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Oncology Social Work in Palliative Care

ith regard to cancer, two facts are clear: cancer is the second leading cause of death in the USA,¹ and the consequences of unmet psychosocial needs for those with terminal cancer have devastating consequences for quality of life experienced.² The medical literature on this topic recognizes the importance of addressing these needs and recommends that the education and training for oncologists include skills necessary for assessing and handling psychosocial issues.³⁻⁵ This body of literature, however, does not address the importance of oncologists understanding the role of the oncology social worker, whose training and experience is focused exclusively on insuring that the psychosocial needs of individuals diagnosed with cancer are addressed. The oncology social worker is an important resource for oncologists, whose time allotted to patients is often focused out of necessity on medical issues and less on psychosocial needs. As the number of palliative care teams continues to grow, oncologists and oncology social workers will increasingly find themselves working together. If the team is to address holistically the needs of individuals with cancer, capitalizing on the social worker's expertise and skills will be crucial.

This article seeks to heighten the awareness and understanding of oncology social work, as well as the contribution this profession can make to oncologists and other members of the palliative care team. First, the reported psychosocial needs of cancer patients and their families are discussed. Next, the skills, knowledge, and theoretical approaches a social worker uses to meet those needs are detailed. Finally, the relationship between oncology social workers and the oncologists with whom they work daily is addressed. It is hoped that the information provided in this article will result in an increased recognition of what oncology social work has to offer individuals grappling with the devastating effects of cancer, and to the oncologists who work to provide these individuals with quality care.

Psychosocial Needs of Patients Diagnosed with Terminal Cancer

Much has been written about the psychosocial needs of individuals diagnosed with terminal diseases, many of whom had a cancer diagnosis. One line of research that has contributed a great deal of insight into the psychosocial needs of individuals at the end of life is the study of the factors that motivate individuals diagnosed with cancer and other terminal illnesses to consider a hastened death.

Research has been conducted both retrospectively with health care professionals and family members and prospectively with terminally ill individuals. In regard to the retrospective reporting, individuals who sought a hastened death were motivated by psychosocial factors, such as lack of enjoyment in life,⁶ loss of control,^{6,7} fear of future pain,^{6,8} loss of meaning in life,⁹ feelings of being a burden,^{6,9} and loss of dignity^{6,9} and autonomy.⁶ Prospectively, terminally ill individuals, many of whom were diagnosed with cancer, reported the same psychosocial factors as those reported retrospectively, as well as others. In regard to social support, individuals reported having few social supports,^{10,11} a lower quality of social support,^{10,12,13} conflictual social support.¹⁵ In addition to social support needs, individuals also reported anxiety,¹² depression,^{12,13} a lack of enjoyment in life, feelings of being a burden and useless,¹⁶ and a lack of control.¹⁶

Studies focused solely on cancer patients have also found psychosocial needs to be prevalent. In a large study of oncologists, 72% reported that their patients experienced psychosocial distress over issues that included logistics, coping with their illness and treatment, and addressing the concerns of their partner and children.¹⁷ In a qualitative study, researchers interviewed young adults diagnosed with cancer, who reported experiences with emotional distress and a lack of social support.¹⁸ Researchers conducted a review of studies on depression and cancer and discovered evidence that depression can make coping with cancer more difficult, and it can negatively affect immune functions.¹⁹ A major study of 4500 patients diagnosed with cancer found that 35% reported experiencing psychological distress, and this distress was greatest for respondents whose cancer had a poor prognosis.²⁰ In another study, fatigue, a key symptom of cancer, was found to be correlated with depression.²¹ Finally, in a systematic review of 94 studies conducted on the prevalence of unmet psychosocial needs, such needs were determined to be present both during and after cancer treatment.²²

Types and Times

In studies of individuals diagnosed with cancer, evidence has been found concerning the psychosocial distress associated with a particular juncture in the cancer journey or with a particular type of cancer. In a qualitative study of 96 terminally ill elders, 15 reported 4 critical events in their dying process that resulted in psychosocial suffering: two-thirds of these individuals were diagnosed with cancer.²³ These 4 events included being given a terminal diagnosis in what was perceived of as an insensitive and uncaring manner; suffering unbearable and untreated physical pain; not addressing the feelings individuals had about having to receive chemotherapy or radiation treatment; and receiving care in a stressful environment. Concerning types of cancer, researchers have found that persons with lung cancer had a significantly high risk of experiencing psychosocial problems, such as depression and anxiety, after both diagnosis and treatment.²⁴ Forty-seven percent of 236 newly diagnosed breast cancer patients were determined to have experienced high levels of distress resulting from worry, nervousness, and depression.²⁵

Knowledge of the types of psychosocial issues experienced by individuals diagnosed with cancer, as well as particular times of vulnerability and cancers that may put people at higher risk of psychological distress, is key to determining how best to intervene and address such issues. Consistently, authors of these studies point out the need for psychological screening and early intervention,^{16,20,25} particularly at the time of diagnosis.²⁴ Researchers also agree on the need for more research to refine current assessment procedures and develop interventions that address more effectively emotional distress in individuals diagnosed with cancer. Both assessment of psychosocial issues and intervention are the key areas of expertise possessed by trained oncology social workers.

