators to track evolving needs over time as the patients’ illnesses progressed, shed light on several unmet needs which could potentially be addressed through social work assessments and interventions. Areas of concern included loss of independence and roles and responsibilities within the family, difficulties with practical tasks like obtaining benefits or understanding and completing paperwork, and lack of

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resources to address spiritual and emotional issues (Clausen et al., 2005, p. 282-283). Interviews with general practitioners who treat these patients revealed that many of them did not have the time or training to talk about ‘non-medical’ aspects of care (Clausen et al., 2005, p. 283).

Social workers, however, can address such ‘non-medical’ elements of care, as well as advocate for patients with advanced cancer regarding bureaucratic issues, provide professional advice, and support patients around issues of loss and dependency that were identified in the study’s interviews. These aspects of care, as well as working with families, advocacy, counseling, discharge planning, and benefits advice, all fall within the social work domain (Clausen et al., 2005).

However, social workers who specialize in palliative care are frequently based in hospitals or hospice settings, and thus less accessible to people living with advanced cancer who receive outpatient treatment (Clausen et al., 2005, p. 284). When social work is not an integral part of palliative care within the community, people living with advanced cancer and their families may be deprived of critical advocacy and therapeutic elements that are so important. Community-based social workers, rather than hospital or hospice-based social workers, may be limited by funding or other structural barriers that prevent them from devoting adequate time to address the needs of people with advanced cancer (Clausen et al., 2005, p. 284).

Clausen et al. (2005) reported that many participants avoid confining the interviews of their experiences to their illnesses alone, but also spoke about their talents, hobbies, and relationships. This tendency to establish themselves as “whole people” is compatible with social work’s holistic, person-centered approach in which narrative approaches are often used to assess clients’ needs (Clausen et al., 2005, p. 284). Social work’s person-in-environment philosophy, which takes into account an individual’s past, present, and future, supports the premise that

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social workers are equipped to support the advanced cancer population in a thorough and well-rounded manner that takes its values and experiences into account.

Cancer is a major chronic illness in the United States, where half of all men and one-third of women will receive a diagnosis of aggressive cancer during their lifetimes (Chen & Chang, 2012, p. 10). A 2001 Harris Interactive Survey found that two-thirds of Americans who do not have a chronic condition expect to develop one in the future, and have significant concerns regarding how to navigate financial and social burdens that accompany illness (Miller, et al., 2007).

A 1996 survey carried out by the National Council on the Aging that assessed the financial knowledge and confidence regarding health and finances of 1,000 American adults revealed that financial literacy was lowest in relation to paying for health and long-term care (Miller, et al., 2007). A follow-up study that interviewed participants by phone found that medical conditions oftentimes are catalysts for “financially devastating series of events” that include unexpected high deductibles, copayments, and medical services that are not covered by health insurance (Miller, et al., 2007, p. 107). Moreover, financial concerns can endure long after treatment; in 2005, interviews with close to 1,500 cancer survivors found that 13% of interviewees quit working within four years of their diagnoses for cancer-related reasons (Miller, et al., 2007, p. 107).

It has been documented that cancer diagnoses often lead to financial burdens and social changes. However, there is little published research that examines how to address these concerns as unmet needs (Miller, et al., 2007). Miller, et al. (2007) investigated the impact of participation in a structured multidisciplinary intervention that included a social service component on improving quality of life for patients with advanced cancer. In this study *quality of life* was

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defined as “a multidimensional construct that incorporates...physical, mental, psychological, social and spiritual domains” of function (Miller, et al., 2007, p. 107). One hundred and fifteen participants aged 18 and above with advanced cancer diagnoses were randomly assigned to receive standard care or an eight-session multidisciplinary intervention that incorporated social support and education. Sessions were 90 minutes in length, led by a psychologist or psychiatrist along with a nurse, physical therapist, chaplain, and/or social worker, and designed to address those domains that impact quality of life. The findings of this study showed that including a social work component within a structured multidisciplinary intervention led to clinically meaningful improvements in overall quality of life for patients with advanced cancer that are actively undergoing medical treatment. These results support the premise that professional guidance and education provided by medical social workers can prevent unwanted distress, confusion, and possibly poor decision-making, and thus has the potential to decrease feelings of perceived helplessness, and promote a sense of personal control and improve quality of life in financial, social, emotional, and legal domains for people living with advanced cancer (Miller, et al., 2007, p. 115).

A significant challenge that Miller, et al's (2007) study revealed but did not directly address is the identification of community resources, for which eligibility criteria vary by state and numerous additional variables such as age, diagnosis, and employment. Navigating available resources and advocating for financial and community resources on patients' behalf is another area in which social workers can make important contributions in the lives of this population. Now social work must carry on its commitment to improvement by learning how to support people with metastatic cancer, and that process begins with an understanding of how they cope.

Gerbino (2014) argues that clinical social workers have the skill set, knowledge, and values needed to make significant contributions to palliative care, by supporting patients with life limiting illness and their families in obtaining the best care possible. Gerbino also asserts that the social work profession's ethical commitment to educating and connecting people with appropriate resources, and social worker's abilities to navigate challenging conversations make the profession a unique and ideal match for people with chronic cancer receiving palliative care (Gerbino, 2014). Coping with chronic cancer involves a number of challenges, including the ongoing need to make complex decisions about treatment options, dealing with changes in body image and sexual functioning, adjusting to changing interpersonal relationships, reassessing future plans, and coping with changes in identity and the reality of incurable illness (Gerbino, 2014). Helping to make medical information and terminology more understandable, providing individual and group counseling, and connecting patients and families to appropriate resources fall within the realm of social work and can help to "relieve patient suffering and improve quality of life," as palliative care treatment for people living with advanced cancer aims to achieve (Gerbino, 2014, p. 74).

Coping

Coping is an important factor in determining the how physical, psychological, and social, cancer-related challenges impact psychosocial outcomes. Zucca, Boyes, Lecathelinais, and Girgis (2010) examined the prevalence and predictors of cancer-specific coping strategies using a sample of 863 long-term cancer survivors. They found that those who have been living with the diagnosis for five to six years utilize less cancer-specific strategies for coping than those with more recent diagnoses. Study participants completed a survey that assessed psychological well-being and lifestyle, individual, illness, and treatment characteristics. The results of this study

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showed that long-term cancer survivors were more prone to maladaptive coping techniques such as anxious preoccupation, helpless-hopelessness, and cognitive avoidance coping, and that the most common predictors of maladaptive coping were employment status and social support.

Increasing access to social support may promote more positive coping responses for long-term cancer survivors. Cancer survivors aged 18-39 were underrepresented and breast cancer survivors were overrepresented in this study. Despite limitations in its sample, the study's measurement of coping with the use of an instrument developed specifically for cancer populations was a significant strength, as it allowed for the focus on coping strategies as they relate to psychosocial outcomes in the context of cancer.

Since coping is a “modifiable risk factor of poor psychological outcomes,” it is important that social workers understand the coping strategies used by people living with advanced-stage cancer so that effective interventions can be developed that will maximize their quality of life (Zucca et al., 2010, p. 1269). Moss-Morris (2013) argues that the ability to cope and the methods used for coping can be condition-specific and offers a new, overarching theoretical working model for coping with the stressors of adapting to chronic illness. The model suggests that personal, social, and environmental “background factors” influence how people respond and cope with illness stressors, and that the factors that are specific to the illness determine whether those stressors are likely to disrupt quality of life. Zucca, et al's (2010) study defined various illness stressors, including threat to mortality, progression, pain, and changes in appearance, and suggested processes for adjusting to those stressors such as remaining active, expressing negative emotions, and finding benefits in one's current situation. Moss-Morris' (2013) model is limited in that it did not include stressors such as the trajectory of illness and change in prognosis. Additionally, factors that impede the coping process were not defined.

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Most palliative care studies have focused broadly on the course of dying and controlling associated physical and psychosocial symptoms. “To be confronted with one’s own mortality is a demanding situation that triggers emotional distress and death anxiety” (Sand, Olsson, & Strang, 2009, pp. 13-14). However, the existential challenges of confronting one’s own impending death and the coping process within that context have not been sufficiently explored (Sand, Olsson, & Strang, 2009, p. 14). Future research should identify all illness stressors and coping strategies relevant to people living with advanced cancer and examine the relationships between them in order to identify specific areas of need that can be addressed by social workers who work with this population.

Lethborg, Aranda, Bloch, and Kissane (2006) conducted a qualitative study that found meaning making to be an effective coping strategy used by patients with advanced-stage cancer. The participants consisted of ten cancer patients, all with prognoses of roughly 12 months. Each subject participated in 26 conversation-style interviews. Transcripts of those conversations were examined via thematic analysis identified three areas of lived experience of meaning in advanced cancer: experiencing the reality of advanced cancer, responding to its impact, and living life fully with continued meaning. Lethborg, et al’s (2006) findings informed a model of meaning-based coping in which “patients move from confronting the threat of illness and grieving any related losses—a process in which assumptions and beliefs are challenged temporarily—to restorative processes that re-establish coherence and sense of self” (p. 41). Although only 10 patients were involved in this study, it is clear that meaning-based coping for people living with advanced-stage cancer deserves a closer look. This study enabled participants to share their stories in a less structured way.

Personal Narratives

Other storytelling contexts such as support groups and patient testimonials have been shown to have a positive health impact for storytellers (Sylvia Chou, Hunt, Folkers, & Augustson, 2011). Personal narratives about cancer experiences are increasingly exchanged on the Internet through social media websites and online blogs, and are another means of meaning-based coping. The stories of patients, caregivers, and clinicians can teach a great deal about living with life-limiting illness, suffering, and experiences of care (O'Brien & Clark, 2012). Over the last two decades, there has been considerable growth in both healthcare workers' narratives about their experiences caring for people who are facing death, as well as stories written by patients and their caregivers about their personal experiences of illness (O'Brien & Clark, 2012).

In their article about research on illness narratives in supportive and palliative care, Bingley, Thomas, Brown, Reeve, and Payne (2008) discussed common, qualitative methods for analyzing narrative data. They contended that narrative research, and specifically thematic analysis of narratives might allow for a deeper and "more nuanced understanding of end of life experiences" (p. 657).

Internet support groups, online resources, social media, and patient-initiated illness blogs have recently emerged as popular health communication tools for cancer patients (Keim-Malpass, Albrecht, Steeves, & Danhauer, 2013). Keim-Malpass et al. (2013) utilized an exploratory, inductive approach in their examination of complementary therapy use among 16 women with advanced cancer who wrote online cancer blogs. A thematic analysis of the online illness blogs identified several themes regarding the women's experiences of diagnosis and treatment, urgency to reach previously-set-aside milestones, anxiety about recurrence, and their use of complementary therapies during cancer treatment (Keim-Malpass et al., 2013). Despite its

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limited sample—study participants were all women aged 20-39 from the United States—this approach to data collection is a unique means for considering patients within their unique social context. For example, some of the young adults included in this study may have chosen to share their illnesses online as opposed to participating in clinic-based support groups because of age differences at diagnosis.

People living with chronic diseases are engaging more and more with online media to share stories, receive support, and conduct health-related networking (Sylvia Chou et al., 2011). A descriptive study using narrative analysis of personal cancer stories on YouTube provided insights into personal perspectives and common challenges among people living with cancer and noted the values of narrative processing for helping patients to synthesize their illness experiences. The information gleaned from online emotional support systems and the exchange of information and personal experiences among people living with advanced cancer can provide insight into their emotional and psychosocial needs. By better understanding their perspectives and experiences, social workers may be able to support them more effectively.

Heilferty (2009) carried out a concept analysis of online illness blogs using the Natural History of the Illness framework, which purports that significant changes in one's social and emotional life from diagnosis to death are closely linked to the chronology of the clinical course. Illness blogs as unique narratives of the experience of illness, that is, that narrative and time are closely linked. Heilferty argues that there is a relationship between patient illness narratives and quality of life, and that reading, analyzing, and incorporating online illness narratives into care will enhance patient-provider relationships.

Researcher Bias and Ethical Considerations

The study of online illness blogs marks a significant area of needed research. Ethical

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approaches for conducting research on Internet communication must be considered and have significant implications for research trustworthiness and patient-clinician relationships. Heilferty (2011) carried out a comprehensive, qualitative assessment of ethical conduct in Internet research and found human subjects, representation, and open source to be the three main research measures taken with regard to ethics in Internet research. Heilferty (2011) concluded that internet research on illness narratives should be considered ‘human subjects’ research to ensure ethical treatment of researchers and patients, and proposes the implementation of a comprehensive system to address ethical concerns.

With these ethical issues in mind, and considering the unique window that online blogs provide into the experiences of people living with advanced-stage cancer, I propose a qualitative-exploratory content theme analysis of illness narratives to identify primary needs that can be addressed by social workers in order to improve continuity of care for this population.

There has been an ongoing debate about the use of narrative research methods in illness contexts. While one camp argues that more objective approaches to data analysis offer “methodological purity,” others acknowledge the need for exhaustive reflexivity but contend that no approach for analyzing narrative data should be thought to effectively eliminate researcher bias (Thomas, 2010, p. 651).

In a comprehensive paper that argued against claims that it is possible to objectively observe narrative data, Bochner (2001) wrote: “The point of much of the work on personal and illness narratives is to move beyond the confines of traditional modes of analysis, methodology, and genres of writing” (pp. 139-140). In the same paper, Bochner (2001) posed that interpretations of narrative material inevitably make use of the researcher’s personal and cultural frames of reference. Offering his personal experience as an example, he wrote:

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Illness narratives have a major role to play in the ill person's quest for authenticity, a journey he or she may never reach but cannot resist. When I read or hear an illness narrative, I take note of the first-person voice, the struggle with adversity, the heartbreaking feelings of stigma and marginalization, the resistance to the authority of canonical discourses, the therapeutic desire to face up to the challenges and to emerge with greater self-knowledge, the opposition to the repression of the body, the difficulty of finding the words to make bodily dysfunction meaningful, the desire for self-expression, and the urge to speak to and assist a community of fellow-sufferers. If we trivialize these stories...we not only invalidate the existential struggles for meaning they represent, but we also risk missing what they have to teach us. (p. 147).

Arthur Frank, another proponent of storytelling as a therapeutic resource, believes that ethics precede matters of methodology when engaging with illness narratives yet dismisses claims that this work can be neutral, wrote, "...ill people's ways of dealing with illness reflect both liberation from medicine and a sense of abandonment by medicine... Only the nuanced interpretations of qualitative methods may be able to disentangle the strains of dependence on medicine and resistance to medicine that pervade...illness experiences (Frank, 2000, p. 363).

People living with advanced-stage cancer have much to teach us about living with life-limiting illness, suffering, and the experiences of care. Addressing this gap in knowledge using thematic analysis may provide new knowledge that is critical to social work practice and interventions.

Rationale for the Current Study

The population of Americans living with advanced cancer and the length of the palliative care phase for this population is growing. Cancer diagnoses influence many domains that

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negatively impact quality of life. As cancer treatment becomes more complex, so does this population's need for a unifying support that facilitates continuity of care, helps navigate bureaucratic systems, and has the proper training to provide emotional support. Yet, almost all cancer survivorship research efforts and programs are created for people who are receiving curative treatments. Survivorship initiatives for those with advanced cancer are much more rare (Park & Rosenstein, 2014).

To date, few studies have addressed the potential role of social workers with this population, and this topic can no longer be ignored. To identify unmet needs and gaps in care of people living with metastatic cancer that can be addressed by social workers, this study examined their online illness blogs. It is the subjective experiences, challenges, and needs of the population itself that will provide a more complete and accurate picture to guide future social work practice.

CHAPTER III

Methodology

As suggested in the literature review, an exploration of online illness narratives written by people living with advanced cancer may help to fill the current gap in the social work literature regarding this population's needs. In this study, blogs were used as research data about the experiences of the study population – people living with advanced cancer – in the context of social work discourse. An inductive, qualitative, descriptive-exploratory analysis of ten publically accessible online illness narratives of individuals living with advanced-staged cancer were gathered and analyzed to address the research question: How can the illness narratives of people living with advanced cancer inform clinical social work practice with this population?

The data sample for this study was selected in part due to concerns about the feasibility and ethics of in-person interviews, which may have been emotionally sensitive and logistically challenging given the vulnerability of the target population. Beyond its practicality, obtaining and analyzing data from public, online illness blogs has important advantages. People living with metastatic cancer tend to be more socially isolated and thus utilize the Internet for support.

The unobtrusive observation and analysis of public testimonies about life with advanced cancer allowed me to focus on the bloggers' subjective experiences without interfering with their lives or blogging activities in any way, and elicited unique data and insight into the experiences of people living with advanced cancer that might not otherwise be accessible via in-person interviews. While surveys or interviews might have limited the scope of data obtained, the

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anonymity of online blogging might have enabled this population to disclose a broader, more candid and more intimate window into their experiences. Additionally, the absence of lab-contrived questions might have reduced the inhibition of participant disclosure due to feelings of intimidation related to a sense that one is being evaluated.

Inductive reasoning that grounds a qualitative study provided a better understanding of this population's needs, as expressed by the population itself. "Inductive qualitative approaches are recommended when there is limited knowledge about a particular phenomenon and allow for the incorporation of the study population's own perspectives, perceptions, and language" (Coburn, 2014, p. 16).

Social work must be informed by the experiences of the individuals and communities whom it serves. Thus social work interventions for people living with advanced cancer should be guided by and respond to an awareness of the range and qualities of this population's experiences and the ways in which it affects their lives.

Sample

The sample for this study was publicly accessible in the form of online illness blogs written by individuals living with advanced-stage cancer. Random selection procedures were not feasible due to the study's sensitive subject matter and hard-to-reach target population. It was not the intention of this study to manipulate its samples by means of surveys or interventions, or make generalizable conclusions about people living with advanced-stage cancer. Non-probability sampling was appropriate for obtaining the data sample because the study's aim was to explore the online illness narratives of a small portion of the sampling frame in order to get a sense of each individual blogger's cancer-related challenges, experiences, thoughts, and feelings, and to identify their needs.

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Inclusion criteria for the study sample were currently active and inactive, publicly accessible online illness blogs written by individuals with advanced cancer diagnoses (regardless of type of advanced cancer or whether the bloggers were alive or deceased at the time of this study). Blogs were written in English, active for a minimum of three months, included dated entries, and addressed the individual bloggers' personal illness experiences.

Illness blogs that were not publicly accessible or that required registration and/or fees for access, and blogs of people living with advanced cancer who had a possibility of remission, were receiving hospice care, or had been informed that they would die within six months, were not included in this study. Given the limited scope of this study, inclusion/exclusion criteria did not factor in the bloggers' demographic information.

Although I anticipated a convenience sampling technique that would include all identified illness blogs that met the inclusion criteria, the sampling process ultimately made use of the snowball approach. Many of the blogs I found led to other blogs that fit within the sampling frame, as bloggers often listed or included links to other blogs about living with end-stage cancer that "followed."

I first looked for relevant online illness blogs by entering a set of search term combinations into the Google search bar. As these initial searches yielded many blogs, I next used purposive sampling (Singleton & Straits, 2005) to narrow the search results to only blogs that were written by individuals with stage IV cancer and were freely accessible without a username or password. Still, including all of the blogs in this reduced sample was not realistic given the scope of this particular study. Despite the principle of theoretical saturation which states that data should be collected until information becomes repetitive or anecdotal in order to increase the likelihood that the data represents a certain reflection of reality (Brunelle,

Cousineau, & Brochu, 2005), the population in question is too diverse in terms of types of cancer to achieve theoretical saturation.

After consultation with my research advisor it was established that, as this study's intention was to gather more information about a population by means of inductive reasoning rather than develop a theory, reaching theoretical saturation would not be necessary (Morse, 1995). To ensure richness of the data sample as well as feasibility, we concluded that this study would include between nine and twelve individual illness blogs. As more than twelve blogs met the study's inclusion criteria, careful consideration was given to determine a minimally biased process for identifying which blogs to include. Additional criteria for choosing the final sample were: 1) ensuring the inclusion of both male and female bloggers, 2) making sure that at least three types of stage IV cancer were represented in the data and 3) verifying that all of the blogs in the final sample contained entries that were relevant to the bloggers' experiences living with advanced cancer.

Limitations

There were several limitations to gathering a diverse sampling population for this study. Given the small sample size, only a few types of advanced cancer are included in the data. As data was extracted from the Internet, the geographic locations of the bloggers were not always determinable. Although the bloggers' physical locations did not impact the sample selection process, it was not possible to ensure that the sample represented a wide range of locations. The inclusion of only blogs written in English added restrictions to the narratives analyzed for this study. Moreover, the use of Internet data limited the racial and economic diversity of the sample studied (Hoffman & Novak, 1998). In addition to the educational (literacy) and financial (access to a computer and Internet) resources necessary to blog, the ability to blog, which was necessary

for inclusion in the study, inherently leaves out those living with advanced cancer who are not well enough to write about their experiences.

Furthermore, because demographic information was almost impossible to gather, this study could not account for differences in resources that may have influenced the needs expressed by the bloggers. Lastly, as participants were not interviewed it was not possible to control for the varied content and level of detail offered by each participant. Due to the small and non-random sample, findings are not representative and cannot be generalized to all people living with advanced cancer.

Ethics and Safeguards

This method of data selection and collection did not cause harm to subjects or interfere with their well-being because it did not involve any interactions or interventions; and the data evaluated was made publically available by the subjects. To ensure the overall ethical soundness of this study, I consulted the Smith College School for Social Work Human Subjects Review committee to confirm that my investigation complied with Federal Human Subjects Review Guidelines, and thus would not require the committee's formal review. Regarding the ethical concern that the bloggers' explicit consent was not obtained for the use of their narratives in this study, I depended upon "the general research acceptance that one offers implicit consent for anyone to think, talk, and write about information that they release into the public domain, especially when it exists as published material" (Coburn, 2014, p. 19).

Ethical considerations related to this study included: 1) the target population is extremely vulnerable (poor health, marginalized, isolated, physically and emotionally suffering); 2) study subjects were not contacted or made aware that their public blogs were being observed and evaluated (participation was not voluntary—although all blogs were available within the public

domain and did not require passwords, login credentials, or registration, some bloggers might have preferred that theirs not be included in a study, or compared with the experiences of other people living with advanced cancer); 3) the integrity and quality of the research is unclear because it is impossible to know if data extracted from online illness blogs was valid.

To ensure privacy, confidentiality, and anonymity, identifying information such as names, usernames, e-mail addresses, and geographic locations associated with the blogs were not included. Study subjects were given pseudonyms and the names and locations of blogs used were not revealed. Direct quotes from the blogs were not included to ensure the protection of bloggers' identities.

Data Collection

Data collection for this study consisted of a review of the existing literature on the needs of people living with metastatic cancer, and the compilation of narrative data produced in the form of blog entries by people living with metastatic cancer. A list of needs for this population was generated from the findings in literature review. The blog data was also examined to identify the population's unmet needs according to the perspectives of members of the population itself. The lists of needs were then compared for overlap and discrepancies to see whether the published literature reflects what the population is saying it needs or lacks.