Oncology Social Work

The main providers of psychosocial services in cancer centers and health care settings in the community are oncology social workers.²⁶ These professionals possess significant knowledge of cancer, the resulting psychosocial issues, and the intervention strategies for addressing such issues.

The training and skills provided to social workers through their graduate education makes them uniquely suited to work with cancer patients. First, the social work profession is distinctive in its use of a person-inenvironment approach, which takes note of the reciprocal relationship between the person and his or her environment, and how he or she is influenced by interactions with the environment. Social workers view individuals as being dynamically involved with systems in the environment that include family, friends, work, social service organizations, religions, health care, educational, government, and culture, to name a few. The person in his or her environment is a whole in which the person and the situation are both cause and effect in a complex set of relationships. The social worker does not assess the person and then his or her environment; rather, social workers advocate treatment of the person within the context of his or her environment. When seeking to address the psychosocial needs of a client, the social worker directs the intervention at improving the interactions between the person and his or her environment.

In regard to oncology social workers, this unique approach provides the social worker with assessment skills that "reflect a patient's place in a broader environment of relationships, resources, and copying history available to him as he struggles to integrate his prognosis and meet the demands of treatment."²⁷ The resulting assessment "communicates that the social worker is interested in the patient as a person who has a valued life beyond cancer treatment."²⁷ Furthermore, it assists in creating and implementing interventions aimed at concurrently strengthening the client's adaptation to being diagnosed with cancer, as well as strengthening the environment's responsiveness to that individual's needs.²⁶

The second aspect of social work training that prepares oncology social workers for their work is the practice of defining the unit of care as both the client and his or her family. This aspect evolves from the person-in-environment approach and, as has been found by researchers, recognizes that family members of cancer patients are also impacted by a cancer diagnosis, particularly when the cancer is advanced and incurable. Research has shown that providing care and support to a loved one at the end of life can be both emotionally and physically challenging; therefore, recognizing and being sensitive to family members' needs are crucial.²⁸

Finally, advocacy and resource acquisition are also skills possessed by social workers, which relate directly to the work performed by those working with individuals diagnosed with cancer. Individuals with advanced cancer may lack the strength necessary to advocate for their preferences concerning care and treatment provided. The oncology social worker can step in and serve as an advocate for the client with family members and/or medical professionals, as well as advocate for family members' needs. In addition, advocating for the client unit also requires

that the social worker be skilled at acquiring the resources requested and needed. Again, the person-in-environment approach comes into play in that the social worker's initial assessment of the client includes the environment in which he or she lives. Recognition of family, neighborhood, community, state, and federal systems provides the social worker with knowledge of available resources and how to acquire them.

Relationships with Oncologists on a Palliative Care Team

The growth of palliative care teams in hospitals has reportedly increased from 600+ teams in the year 2000 to approximately 1500 in 2011, a growth of about 138%.²⁹ Data remain limited as to the effect of palliative care teams but some studies have found that family satisfaction is increased³⁰; the benefit is greatest for home care,³¹ and experiencing regular oncological care along with the early involvement of the palliative care team can lead to increased quality of life and survival.⁴ Evidence is available, however, showing that nonmedical team members experience challenges concerning communication and collaboration with team members. In particular, the nonmedical team members have been shown to express some dissonance because of the dominance of physicians around decision-making.³² The discord experienced between medical and nonmedical team members may be due in part to a lack of education concerning the expertise and skills that each professional brings to the team. Education on the part of all disciplines should include such information, as well as more training on working effectively as a team.

In regard to the relationship between physicians and social workers, the training provided to each differs. Physicians are trained to be team leaders and to serve as the "final authority for all decisions," a trait that is underlined by the life and death decisions they make, as well as the possibility of malpractice suits.³³ By contrast, social workers are trained to "collaborate and build consensus on teams and that they are experts in communications and counseling" such that decision-making is to be shared.³³ In addition to the differences in their training, personality, level of self-confidence, and control needs can also present as challenges.

Recognition of differences and strengths may serve to contribute to a more collaborative relationship between oncologists and oncology social workers. It is hoped that articles such as this one will increase the awareness of the role that oncology social workers can play in meeting the psychosocial needs of individuals diagnosed with cancer.

Conclusions

The training and education provided to oncologists often focus on how to initiate discussions of patients' psychosocial issues, as well as how best to address them. Research continues to show, however, that although oncologists recognize the importance of doing so, a large proportion of them do not follow through in practice.⁵ Just as the oncology social worker's expertise lies with assessing and developing interventions to address the psychosocial needs of cancer patients, the expertise of the oncologist is to address the medical needs of these patients. Working together on interdisciplinary palliative care teams, oncologists and oncology social workers can each bring their expertise to the table and insure that cancer patients and their families receive the quality holistic care they so richly deserve.

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