The qualitative, narrative data collected for this study came directly from publicly accessible, individual, online illness blogs written by people living with advanced-stage cancer. The data collected—blog entries—were generated independently at the bloggers' own will, in their own words, and at their convenience. No structure or prompts such as surveys, questionnaires, or interview questions were provided that could have influenced the data produced, and no manipulations were made to the data collected. Thus, although not

confirmable, the validity of the data analyzed for this study was not biased or influenced by interviewer pressure, time limitations, or the writers' discomfort due to unfamiliar people (such as an unknown interviewer) or spaces (such as a laboratory setting). As such, this study obtained and analyzed unique data that, due to the sensitive nature of the research topic, would have been difficult to obtain via surveys or interviews, and may be more authentic to bloggers' actual feelings and experiences.

Collecting current and ongoing data during a designated time frame was impossible because not all of the blogs in the data sample were active when this investigation took place (bloggers who were no longer living and posting blog entries). Since limiting data collection of naturally occurring online activities to a one-month period, or less has been commonly practiced in several prior studies (Kim & Gillham, 2013), the decision was made to collect data published over a three-month period for each blog to obtain a richer sample, and adjust for the variation in online blogging activity among the ten bloggers.

Data collection was retroactive, dating three months back from each blog's most recent posting (as of November 20, 2014, when the data was collected). For each of the ten blogs, all entries posted within three months of the blog's most recent posting (no later than November 20, 2014) were copied and pasted into Microsoft Word documents, with one Word document designated for each blog.

The frequency and length of individual blog entries, and the length of time each blog had been active, varied greatly. Of the ten blogs, entries within the most recent three months of activity ranged from as few as four to as many as 25. The shortest blog used only four pages in its respective Microsoft Word document, whereas the longest was 46 pages.

Although the data used in this study was generated naturally by bloggers, as an outsider my understanding of the bloggers' experiences was limited, as was my ability to assess the credibility of the data. Moreover, lack of prolonged engagement with the data posed limits on the trustworthiness and rigor of the study findings. Without direct communication with the bloggers I could not gather the same data for all of the participants, nor could I evaluate the bloggers' mood states in order to assess whether mood bias was at play in their blog entries.

Data Analysis

Once the data was collected, the analysis began with re-reading the existing literature (included in the literature review) on people living with advanced cancer and the roles of social workers with this population in order to generate a list of what the current literature indicates as unmet needs of this population. Next, I read through each of the ten blogs to familiarize myself with their content and obtain a general sense of what their entries addressed. From this read-through it was apparent that all of the bloggers discussed cancer and treatment-related challenges and the ways their lives were affected by their illnesses—experiences and information that may allude to the population's unmet needs.

The next step involved re-reading the three-month chunks of blog postings for each of the blogs, which were copied and pasted into ten separate word documents. As a complete (but not overt) observer, I examined the narratives for statements or indications of each blogger's needs, feelings, and challenges related to life with advanced-stage cancer. In each blog's Word document I made notes in the margins as I read about the needs, grievances, challenges, obstacles, desires, fears, and gratitude expressed by the bloggers that I thought might relate to areas of need that each individual blogger was experiencing. I reviewed my notes for the first blog document I re-read and grouped what appeared to be similar or overlapping needs to

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identify themes to describe the data. Then, I continued to take notes as I re-read each of the subsequent documents to look for new themes as well as link any emergent themes to those that were identified in the other blogs. I interpretively assessed the groups of themes apparent in each blog for interrelatedness to identify themes that I felt sufficiently described the most prominent and salient areas of need conveyed in the data sample.

Next, I compared the list of themes identified in the blogs with the original list of unmet needs that were indicated in the review of the literature to assess whether the current literature reflects this population's needs as experienced and expressed by the population itself, in the ten blogs. This comparison revealed and reinforced the issues, as expressed by the population itself through online blogs, which were acknowledged and reflected in the literature, and perhaps more importantly, those that have been overlooked but can be addressed in the future by social workers who work with this population.

As an outsider and the sole rater of the data, my subjectivity and positionality may have influenced my interpretations of the data and identification of areas of need. In order to minimize the influence of my various, intersecting identities and personal experiences on my interpretations of the data and classification and grouping of themes, I consulted with my research advisor on an ongoing basis.

CHAPTER IV

Findings

This chapter contains the findings from a thematic analysis of ten online illness blogs written by individuals living with advanced-stage cancer. For each blog, all entries posted within a three-month time span were examined.

Overall, it was noted that many bloggers wrote about the unpleasant, physical side effects of cancer treatments, such as pain, nausea, weakness, and “chemo brain.” In addition, bloggers tended to write about challenges relating to changes in physical appearance, due to cancer treatment, with relative frequency. Non-physical aspects of treatment that emerged repeatedly in the blogs included “scanxiety” (waiting for treatments and the anxiety awaiting test results), uncertainty about treatment decisions and length of life remaining, and social isolation.

The data from these blogs were organized into two categories and are presented in the following sequence: 1) the challenges of living with advanced-stage cancer and 2) useful supports and resources for people living with advanced cancer. Both categories are further broken down into themes. The challenges of living with advanced-stage cancer includes the following themes: side effects of cancer treatments, financial costs associated with advanced cancer, the all-consuming nature of living with and treating advanced cancer (including the logistics of arranging care and the cognitive and emotional toll), making difficult treatment decisions, lack of continuity in treatment progress, uncertainty about the unknown, dealing with changes, and alienation from their communities.

Useful supports and resources for people living with advanced cancer are suggested in relation to the bloggers' reported negative and positive aspects of treatment. The positive aspects of treatment are discussed in terms of what bloggers found helpful in their personal illness experiences, and the components of treatment that bloggers identified as important both for cancer patients and their medical providers.

The Challenges of Living with Advanced-Stage Cancer

Side effects of cancer treatments

Five out of ten bloggers chronicled their experiences with various side effects of their cancer treatments. The most common side effects among these bloggers, about which they wrote frequently, were pain, lack of energy, and "brain fog."

Pain. Experiences of physical pain from painful procedures such as injections and biopsies, as well as post-treatment aches, pains, and soreness, was a theme that emerged frequently in the blogs. Blogger 1 wrote "I'm still suffering with dizzy spells, headaches, near fainting experiences," and blogger 2 referred to "the after-chemo bone pain, headaches, sore scalp, baldness, [and] fatigue." As coping with pain can consume a lot of energy and contribute to exhaustion, it was no surprise that fatigue was another major issue that bloggers struggled with.

Lack of energy. The bloggers who wrote about the treatment side-effects all described physical and emotional exhaustion. Struggles with lack of energy were referenced frequently and appeared to be a prominent aspect of their day-to-day lives. Blogger 1's description of "extreme tiredness and lack of sleep" referred to a deficit in physical energy, and blogger 2's statement, "once you know you're going to lose, that energy just disappears," alluded to a depletion in emotional energy to keep on going/enduring the hardships with the knowledge that things may not get better. Anticipating an upcoming cancer treatment, blogger 4 wrote, "Yet another dose of

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chemotherapy, toxic poison that will bring me to my knees with exhaustion, nausea, and brain fog while hopefully keeping me alive a while longer.” In addition to lack of energy and nausea, this blogger mentioned a third side effect that emerged frequently throughout the bloggers’ entries: “brain fog.”

Brain fog. Brain fog, also referred to by some bloggers as “chemo brain,” refers to a sense of confusion, memory loss and a general lack of sharpness of the mind resulting from chemotherapy treatments and/or other medications. Blogger 1 wrote, “I have been experiencing some memory issues lately (forgetting what I did the day before, etc.)” Blogger 2 experienced the “fog” as a result of treating severe physical pain: “The amount of pain medication I need to take each day to dull my organ-throbbing aches puts me in a serious fog and makes me pretty nauseous.” “Brain fog” was perhaps described most fully in the following excerpt by blogger 5:

I’m still tired a lot and get confused or lose track of my thoughts very easily. I still have a hard time focusing and filtering things out if more than one thing is going on at a time. Conversations are still hard, my memory is shot, I can’t focus for anything, my brain is slow, and foggy, and awkward, there are connections that I can almost feel my brain trying to make, but it just can’t now.

Side effects like brain fog and lack of physical and emotional energy do not simply cause discomfort; they can be obstacles to coping with other challenges of living with advanced cancer such as determining one’s eligibility and applying for medical coverage, managing financial costs, making difficult decisions about the course of treatment, and the logistics of coordinating treatments.

Financial costs associated with advanced cancer

Four out of the ten bloggers expressed concerns related to the financial costs inherent in

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living with advanced cancer. These concerns include the costliness of cancer treatments and medications, lack of or challenges securing insurance coverage, and fears about the inability to continue working and earning an income.

High treatment costs. Blogger 1 recalled walking into a clinic for treatment and seeing a sign that read, “All patients receiving oncology treatment must submit a deposit of £30,000” (fortunately, this blogger’s “consultant” was able to obtain charitable funding and the blogger incurred no charges for treatments at the clinic). Blogger 5 alluded to the financial burden of for paying seizure medication (a component of this individual’s cancer treatment regimen):

I can stop my seizure meds! That’s saving \$106 a month! It sure will be nice to feel like we can save a little and watch a little bit less flying out the window...I hate how expensive the drug is (we never got prescription coverage – ugh!).

Obtaining coverage for medical expenses was another financial challenge that emerged in the blogs.

Insurance coverage. Several bloggers experienced difficulties identifying available insurance benefits and meeting the qualification criteria to receive them. Blogger 4 wrote, “Peer to peer sharing of the [Medicare] basics can be more powerful than confusing expertise.” Perhaps for that reason, the same blogger offered information on the topic in subsequent entries: “Accessing Medicare when you are under 65 can be confusing. First, few of us are aware of our eligibility and able to afford the waiting period. Second, the system is geared for elders.” Later, in an entry about the complexities of selecting prescription drug plans and the nuances of insurance eligibility, which often depends upon one’s state of residence, blogger 4 wrote, “Finding a Medicare insurance broker in your state...is ideal.”

Medical insurance can be difficult to obtain and oftentimes does not cover all treatments or

medications. Although maintaining gainful employment is a potential means to cover high costs, busy treatment schedules and side effects make it increasingly difficult to continue working.

Inability to work. In addition to maintaining a semblance of normalcy and predictability in one's day-to-day life, remaining employed while living with advanced cancer offers the advantage of offsetting the financial costs incurred from cancer treatments. However, many obstacles stand in the way of one's ability to continue working while living with advanced cancer, and losing one's source of income would add to the financial stressors that the bloggers expressed. The following excerpt from one of blogger 8's entries illustrates the fear of losing one's job and income (perhaps as a result of cancer-related discrimination): "Do you tell your friends at work? What if HR finds out? What if they need to downsize and figure they need to get rid of your potential high cost? Or if they decided you need more personal time so you're the best choice? What if you're the family breadwinner and you need that job?"

Sorting out how to pay for medical treatments is just one of many issues those living with advanced cancer must deal with. In fact, there is so much to do—and think about—that many bloggers described feeling completely consumed and overwhelmed.

All-consuming nature of living with and treating advanced cancer

Six of the ten bloggers wrote that they felt their lives had been taken over by the many demands of living with advanced cancer. The all-consuming nature of living with and treating advanced cancer was chronicled by bloggers in terms of exhaustion of emotional and logistical energy.

Emotional energy. Four bloggers wrote of the toll of emotionally taxing thought processes. Blogger 2 wrote: "I'd spent so much time focused on treatment and doing everything right that I never even had a chance to start healing and having a life again...my life was comprised entirely

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of cancer or cancer treatment.” Blogger 10 wrote: “I’ve been obsessing about the unknown lately...I’m afraid of a variety of things, some rational, some irrational. The funny thing is, some of the irrational things I’m afraid of are eating up the most of my brain power!” The same blogger later added, “In some ways, waiting for this surgery has been like training for a marathon. I will have had a full month (Too long! Too long!) to ‘train’ for this procedure.” Blogger 7 also described constant preoccupation, noting that others with advanced cancer apparently suffer from the same “affliction”:

Before you tell me “not to think like that,” just know that it’s impossible. From what I can tell from the other cancer blogs I follow, I am not alone in this feeling of not being able to shut my brain off. Something about this just kicks your mind into overdrive. Perhaps we are just trying to make sense of this, or maybe we just want to make sure we don’t leave with things unsaid. Either way, it seems to be a common affliction.

The same blogger underscored the all-consuming nature of life with advanced cancer in a subsequent entry: “I have let this cancer seep into every single part of my being, it controls my thoughts, my appearance, and my day to day life. Just about everything in my life now is either determined by or the result of my cancer.”

Logistical energy for practical matters. Coordinating adequate care and undergoing treatment requires a lot of time and energy and encompasses endless logistical tasks like arranging transportation, applying for medical benefits, investigating treatments and making treatment decisions, managing payments, and obtaining and administering medications, to name a few. Although necessary, these tasks can impinge upon the time and energy needed to carry out some of the most basic activities of daily living, like preparing food for oneself or cleaning one’s home. Blogger 1 wrote: “Four hospital appointments in four consecutive days...was fairly

exhausting. It really does never end...the cumulative effect of the chemo cycles seems to be taking its toll on my energy levels.” Blogger 2’s recounting of a week’s activities—“I spent a good week just answering questions, signing paperwork, giving blood, [and] getting marrow stolen...”—also alluded to the endless nature of living with advanced cancer. Blogger 4 wrote about the time and effort spent navigating “the macro challenges of trying to access the care that I think is best suited for my current situation” as well as “handling logistics for my next journey to treatment.” The same blogger wrote: “treatment is hard...the frequency, toxicity, length and travel...medical appointments, surgeries, treatments, and side effects disrupt my days.”

The emotional and physical demands of living with and treating advanced cancer are exhausting, and make coping with challenges, such as making difficult treatment decisions, even harder to do.

Making difficult treatment decisions

Although cancer research continues to advance, so much remains unknown. Treatment decisions can be high stakes within the context of advanced cancer; outcomes cannot be guaranteed and risks and success rates vary by treatment. Since medical professionals are oftentimes unable to provide the definitive answers or guidance that their cancer patients seek, they frequently leave it up to their patients to choose how to proceed. Seven of the ten bloggers wrote about the difficulties of not knowing which course of treatment to take. Of those, several indicated that they lacked sufficient information to help guide their treatment decisions.

Insufficient information to inform decisions. Several bloggers wrote about doing their own investigation to gather more complete information about treatment options and outcomes because the information their doctors provided was unsatisfactory. Moreover, with treatment decisions in their own hands, they were compelled to gather as much data as possible to decrease

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the sense of uncertainty about which course to follow. Blogger 4 wrote, “We are thrust...into making life-and-death decisions, lacking any real information about what may—or may not — buy me even a few more months of life.”

In an informative entry describing a potential treatment option, blogger 2 wrote, “I managed to dig up some of the phase 1 study prelim data. Keep in mind I found that article on my own.” Blogger 5’s reports of being in a clinical trial for a new drug that was not FDA approved alluded to the unease one can experience when those who are expected to know the answers—doctors—are also in the dark:

It’s so new that they actually don’t know anything about it, seemingly. So every time I go in, my doctor asks 100 questions and types all the answers into his computer. If I ask, “Is that normal?” I’m typically met with a “We don’t really know.” [It is] a little unnerving.

Along these lines, blogger 2 wrote, “It still blows my mind that simply talking to a different doctor and your treatment options can change drastically.” Yet even when treatment appeared to be going well, however, progress is inconsistent at best. Blogger 2 also wrote, “I was not the slightest bit excited about meeting new doctors, never mind a new hospital administration. I’ve lost anything approaching continuity at this point.”

Lack of continuity in treatment progress was another unsettling—and extremely upsetting—aspect of treatment that bloggers wrote about.

Lack of continuity in treatment progress

All ten bloggers described times in which they felt relieved for having made the “right” treatment choices, and felt hopeful about the future. For all ten bloggers, these periods of progress were met with deep, heartbreaking disappointments. Such ups and downs—the restoration and re-shattering of hope for recovery—were a prominent theme among all of the

blogs that appeared to cause the bloggers a great deal of emotional suffering.

Ups and downs. The ups and downs of treatment progress are clearly demonstrated in the following two quotes. “When I ended up back in the ER it was soul crushing. Everything had been going so well and almost overnight everything came crashing to a halt and I was back to square one. Why would I have any faith?” (blogger 2)

This morning I found out that my cancer seems to be breaking through treatment. I grieve; unbelievably short cancer vacation interrupted by a truly shocking cancer surge...

Treatments that we thought were working, cease to work months earlier than expected. I no longer know my next steps. (blogger 4)

The latter quote alludes to a sense of not knowing is in store for the future. Uncertainty about the unknown was another theme that frequently appeared in the bloggers’ entries.

Uncertainty about the unknown.

It’s not pain that keeps me from sleeping, it’s anxiety unfortunately. For me, the hardest part by far is the not knowing. I’m scared for when/if this cancer comes raging back. I had been too scared to know, too scared to ask. (blogger 5)

“As always with this disease I don’t know any more than anyone else about whether or not this chemotherapy will work.” (blogger 2)

Nine of out ten bloggers conveyed feelings of uncertainty about the unknown. They chronicled ambiguity when faced with multiple treatment choices (versus obtaining a confident doctor recommendation), insecurity about treatment choices already made, doubt in the face of promising test results, and fear and anxiety in anticipation of—and while awaiting results for—scans and biopsies. Uncertainty about test results, also referred to by several bloggers as “scanxiety,” and about length of life remaining appeared most often in the blogs.

Scanxiety. The following excerpt from blog 5 defines the concept of scanxiety that was addressed in the majority of the blogs:

Scanxiety. It's the anxiety one feels when they know they have an upcoming test or scan, or even worse in my opinion, waiting for results. Waiting for test results is the most excruciating, claustrophobic, helpless feeling. You know there are dozens of possible outcomes but can't even come close to planning for any one of them.

Blogger 10 expressed fears in one blog entry about test results that would come later that same day:

Later on today, I will get the results of my sentinel lymph node biopsy. I came to this blog today to say out loud that I have never been so frightened of anything in my entire forty-five years of life...and I've been pretty afraid a few times in the past.

Blogger 9 wrote about the irritability that scanxiety causes: "I'm not lying when I tell you That you're better off just not to talk to me the day I get scans. Just wait until I receive the results. Scanxiety makes me such a little brat."

In addition to the fear of learning that treatment was unsuccessful or that the cancer has spread, fears around dying were also expressed by many of the bloggers.

Impending death/length of life remaining. A diagnosis of advanced cancer implies that the cancer cannot be cured. Although people living with advanced stage cancer may live with the disease for many years, it is likely to be the culprit of their eventual death. It is not surprising that most of the bloggers, however uncertain they were about how much longer they would live, wrote about dying. The bloggers approached the topic of impending death in a number of ways, including how they might die, fear of dying, and sadness about not having more time to be with loved ones. Blogger 4 wrote, "The ultimate challenge of life: facing my own death. After

learning I was terminally ill, it is a constant tremor radiating from my stomach.” The following quote from Blogger 7 addresses impending death and also speaks to challenge of making difficult treatment decisions, which was discussed above:

We'll be making a decision in days ahead whether to pursue other options or not. It's a brutal decision to finally wave the white flag. To say, "Enough. I'm done." To know there's no alternative to surrendering. To tell yourself, "Death is near." I have no particular sense of what I want my last days or weeks to look like. I now mostly want to be around family and friends. I pray to God that I would now die a good death.

Blogger 2 also shared preferences about “how” to die: “I was mostly just concerned with how I would die. I just wanted to be comfortable and die in my own home. I'd much rather die at home with a modicum of comfort and with the people I love.” And blogger 3 wrote about the “fear of leaving children behind” on several occasions, alluding to “anxieties about living to see my baby boys grow up” and “the panic in my gut that told me I may not see these beautiful beings grow up.”

Uncertainty about what the future holds intensifies when one learns they have a terminal illness. Unfortunately, living with advanced cancer brings about many unanticipated and unwelcome changes that reach far beyond the diagnosis itself and affect many other areas of a person life.

Dealing with changes

Seven out of ten bloggers wrote about major life changes that were the products of their illnesses. Bloggers chronicled their struggles adjusting to a wide range of difficult changes that related to lifestyle, relationships, physical appearance, and plans for the future, to name a few.

Two major changes that the bloggers appeared to grapple with most were a shift in their sense of

self and loss.

Shift in sense of self. The bloggers wrote about the ways in which their lives with advanced cancer had little semblance to their lives prior to their diagnoses/the onset of their symptoms. Blogger 3, possibly in response to sense of feeling reduced to an illness or status as a patient, wrote, “Patients are so much more than the numbers that fill their charts.” The same blogger also wrote about changes in physical appearance resulting from cancer treatments: “The 4 infusions of chemotherapy that robbed me of my hair but gave me 10 extra pounds.” Blogger 4 wrote, “I chafe at being invisible as a person with cancer.”

In addition to physical transformations and the bloggers’ perceived changes in the way others saw (or didn’t see) them, some bloggers wrote about difficulties keeping up with the responsibilities they used to manage with ease. Blogger 4 wrote, “I identify only as a cancer veteran. Maintaining a former life is a challenge.” Blogger 5 also alluded to a shift in self-perception due to decreased capacity to fulfill roles that were inherent to her pre-cancer identity:

I grieve the fact that I can’t give [my kids] all of the time and energy that I want to because of how I’m feeling...I miss the life I had. I miss the stress of getting the kids ready for daycare and I miss working. I miss driving and independence. I miss feeling productive and valuable.

Most of the bloggers wrote about their inability to carry out various tasks that were integral to their pre-cancer lives and routines. They chronicled their experiences of loss—lost independence, lost roles and responsibilities within their families, lost hair from chemotherapy. These changes led to shifts in the bloggers’ sense of self, which they struggled to come to terms with.

Loss. The bloggers described the loss of previous, carefree lifestyles, the inability to partake in the activities they love, and the loss of their visions for the future. Blogger 9 wrote, “I still miss the worry-free feeling of sunshine on my skin.” Blogger 10 also alluded to a change of perspective—“Will I ever look at the sun in the same way again?”—and dreams lost: “Today I had the unpleasant task of having to cancel our trip ... The sad reality is that we've been dreaming of taking this trip with our boys since before our oldest son was born 17 years ago.” Blogger 7 wrote of losing a cherished pastime, and desires diverted:

It's very hard for me to accept this slow loss of mobility. I haven't run in three months now and likely won't again, which in itself is a small death. The process of gradually giving up things I love is sad...I'm not happy about how melanoma has sidetracked the life I'd hoped to have while approaching my 60th birthday.

Blogger 5 wrote about the loss of “life as [she] knew it” before cancer, as well as anticipated loss from a life cut short:

If you've been through something like living with a terminal illness, you can totally understand the feeling of grieving for something you never had. I grieve all the time for my kids and my husband and the time that I feel like is getting stolen from me. I feel a sense of loss knowing that the most likely scenario is that I will not get to see my children grow up. I grieve the fact that they will not have a “normal” childhood. I grieve the fact that I can't give them all of the time and energy that I want to because of how I'm feeling. My whole life as I knew it was taken from me. I knew that cancer could take my life, but I never imagined that it could take my spirit, my personality, my “me-ness.” This is about as close to despair as I've ever been. It's a sense of loss, a sense of grief, and a very real sadness when I think of all the things that I will miss out on. Stories at night,

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little sicknesses here and there, silly dances and jokes, prayers and devotions, baptisms, sports games, report cards, driver's licenses, weddings, etc. I feel a sense of loss for all of these things.

In addition the shifts and losses identified thus far, another difficult change that bloggers wrote about was feeling increasingly alienated from their communities.

Feelings of alienation

Six out of ten bloggers wrote about the ways in which living with advanced cancer impacted their interpersonal relationships. It appears that several factors contributed to the bloggers' feelings of alienation, including physical and emotional isolation, the difficulty of explaining their sickness to loved ones, and barriers to connecting with others who are experiencing similar challenges.

Feeling alone. Contact with the outside world is certainly limited by the process of undergoing and recovering from cancer treatments certainly necessitates. Blogger 5's experience may indicate that protracted isolation from one's community may make the idea of re-entry feel quite daunting:

I find myself drawing more and more inward...My home is beginning to feel more like a cage or prison, I mean, I'm pretty much always here. But, on the same token, the world outside is getting less and less inviting and everyday seems a little bigger and a little scarier than the day before and this makes me more and more hesitant to go anywhere or do anything, no matter how anxious I am to leave.

Similar to this hesitance to bridge the gap with the world outside, all six of the bloggers who wrote about feeling alienated expressed apprehensions about explaining their illnesses to friends and family.

Explaining the illness to friends and family. Blogger 8's questions—"How do you tell your parents? Your siblings? Do you tell your friends?"—seemed to be the same questions that the other bloggers also grappled with in one way or another. Blogger 9 wrote, "I didn't want to talk about the seriousness of what I was going through. I didn't know how to tell people without downplaying it or making a joke. I was completely shutting down." The same blogger also wrote about the sadness of seeing loved ones take in bad news about his prognosis: "Receiving bad news is terrifying. Having to look over and see how your family is reacting to bad news is heartbreaking. I never want my family to experience that again." Blogger 2 wrote:

I'd had a really hard time including my friends in what was happening to me. I'm sure to them it seemed like sometimes I'd call and things would be going great then next time we talked I was about to die again. I bet I came off as pretty cold to most people. I just didn't have the energy to spend on it at that point; I didn't want to watch my family have to accept all over again in a few weeks that I was still going to die.

It seems that Blogger 4's own struggles to accept her prognosis was itself so draining that it left her no reserves for making efforts to explain it to others:

I found my situation too demanding to cope with my many friends' confusions. My rollercoaster ride...seemed to jar many friends off the course...just as my own vocabulary and capacity for explaining what I have always expressed as a terminal path, diminished...I dropped seeing folks. I didn't have the energy to support external confusion about my saga.

Awkward peer interactions. In a subsequent entry, blogger 4 described running into a friend on the street who, at a loss for words (blogger 4 suspected) exclaimed, "I heard you're doing great!" The blogger wrote that this superficial exchange negated her actual experience: "I

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hear too often ‘You look too good to have cancer’ from people who don’t understand how that innocent, off-hand comment can disappear my reality of living for five years with continuous chemotherapy treatment.” Perhaps in an effort to make sense of these “off-hand comments,” blogger 4 continued: “Disease creates isolation and barriers from the world of the well...[which] distances [it]self from...me—and from the reality of protracted death.” These barriers resulted in the blogger’s avoidance of in-person interactions with loved ones:

This summer I have had minimal social contact – these slight encounters leave me bruised and confused. Alone...I checked my email on the hour hoping for virtual connections.

There were few...I can feel the truth of being gone. The party continues. I am gone.

Despite the pain caused by mounting distance from loved ones, or perhaps precisely because of such isolation, some bloggers sought connections with others living with advanced cancer. Unfortunately, making those connections was itself a challenge for several of the bloggers. Blogger 4 wrote most directly about the difficulty connecting with others who have had similar experiences:

I sought out other women living with a pink slip from life and discovered how hard it is for us to find each other. Medical privacy laws don’t help. Advocacy groups are often Web- or hospital-based, but not everyone flourishes in those settings.

The value of such support groups for people living with and receiving outpatient treatments for advanced cancer (in relation to the difficulty talking about illness to family members and facing death) was clear once this blogger started a group of her own:

I created my own support circle of other women with terminal cancer. Our goal is to explore the rich and peculiar territory of facing our own deaths. Together we can mine the humor, strangeness, and beauty of a life turned upside down. Our group meetings provide a

cherished time to speak our truth without taking on the emotions of friends and family.

When people with terminal diagnoses communicate about their experience, it may make their walking toward death more doable...I have made a certain peace with leaving this world, a peace experienced only after pondering what I might do, where I might be, what I might become after I die.

The inability to find social support in the midst of grappling with the reality of impending death was certainly a challenge for this blogger, and may indicate an area of unmet need for many people living with and receiving outpatient treatment for advanced cancer. Fortunately, she was able to create her own support circle, which gave her the opportunity to talk about her experiences with other women who were also living with late-stage cancer, and find some peace.

Nevertheless, many others who receive outpatient treatment for late-stage cancer could also benefit from support groups but are not able to start them on their own. Thus, what was a significant support for this blogger is not available to many others facing similar challenges. The second category in this chapter discusses the bloggers' reflections on what they found disappointing and difficult, what they felt grateful for, and aspects of their cancer journeys that they indicated were helpful or important, and outlines several supports and resources that could benefit this population.

Useful Supports and Resources for People Living with Advanced Cancer

All of the challenges of living with advanced cancer presented thus far, including the aspects of treatment that bloggers were positive about (such as having their treatment costs covered or obtaining speedy scan results), speak to the various needs of people living with advanced cancer. The bloggers' negative and positive experiences of treatment are valuable data that may indicate which areas of need are being met, as well as which in areas this population

can benefit from increased support.

Negative aspects of treatment

The negative aspects of treatment addressed in the blogs may indicate areas of unmet need for people living with late-stage cancer. These include: 1) lack of information and patient autonomy to guide and inform important treatment decisions, 2) medical providers' disregard of the patient's preference in matters of treatment versus quality of care, 3) difficulty finding a support group and 4) barriers to obtaining insurance benefits.

In an entry not long after receiving her cancer diagnosis, Blogger 8 wrote the following, indicating that she had not been given sufficient information to understand its implications: "It's Lentigo Maligna. That makes me cry right now and I don't even know what it really means." Blogger 2, who was considering participation in a clinical trial, also felt that the information his physician provided was insufficient: "I managed to dig up some of the phase 1 study prelim data—keep in mind I found that article on my own." Blogger 1 expressed disappointment at his lack of autonomy regarding how to proceed with treatment in a statement that also suggested that his preference or values regarding treatment versus quality of life conflicted with that of his physician: "I am disappointed in the Royal Marsden – they effectively made that decision for me, telling me to go home for 'symptom management', based on their rigid 'flow chart' style of treatment options."

The difficulty blogger 4 had finding an in-person support group for others receiving ambulatory cancer care suggests that this is a resource that many others receiving outpatient care are missing. Her positive experience in the group may indicate that offering support in process of thinking about death and what comes after may help bring peace to cancer patients while they are still living. A separate grievance from the same blogger speaks to the exhausting struggle to

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obtain benefits and may indicate lack of advocacy and resources to help facilitate that process: “the harsh fight for disability claims I had heard from ill friends where they needed to “lawyer – up” and plan to fight for years.”

Bloggers also chronicled the more positive experiences aspects of their cancer journeys, including those related to their treatments and the support they received.

Positive aspects of treatment

In addition to the litany of challenges they faced, the bloggers also wrote about experiences they found helpful and were grateful for., Bloggers also noted components of care they felt were important—both for people living with advanced cancer and their medical providers.

Helpful. Components of care that bloggers found beneficial included obtaining guidance and support from social workers and consultants and exchanging health information with others in the advanced cancer community, the perks of inpatient treatments, and receiving government benefits. Bloggers also valued the help they received from providers, friends, and volunteers to coordinate treatments, meals, and transportation.

Social workers and consultants. Bloggers 2 and 7 both indicated ways in which social workers were helpful to them: “I met with a social-worker friend this afternoon to talk about hospice care and the choices to be made. It was a good exchange of practical information” (blogger 7). “One of the social workers did a good job of stealthily making sure my family would all be at the hospital when they told me I was going to die” (blogger 2).

Blogger 1 had a consultant who lifted some of his financial stress by arranging for donations to fund his treatment costs and helping to coordinate his treatments:

I didn’t need to leave a deposit – I have been granted charitable funding via The London Clinic, and therefore receive the treatment free of charge. Our consultant seems to have

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handled that side of things, all I did was sign a form...we owe him a big thank you. I am grateful to my new consultant for giving me the opportunity to be able to continue to fight this disease.

In addition to obtaining helpful information from professionals, blogger 4 noted that “peer to peer sharing...can be more powerful than confusing expertise” in relation to the advice she received about navigating various hurdles throughout her protracted efforts to obtain government benefits.

Inpatient treatment. The same blogger wrote about some of the benefits of having inpatient treatment, including attaining speedy scan results, speedy coordination of treatment, and having a team of doctors who knows your face and history: “By being an inpatient I met many more of the team looking after me. In my experience it’s helpful if they know your face and a bit of your history.” He expressed gratitude to his medical team “for organizing the treatment at such short notice” and added, “We were able to get my CT results very quickly, as opposed to waiting and worrying for a few days.”

Government benefits. I qualified for Social Security disability income thanks to the government’s ‘compassion clause,’ and this got me Medicare two and a half years later. Medicare was my ticket to being able to access the best doctors for my disease wherever they are located and to compete for the best clinical trials. (blogger 4)

Help coordinating care, meals, and transport. Blogger 7 also valued receiving help for organizing treatment: “I’m relieved to know they can have a nurse here within minutes the load for arranging for my medical care thus doesn’t fall totally on family.” This statement suggests that this blogger found having an on-call nurse to be helpful, and that the task of arranging medical care can be burdensome, and may fall onto family members if outside help is not

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available. This same blogger noted that food contributions were also immensely helpful, as preparing meals would have been difficult for him and his family to do on their own: “I’m getting plenty of nutritious food, thanks to the many contributions of prepared meals by so many of those whom we love. It would be hard for us to get this all done by ourselves.” Blogger 4 also wrote about the practical and emotional support she derived from the help of others, including help with transportation to get to her treatments:

I have survived with the help of strangers. The simple yet extraordinary lengths they went to provided deep solace. They asked nothing from me and have been driving me, feeding me, and loving me. Volunteer pilots flew me from Portland to California.

In addition to these elements of care, the following line written by blogger 8 soon after receiving her advanced cancer diagnosis (also referenced above in “Negative aspects of treatment”) suggests that emotional support could be helpful in the wake of such scary and confusing news: “I sit in the conference room where I’ve taken the phone call and cry some more.” Finally, blogger 3 described a package of “goodies...selected...for [their] significance in the chemo game” that she assembled for a friend who was recently diagnosed with cancer. The care package included “a journal for notes/questions/concerns, crackers for a queasy stomach, water for hydration.” Perhaps these items, which this blogger found helpful during her own chemotherapy treatments, would also be helpful to others receiving cancer treatment.

Important. Bloggers wrote that patient autonomy, having patience, accepting one’s illness, focusing on the positive, maintaining balance, and religious faith are important for dealing with the many challenges of living with advanced cancer.

Having a say in decisions made about one’s treatment is something that several bloggers indicated was important to them. Blogger 1 expressed frustration that his physician made an

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important decision regarding his treatment on his behalf, and made it clear that he values patient autonomy in the following excerpt:

I am disappointed in the Royal Marsden – they effectively made that decision for me, telling me to go home for ‘symptom management’, based on their rigid ‘flow chart’ style of treatment options. The choice between treatment and quality of life is one that I strongly believe should lie largely in the hands of the patient.

Bloggers also indicated that patience and acceptance are important for those living with advanced cancer. “Acceptance is key in this cancer game...When you are thrown something like this, that puts the brakes on your life and makes you reevaluate everything you thought you knew, it takes an adjustment period.” (blogger 5)

There are so many things I need to be patient about right now. Be patient while waiting for my...wounds to heal. Be patient waiting to rejoin the outside world...Be patient about waiting to drive. Be patient about getting the results of the second opinion on my...biopsy. Be patient about having a final stage for this melanoma. Be patient about finally getting that designation of N.E.D (no evidence of disease) so I can start marking how long it will have been since I put this cancer in my rearview mirror! (blogger 10)

Other statements by the bloggers revealed that focusing on the positive, balance, acceptance, and religious faith are important for those living with late-stage cancer. “The trick is to focus on the positive (not always easy)” (blogger 1). “Increasingly I believe that balance is a core purpose of life. Acceptance is the bridge.” (blogger 4)

When I make my cancer all about me, it’s a sad little story, that’s for sure. But when it’s about God, it becomes something beautiful and something useable. I don’t have to necessarily like it! Something tells me that Jesus didn’t necessarily like being up on that

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cross, but when there's acceptance and a vision that looks beyond how these things affect ourselves only, then there can be peace and joy in the suffering. (blogger 5)

Blogger 7 also wrote about the value of prayer for the healing process of those living with advanced cancer:

As good as much of my medical care has been, it's not the sole reason I'm still around. I have asked God to preserve my life, as I know others have as well, and for reasons that remain a mystery, he has seen fit to do so. "Many studies have shown that patients with serious diseases who are prayed for by others actually heal better and faster than those who are not prayed for by others. Praying for the healing of others is a form of alternative medicine known as "distance healing."

Bloggers 3 and 4 also wrote about what they valued in terms of their doctors' approaches to treatment. Blogger 3, who had the opportunity to address a group of medical students at a hospital, offered them the following advice (which she also included in her blog), which suggests that connection with her providers is important to her:

Patients are so much more than the numbers that fill their charts. Find a way to be compassionate, patient-centered physicians and personally connect with those you will treat. The connection does not need to be long or lasting, it just must be meaningful.

Blogger 4 wrote to the importance of doctors who respect their patients' wishes to take a less traditional treatment route: "It is a rare oncologist that can set aside traditional doctrine and agree to a more daring protocol led by the patient."

Summary

This chapter presented findings from a thematic analysis of ten online illness blogs written by individuals living with advanced-stage cancer. The findings were organized into two

categories: the challenges of living with advanced-stage cancer and experiences of treatment.

The challenges discussed in the blogs were presented in eight themes.

Among the themes presented, that which emerged in all ten blogs was emotional suffering caused by lack of continuity, which bloggers described as periods of hope followed by devastating letdowns. Uncertainty was another prominent theme, which all but one blogger wrote about. The challenges of being faced with making difficult treatment decisions, as well as uncertainty about the future, were themes that seven of the ten bloggers wrote about. Six of the blogs included in the study included themes of alienation and the all-consuming nature of living with advanced-stage cancer. Finally, the unpleasant side effects of cancer treatments and financial concerns due to the high medical costs and the inability to work were themes that emerged in five and four of the blogs, respectively.

The second category, useful supports and resources for people living with advanced cancer, chronicled the negative and positive aspects of treatment that were discussed in the blogs. The struggles and disappointments, as well as the components of care that bloggers identified as helpful and important, revealed the broad range of experiences of people living with advanced cancer. These themes of experience may indicate areas of unmet needs for many people living with advanced cancer and offer important information about the areas in which this population needs more support.

The key findings from this chapter about the needs of people living with advanced cancer will be reviewed, and compared and contrasted with the literature in the Discussion chapter that follows. Areas of need that remain unmet and can be addressed by social workers, if any, will be identified, and implications for clinical practice as well as recommendations for clinical research will be discussed.

CHAPTER V

Discussion

The objective of this qualitative study was to explore how the online illness narratives of people living with advanced cancer can inform clinical social work interventions with this population. With no prior experience with or exposure to this population, I embarked upon this investigation without a hypothesis or expectations about what I might discover. This study has revealed important information that can influence and improve continuity of care, treatment outcomes, and quality of life for people living with advanced cancer.

Literature on the unmet needs of people living with metastatic cancer, and the current and potential roles of clinical social workers in supporting this population was reviewed. The experiences of ten individuals living with advanced cancer, described in their own words, were examined by way of thematic analysis in order to identify themes of this population's experience.

Many of the challenges of living with advanced-stage cancer and the unmet needs that were identified by the bloggers were also found in the literature. Despite overwhelming overlap between the literature and findings, several inconsistencies were found in both sets of data when they were compared and contrasted.

This chapter is organized in the following order: 1) key findings, 2) implications for clinical social work practice, 3) strengths, limitations and biases, and 4) recommendations for future research. The key findings, which are organized according to the same major categories as the literature review in Chapter II, are compared and contrasted with the findings from the blog

data presented in Chapter IV. Of note, many of the challenges and useful supports that the bloggers chronicled were reinforced by the existing literature on the needs of this population.

The first category within the key findings—population—addresses the symptoms and unmet needs of people living with advanced cancer. The second category—coordination of care for people living with advanced cancer—reviews how opposing perceptions and inadequate communication between doctors and patient poses challenges to care coordination for this population, and also discusses the current state of ambulatory and palliative care for people living with metastatic cancer, as well as the existing supports for family caregivers. The third category examines the current and potential role of social workers working with this population. The fourth category describes methods of coping with end-stage cancer. And finally, the fifth category includes any important information gleaned from the blogs that was not found in the literature.

Key Findings: Compare and Contrast of Blog Data with Existing Literature

The experiences of ten individuals living with advanced-stage cancer were explored through online illness narratives. This section will compare and contrast the findings from those illness narratives with the existing literature on this population. Information from the literature that was not included in the blogs is also noted.

Population

Needs. The needs of people living with advanced cancer were discussed in the literature review in terms of the symptom burden, psychosocial stressors, and culture and context-specific needs as experienced by this population. The bloggers' accounts were largely consistent with the literature in these areas. Overlap and discrepancies between the literature and findings are discussed in further detail below.

Symptom burden. Ng et al. (2012) wrote that advanced cancer is associated with increased physical symptoms and more invasive, burdensome treatments. This finding was consistent with the bloggers' narratives, which described painful injections and biopsies. One blogger referred to chemotherapy as "toxic poison." Bloggers cited many side effects and physical symptoms. Pain, including headaches, "after-chemo bone-pain," and "organ-throbbing aches" was a physical burden reported by a majority of the bloggers. Other physical symptoms and side effects that appeared frequently in the blogs were lack of energy, fatigue, weakness, nausea, dizziness, and brain fog. These responses were also in accordance with a study of 25,000 people with advanced cancer cited by Park and Rosenstein (2014), in which pain, lack of energy, fatigue, and weakness were four of the five most commonly reported symptoms among participants. The fifth most common symptom, appetite loss, was not addressed in the blogs (Park & Rosenstein, 2014). Additionally, brain fog, which was frequently cited by bloggers, which they variably described as confusion, memory loss, and a lack of sharpness, was not mentioned in the literature. The physical symptoms and side effects experienced by the bloggers created practical and psychological challenges for them, leading to psychosocial stressors.

Psychosocial stressors. A common side effect of treating advanced cancer is changes in physical appearance. Many bloggers chronicled weight gain and loss, hair loss, and scarring, which were difficult for them to adjust to. The bloggers' reported challenges were also noted in the literature by Zucca et al. (2010), who identified changes in appearance as a stressor of adapting to chronic illness.

Most of the bloggers also wrote about their difficulty or inability keeping up with tasks of daily living, such as cleaning, coordinating medical treatments, driving to and from doctor appointments, and preparing food. Bloggers expressed deep gratitude for friends, family

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members, and volunteers who made donations of healthy, prepared foods and brought them to their appointments. Although these areas of need were affirmed by a study by Hwang et al. (2004), in which activities of daily living and nutrition were frequently reported areas of unmet need reported by participants with advanced cancer, help with food, transportation, and cleaning were not specifically noted in the literature as necessary or potential supports for this population

Worries about the high cost of medical treatments and medications were common among the bloggers and supported by several studies in the literature. Cui et al. (2014) noted that economic issues are associated with the diagnosis, treatment, and symptoms of incurable cancer, and Miller et al. (2007) found that cancer diagnoses often lead to financial burdens. Also affirming the bloggers' economic struggles are findings by Effendy et al. (2014) that financial concerns are prevalent among people living with late-stage cancer, and Ng et al. (2012) that unmet financial needs are a major area of concern for cancer patients.

Many bloggers chronicled their struggles obtaining insurance benefits, finding out about which resources were available to them, and identifying whether or not they met qualification criteria for receiving those services. Bloggers also wrote of the overwhelming quantity of paperwork and administrative duties involved in coordinating treatments, and applying for benefits and clinical trials. An investigation by Clausen et al. (2005) also found difficulties with bureaucratic issues and practical tasks, such as obtaining benefits or understanding and completing paperwork, as well as needs for advocacy and benefits advice, to be areas of concern for people living with advanced cancer.

Lack of information about their illnesses was another source of psychosocial stress for the bloggers, which made it difficult for them to make important decisions about how to proceed with treatment. Their concerns were supported by a study by Ng et al. (2012), in which patients

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with advanced cancer reported that disease information was a primary unmet psychosocial need. Ng et al. (2012) stressed the important role of healthcare providers in providing information and education to clarify confusing and oftentimes unverified information that is made available to patients. A study by Soelver et al. (2014) in which participants with advanced cancer reported that their doctors failure to address their needs for guidance and involvement acted as a barrier to the resolution of their physical and emotional needs is also consistent with blogger's struggles due to lack of information to guide treatment decisions. Additionally, interviews with patients with advanced cancer and their caregivers revealed that the need for professional advice is a primary concern for this population (Clausen et al., 2005).

The physical symptoms and side effects of living with and treating advanced cancer also made it difficult or impossible for bloggers to carry out the day-to-day activities that were part of their routines prior to becoming ill. Increased dependence on others for help, loss of independence, and loss of or changing roles and responsibilities within the family were noted in the blogs. Findings by Miller et al. (2007) that cancer diagnoses often lead to social changes, and by Ng et al. (2012) that patients with advanced cancer report increased social support needs, are consistent with the bloggers' reports. A study by Clausen et al. (2005) which found issues of dependency and loss of roles and responsibilities with the family to be areas of concern for people living with advanced cancer also affirm the bloggers' experiences.

Another prominent struggle reported by the bloggers which also supports the literature's claims that this population experiences social changes and social support needs was feelings of social isolation and alienation from their communities. Bloggers wrote of feeling alone in the world and feeling that no one understood them or what they were going through, and described awkward interactions with friends, which they attributed to their friends' uneasiness regarding

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what to say or how to act around them. Their accounts are consistent with Park and Rosenstein's (2014) assertion that this population often feels marginalized and isolated. Kleban (2014) also noted the emotional isolation, shame, and withdrawal from life's activities experienced by people with end-stage cancer. Kleban's argument that the fear of death distances people with end-stage cancer from the rest of society, and how the resulting isolation can feel like "little slice of...death before it happens," (p. 7) is supported by the following quote from one blogger:

I think that those who condemn our process [of blogging about terminal illness] are distancing themselves from...me—and from the reality of protracted death.... Disease creates isolation and barriers from the world of the well, insulate[ing] people in our culture from sitting with death...we are avoided. Alone...I can feel the truth of being gone.

The bloggers' accounts of their sadness, despair, helplessness, fear, uncertainty about the unknown, anxiety about sharing a grim prognosis with family members, scanxiety, and panic, made apparent the psychological toll of living with and treating end-stage cancer. Bloggers also wrote of grief, loss of faith, insecurities about treatment, and the "soul crushing" experience of learning that treatments were not helping to keep their cancer at bay. These findings are consistent with statistics presented by Park and Rosenstein (2014), which indicate that roughly 20% of patients with advanced cancer have symptoms of a depressive disorder, and about 14% of the population meets diagnostic criteria for an anxiety disorder (p. 280). Although scanxiety was not explicitly mentioned in the literature, it may be inferred that participants' "fear about the cancer spreading" in Lam's (2011) study experienced anticipatory anxiety before undergoing treatments or about receiving test results indicating that their diseases had progressed (referred to as scanxiety by the bloggers).

Another anxiety-producing aspect of living with advanced cancer—the inescapable inevitability of impending death—was addressed in the literature and in the blogs. Park and Rosenstein (2014) wrote, “For many individuals with incurable illness, the specter of their own mortality becomes increasingly powerful and unavoidable” (p. 279). Sand, Olsson, and Strang (2009) also noted the anxiety and emotional distress triggered by the experience of confronting one’s own mortality. Fittingly, most bloggers grappled with how they might die, and wrote about their fear of dying and sadness about not having more time to be with loved ones. One blogger referred to facing death as “the ultimate challenge of life” and wrote that living with terminal illness is “a constant tremor radiating from my stomach.” Diminished contact with the outside world makes socialization and discussing one’s illness with others seem even more difficult to do. Similarly, it is possible that the perceived or actual difficulty of such conversations in turns leads to avoidance, which then reinforces this population’s isolation.

Culture and context-specific needs. While the literature addressed differences in perceived unmet needs according to geographic location and cultural context among groups of people living with advanced cancer (Effendy et al., 2014 and Lam et al., 2011), there was no mention of this topic by the individual bloggers. The challenges relating to loss of independence which were reported by several bloggers, who were overwhelmingly from the United States, appears to be consistent with an investigation by Effendy et al. (2014) in which Dutch patients reported more autonomy-related problems than their more collectivist Indonesian counterparts. It is feasible that loss of independence was experienced as problematic by many of the bloggers because like the Netherlands, the culture within the United States emphasizes the value of independence. Nevertheless, given the small sample size (n=10), it would be difficult to determine if any of the bloggers’ expressed needs were culture-specific.

However, since all of the bloggers had advanced-stage cancer and were receiving outpatient cancer care, their experiences navigating the healthcare system and the services available to them in their communities may have been context-specific. The bloggers' experiences with and the literature regarding ambulatory cancer care for metastatic cancer will be addressed in the following section on coordination of care for this population.

Coordination of care for people with advanced cancer

Park and Rosenstein (2014) identified the potential to enroll in clinical trials as an aspect of care coordination that is unique to people with advanced cancer, noting the difficulty inherent in weighing current treatment options and outcomes with timing and meeting eligibility criteria for investigational treatments. Bloggers also chronicled challenges learning about and accessing clinical trials, including not being provided with adequate information about trials by their doctors, or not having the Medicare benefits necessary to “compete for the best clinical trials” (blogger 4). The literature on other obstacles to care coordination for people living with advanced cancer was also supported by the blogs.

Differences in perceived needs. Soelver et al. (2014) found that the perceived needs of terminal cancer patients differ from their doctors' understanding of their perceived needs. This finding is supported by one blogger's disappointment that his physician made the decision to send him home from the hospital for symptom management without considering his desire to continue treatments—his values and desires conflicted with those of his doctor, and he did not feel that his needs were heard or considered in the decision making process regarding his own treatment.

Such discrepancies between the values and perceived needs identified by cancer patients and their medical providers may be a symptom of faulty communication between people living

with metastatic cancer and their doctors.

Communication. One blogger's reminder to doctors that patients are not just the numbers in their charts and another blogger's frustration as "being invisible as a person with cancer" may indicate that they feel cast off and perceive a loss of social status within the healthcare system, as was discovered in a study of patients with advanced cancer cited by Soelver et al. (2014). The bloggers' sentiments echo those of patients with metastatic cancer from a previous study that revealed that they felt neglected by their doctors, insecure about whether they belonged, and anonymous when interacting with many providers in different wards (Soelver et al., 2014). Likewise, another blogger's claim that it is helpful when doctors "know your face and a bit of your history" also reinforces the notion that patients value feeling acknowledged by their doctors. The bloggers' accounts uphold previous findings by Lee, et al. (2012) that inter-professional collaboration, continuity of care, and patient-centered models improve satisfaction for patients receiving ambulatory cancer care.

Lack of communication between providers in outpatient settings and hospital emergency rooms in the United States was cited by Smith et al. (2009) and indirectly acknowledged by one blogger who wrote: "It still blows my mind that simply talking to a different doctor and your treatment options can change drastically." Another blogger's statement that "peer to peer sharing...can be more powerful than confusing expertise" points to a lack of clarity and confidence in medical providers' capacity to effectively provide counsel or answer questions, which may result from doctors' reported lack of time and training to discuss 'non-medical' aspects of care with their patients (Clausen et al., 2005, p. 283).

An aspect of communication between patients with end-stage cancer and their doctors that was presented in the literature but not noted in the blogs was this population's tendency to

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avoid revealing problems to medical professionals in order to curtail conflict, as well as the inclination toward self-blame for problems or the inability to find solutions (Soelver, 2014). Additionally, the bloggers did not indicate that they desired specialized palliative care services but did not request them, or that they wished their doctors had recommended them, as indicated in previous research by Schenker et al. (2014). The literature also revealed several barriers to optimal care coordination for this population in hospital emergency departments.

Ambulatory cancer care. Although the previous literature indicates that it is not uncommon for people with advanced cancer to present to hospital emergency departments (Jelinek et al., 2013), no mention of emergency room visits was made in the blogs. Jelinek et al. (2013) and Smith et al. (2009) noted differences in training, expertise, and beliefs about the roles of emergency room workers, and lack of coordination, communication, and documentation among staff providing care for this population, as obstacles to providing optimal care for patients with advanced cancer who present to hospital emergency rooms for care.

Although these barriers were not noted in the blogs, an advantage of receiving treatment in hospital emergency departments for this population that was presented in the literature—immediate access to diagnostic tests and rapid assessments (Jelinek et al., 2013)—is directly supported by one blogger’s relief at having received quick scan results during a brief inpatient stint, and indirectly supported by the scanxiety reported by most of the bloggers, which suggests their desire for quicker test results.

One blogger described her difficulty finding a support group in her community—she wrote that “advocacy groups are often Web- or hospital-based”—revealed a disadvantage of receiving ambulatory cancer care. This challenge was acknowledged in a study by Clausen et al. (2005), which noted that many social workers who work with patients with advanced cancer are

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often based in hospitals, and that many patients receiving outpatient care for end-stage cancer lack resources to address emotional issues.

Although some bloggers wrote that they preferred not to socialize with certain people, obstacles that prevent people living with advanced cancer from connecting with others in a support group setting—a form of socialization that bloggers did express desires for—may further isolate this population. Support groups for people living with advanced cancer who are receiving outpatient care could provide opportunities for affirming connections with others who are experiencing similar challenges as well as a space for this population to discuss ways to cope with isolation and methods for improving interactions with others.

Bloggers also cited the value of receiving help in areas that are pertinent to those receiving ambulatory cancer care including coordinating and arranging treatments, meals, and transport. However, the literature reviewed did not address the existence or need for these types of supports for people with advanced cancer.

Palliative care. Almost all the bloggers made no explicit mention of palliative care. However, one blogger expressed relief at having an on call nurse may support claims by Soelver et al. (2014) about the value of having resources available to this population at home as their illnesses and palliative care needs progress.

Support for family caregivers. Although the blogs were all first-person accounts of their personal illness experiences, bloggers expressed concerns about the many responsibilities taken on by their family caregivers as they became sicker, and gratitude when outside support lifted some of the load their families took on. One blogger who was the family breadwinner wondered how she would support her family once she could no longer work. Another wrote of the heartbreaking task of having to share the grim news of his prognosis with family members.

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Similar concerns were also revealed in a study by Clausen et al. (2005), in which patients with advanced cancer and their caretakers indicated increasing needs for family supports as patients' illnesses progressed.

Cui et al. (2014) noted the increased demands placed on family caregivers of patients with metastatic cancer, including profound financial burdens, and emphasized the importance of implementing supports for family members. Soelver et al. (2014) also noted the need for additional resources to meet patients' palliative care needs at home as their diseases progress. Lightening the load placed on family caregivers as well as addressing their emotional, social, physical, and financial concerns could improve their well-being and quality of life, thus enabling them to provide more effective care for their loved ones with advanced cancer.

Implicit in the bloggers' written concerns about the increased demands and emotional strain placed on their family caregivers is the bloggers' own discomfort or fears about being an imposition to their loved ones. Thus, lack of support for family caregivers may add additional psychological stress for this population. One blogger, for example, wrote about not wanting to take on the emotions of grieving family members.

Perhaps by ensuring that people who are living at home with advanced cancer have access to professional supports for things like arranging treatments and transportation, obtaining prepared food, assistance with household tasks, and financial counsel—a few of the duties that bloggers mentioned had fallen to their family members or that they were grateful to volunteers for—would relieve psychosocial stressors for this population and their family caretakers.

Role of social workers

Bloggers noted the help they received from social workers in their narratives. One blogger credited a social worker for ensuring that his family members were present at the hospital when

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doctors told him that death was forthcoming. Another obtained concrete information about hospice care from a social worker. These accounts are consistent with previous research by Reese (2011), which revealed that social workers are qualified to facilitate social support and counseling about anticipatory grief and death anxiety, as well as provide referrals for people living with advanced cancer. The same study also found that social workers are considered more capable than other professionals who work with this population at providing financial counseling. Although the blogs made no mention of financial advising by social workers, the economic concerns and efforts to obtain insurance benefits expressed by several bloggers. One blogger's report that a consultant helped to significantly lower his high treatment costs, indicate that support around managing costs associated with end-stage illness is important for this population.

Only two bloggers obtained support from social workers. One of the social workers was hospital-based and the other was a blogger's personal friend. These responses reflect previous research by Clausen et al. (2005), which stated that social workers are less accessible to people with advanced cancer who receive outpatient treatment.

Reese's (2011) investigation also found that social workers were considered most qualified to 1) intervene in crisis situations, 2) provide suicide, denial, and bereavement counseling, 3) promote cultural competence and 4) assess emotional and social problems with this population. Though the bloggers did not specifically indicate needs for support in these areas, patients with advanced cancer indicated needs for counseling and concerns regarding lack of resources to address emotional issues in a study by Clausen et al. (2005), thus demonstrating compatibility between the unmet needs of this population and the services that social workers are trained to provide.

Reese's (2011) study also found that social workers were deemed more qualified to conduct community outreach than other providers working with advanced cancer. Yet research by Clausen et al. (2005) revealed that social workers who are community-based generally have less funding and face more bureaucratic obstacles than those who are hospice or hospital-based. These barriers limit community-based social workers' capacity to allocate adequate time and resources to address the unmet needs of people living with advanced cancer. While the bloggers made no explicit mention of community outreach, they described social and emotional struggles and desires for access to services in their communities. The lack of community supports available to the bloggers is in accordance with the argument by Clausen et al. (2005) that people with metastatic cancer and their families can miss out on crucial supports when social work is not a primary element of community palliative care.

Coping

According to Park and Rosenstein (2014), the significant toll of physical and psychological symptoms can profoundly affect quality of life for people living with advanced cancer. Although the bloggers did not explicitly refer to their use of or need for coping strategies, they wrote about having to make complex treatment decisions, dealing with physical, social, and identity changes, and facing the reality of terminal illness, all of which Gerbino (2014) identified as elements of coping. Issues of mortality, illness progression, pain, and changes in physical appearance were also presented in the blogs and have been identified by Zucca et al. (2010) as illness stressors experienced by people living with advanced cancer.

Moreover, the bloggers' fears about the inability to earn an income and their challenges maintaining meaningful interpersonal relationships support findings by Zucca et al. (2010) that unemployment and lack of social support are common predictors of such maladaptive coping

techniques. Maladaptive coping strategies commonly employed by long-term cancer survivors, according to Zucca et al. (2010) include anxious preoccupation, helplessness, and cognitive avoidance. Each of these strategies was evident in blogs, which chronicled constant and all-consuming trepidation, vulnerability and defenselessness, and avoiding overwhelming situations.

Zucca et al. (2010) found that physical activity, expressing negative feelings, and finding benefits in one's situation promote adaptation to these stressors. One blogger acknowledged the importance of remaining physically active, and though the blogs made no mention of cancer's advantages, several bloggers noted the importance of accepting their prognoses and focusing on the positive elements of their lives. All of the bloggers expressed negative emotions in their entries. Perhaps maintaining illness blogs provided an emotional outlet for the bloggers that helped facilitate their adjustment to the many stressors they experienced. Furthermore, it is feasible that the bloggers' repetitive and detailed documentation of information about treatment options and outcomes that they obtained from their physicians and their own investigations was a method for synthesizing, and thus coping with, the constant influx of information they received.

In addition, participation in a support circle provided one blogger with a semblance of peace and made her impending death "more doable," which supports Zucca et al.'s (2010) finding that access to social supports may increase positive coping strategies for people living with long-term cancer. This blogger's experience exploring "the rich and peculiar territory of... facing [her] own death" and "min[ing] the humor, strangeness, and beauty of a life turned upside down" in a support group with other people living with advanced cancer is also consistent with Lethborg et al.'s (2006) finding that meaning making is an effective coping strategy for this population.

Since the length of time each blogger has been living with an advanced cancer diagnosis is

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not known, their utilization of maladaptive coping strategies cannot be attributed to Zucca et al.'s (2010) finding that people with advanced cancer use less adaptive coping strategies after five or more years of living with their diagnoses. Due to advances in treatment more and more people with late-stage cancer are living with their diagnoses for longer than five years, thus it is imperative that this population receives supports that will enable adaptive management of the many challenges it faces.

Additional Information from Blogs

While there is significant overlap between the population's needs as presented in the literature and blogs, several areas addressed in the blogs were not mentioned in the literature. Most of the bloggers struggled with uncertainty about the unknown, including the best course of treatment, how much longer they would live, and what would happen after they died. The bloggers wrote about how they felt about their fears and uncertainty and oftentimes their unmanageable loads of logistical tasks consumed their entire existence.

Additionally, a few helpful supports that some bloggers were thankful for were not cited in the previous literature but may help to inform the implementation of future interventions for this population. These were having an on-call nurse, receiving donations of prepared food, and volunteers who drove to and from their treatments.

Implications for Clinical Social Work Practice

People with advanced cancer are living longer due to advances in treatment, and the number of patients receiving outpatient treatment will increase as this population continues to grow. Despite the existing shortage of social work services accessible to people receiving outpatient treatment, the demand for community-based clinical social workers is rising, and more

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supports are necessary to address the wide-ranging needs of this vulnerable group and to ensure their proper care.

Though the experiences of ten people with advanced cancer that were reflected in this study certainly do not represent those of all people living with end-stage cancer, the bloggers' narratives contain valuable data about the needs and challenges associated with chronic disease and its treatment, and can help to inform and guide community-based social work practice with this population.

Both the blogs and the previous literature conveyed that physical, emotional, and psychosocial symptoms and burdens pose significant challenges for people with advanced cancer, and that controlling them is an essential component of providing adequate care for this population. The previous literature and the blogs illustrated that clinical social workers can provide a wide range of support for people living with advanced cancer, while many physicians do not have the capacity to provide 'non-medical' care for this population (Clausen et al., 2005, p. 283).

Many significant, non-medical issues and areas of concern for people living with advanced cancer were revealed in the blogs and the previous literature, including social isolation, grief, and issues of loss, dependency, and change. Clinical social workers can help this population develop adaptive coping strategies around these concerns, as well as death anxiety, scanxiety, uncertainty about the unknown, and discomfort with physical side effects, and promote acceptance of terminal illness, in support groups and individual counseling. Additional non-medical aspects of care indicated as unmet needs or desires by the bloggers were 1) help understanding medical and legal information and terminology, 2) assistance in completing paperwork, 3) support around making difficult treatment decisions, 4) financial counseling and

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5) help with referrals and applications for benefits and local services. Social workers can help people with advanced cancer navigate the challenges of identifying eligibility for community resources, which oftentimes vary by state of residence and additional factors such as employment status and diagnosis. Furthermore, advocacy for the implementation of new services in patients' communities and support for patients' family members and caregivers, also fall within the realm of social work and are areas of need for this population.

The literature and the blogs both demonstrated that communication between patients with advanced cancer and their doctors can be problematic. Clinical social workers can promote continuity of care by acting as liaisons between patients and their doctors to ensure that patients' questions and concerns are communicated and addressed, and goals of care clarified. Furthermore, clinical social workers possess the skills to complete risk assessments and discharge planning and evaluate social, spiritual, and emotional problems—interventions that the literature indicated are important for people living with late-stage cancer (Reese, 2011).

All of the aforementioned interventions can help reduce suffering and improve quality of life for people with advanced cancer. The ethics, values, and training of the social work profession equip its workers with the skills to navigate complex, cancer-specific challenges. Moreover, social work's person-centered approach, which considers each individual's cultural and environmental context, can enable meaningful contributions to this population. For all of these skills, abilities, and commitments, Gerbino (2014) strongly recommends that clinical social workers work with people living with end-stage cancer, arguing that they are the best match to address this population's needs.

Strengths, Limitations and Biases

Internet groups, blogs, and social media networking have become popular platforms for health communication among cancer patients, and allow for significant anonymity if desired. Thus the online illness blogs of people living with advanced cancer, which often chronicle bloggers' experiences, predicaments, obstacles, thoughts, and emotions, provide a less invasive medium for accessing rich and diverse narratives describing this population's experiences. Bingley et al. (2008) noted that thematic analysis of narratives can lead to a deeper and "more nuanced understanding of end of life experiences", further supporting the strength of this approach. Face-to-face interviewing about sensitive topics such as the concerns and unmet needs of people with metastatic cancer, in contrast, may further alienate this vulnerable population, for whom communication with medical personnel about their illness experiences has been challenging.

In order to maintain the efficacy of this study design, and mitigate my personal biases and their potential influence on my research question and data analysis, I maintained reflexivity by working closely with my advisor to monitor my methods for searching, identifying, and analyzing blogs. Together, my advisor and I frequently data checked and revisited my personal feelings around illness experiences and blogging to reflect upon potential shifts in my positionality.

Despite the advantages and safeguards listed above, this study's research design also had several limitations. The small sample size provided a narrow glimpse into the experiences of people living with advanced cancer. Moreover, the sampling frame's sole inclusion of publically accessible, English-language Internet data excluded the experiences people with advanced cancer who are not well enough to blog, cannot write or type, do not have computer access, are not

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computer literate, do not maintain public blogs, blog in languages other than English, or do not blog at all. Thus, the likelihood that the study sample would be socioeconomically and racially diverse, and the transferability of the study, was further limited (Hoffman & Novak, 1998).

As an “outsider” without experience or prior exposure to inform my understanding of life with late-stage cancer or online blogging, I risked overlooking significant data and/or overvaluing irrelevant data. My own subjectivity, background, values, and experience, may have biased my observations and led me to draw inaccurate conclusions.

The trustworthiness of this study was influenced and potentially compromised in several areas. Outsider bias (my own subjectivity), and the inability to confirm the credibility of the blogs limit the dependability of analysis methods. As the gatherer of the study sample and sole observer and analyzer of the research data, the potential presence of rater bias posed limitations to the study findings.

Another limitation of the study design is that I did not ask questions to elicit information relating to the specific themes I wished to explore. As a result, I was not able to collect similar data from each blog. Although the information gleaned from this study may be informative and influential, small sample bias (people living with end-stage cancer who have individual, publicly accessible online illness blogs comprise a small percentage of people living with late-stage cancer) is a barrier to confirmability because measuring the reliability and validity of the study findings and generalizing the results would be difficult.

Recommendations for Future Research

There remains much to learn about how best to address the unmet needs of people living with advanced cancer. With this population living longer now than ever before, future research could focus on the needs of those living with metastatic disease for over five years in order to

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learn more about how their needs evolve over time. Future studies might also look at the experiences of those who are too sick to maintain written narratives, regardless of length of time with diagnosis, in order to better understand their unique needs.

While previous research has found that use of adaptive, cancer-specific coping skills tend to decline after five years living with metastatic diagnosis (Zucca et al., 2010), perhaps another focal point for future research would be to identify the impact of various cancer-specific challenges, such as social isolation, death anxiety, and feeling consumed by illness. Comprehending their effects may be an important step that will enable the development of more effective cognitive strategies skills and services to address them.

Earlier studies found that the inclusion of a social work component in structured disciplinary interventions that include can help to positively impact overall quality of life for people living with advanced cancer (Miller et al., 2007). Examining factors that prevent and promote this population's communication with providers about their needs and concerns, and how clinical social workers can help facilitate optimal communication and continuity of care for this population is another potential area for future research.

The analysis of online blogs in the current study offered rich narrative data regarding the lives and experiences of ten people living with advanced cancer in the United States. A more comprehensive exploration of the online accounts of people worldwide living with metastatic cancer may provide a more complete picture of this population, and reveal which experiences, concerns, and needs tend to be universal or location and culture-specific. In addition, the narratives of family caregivers of people living with advanced cancer may also provide unique perspectives on how this population can be better supported, and is another recommended area of concentration for future studies.

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The population of people living with advanced cancer is growing. Two-thirds of Americans who do not currently suffer from chronic illness expected to develop one in the future (Miller, et al., 2007). Until a cure for cancer is discovered, end-stage cancer is likely to affect most people one way or another during their lifetimes. There remains much to learn about how best to care for people living with advanced cancer. The current study and prior research have exposed areas of need and concern for this population, and the suitability of clinical social workers to assist people living with advanced cancer in order to help them preserve the highest possible quality of life.

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