

Psychosocial Care for End of Life Patients – Social Work Perspective

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ABSTRACT

Introduction: For cancer patients, comfort care is essential at the end of life. It is care that helps or soothes a person who is dying. The social worker tries to prevent or relieves suffering as much as possible while respecting the dying person's wishes. The social workers routinely elicit the symptoms history, painful affects, faced difficulties because of disease, and psychosocial ways of coping. They work in multidisciplinary team at individual level, system (family) level to create balance and hope with compassion. Further dying is relational event. However, social workers who provide end-of-life care do not see always themselves as clinicians. They work with dying, often stand in the most intimate spaces, and therefore use themselves inter subjectively. This work requires considerable courage and Self care.

Summary and Conclusion: This paper aims to highlight the social work at the end of life care in terms of utilization of self, the essentials required to provide the best individual psychosocial care, family care and ethics to be followed while working with the dying patients. It also focuses the professional self care to be followed and the limits of social work education at the end of life care.

1. Introduction

Cancer begins in cells, the building blocks that form tissues. Tissues make up the organs of the body. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die and new cells take their place. Sometimes, the orderly process goes wrong. New cells form when the body does not need them, and old cells do not die when should. These extra cells can form a mass tissue called a growth or tumor. These two are two kinds benign or malignant. The benign tumors are not cancer and the malignant tumors are cancer. Most cancers are named for where they start. Care of the dying patient with cancer has become a specialized discipline within the medical field. Psycho social care as defined as is care concerned with psychological and emotional well being of the patient and their family carers, including issues of self esteem, insight into an adaption to the illness and its consequences, communication, social functioning and relationships. It is form of care that encourages patients to express their feelings about the disease while at eh same time providing ways by which the psychological and emotional well-being of such patients and their care givers are improved. End of life care has been receiving a significant and growing amount of attention from a variety of sources(Field and Cassel,1997) however much of the emphasis has been on the medical aspects of caring for the terminally ill, with significant less attention on the relevant psychosocial issues. This is unfortunate because of the important role that psychological and interpersonal factors play during the dying process (Block, 2001). In fact, the World Health Organization (1990) has stated that control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount in palliative care. Thus, although physical problems are important and should often take first priority, truly comprehensive end of life care requires that psycho social matters be assessed and addressed.

2. The role of Psychological factors:

Research in clinical experience has demonstrated that psychological issues play important roles in end-of-life issues play important roles in end-of-life decision making (Wilson et.al).The decisions that patients and their loved ones make near the end of life may affect not only the timing of death but also the care that is received. Mental health professionals can play key role in reducing suffering and therefore improving the quality of life of dying people and their loved ones.

3. Psychosocial issues with Dying people

They are number of psycho social issues that must be assessed for end and if present, addressed in order to alleviate the suffering a dying peers experiences and maximize his or her quality of life. A complete discussion of psychosocial issues are out discussion in this paper but the most common identified psychosocial issues were mentioned such as anxiety disorders(Barraclough,1997,Block,2001,Strang,1997),clinicalde pression(Baileetal.,1993)delirim(Barraclough,1997,Lawloretal.,2 000),dementia(Larson&Imai, 1996), personality disorders (Baileet al., 1993), substance abuse (Block & Billings,1998), other interpersonal issues such as autonomy or control(Sullivan et al., 2001), issue of dignity (Lavery et al., 2001), existential and spiritual beliefs (Daaleman&Vander Creek,2000), fear of death and uncertainty (Stang,1997),hopelessness(Beck et al.,1985), being burden(Ott,1998), cultural values(Braun et al., 2000),financial issues(Emanuel etal.,2000), and issues related to isolation and loneliness(Pearson,2000).

4. Role of social worker as mental health professional

4.1. Social worker using self for providing Psychosocial Care

Social workers tend to be drawn to work with the dying out of their own loss experiences, the wounded healer where the

practitioners is portrayed as reworking past experiences in the present with new outcomes. Dying is not pathological event, it is just inevitable one. Those who choose to work with dying have stories about how they came to the work. Sometimes the work chooses them. Often they say that loss experience changed them and that they needed to give something back. Many felt disenfranchised in grief. Some lost children, husbands, parents, or siblings, and work with the dying offers meaning to one's own. Work with the dying revives the clinician's past losses and fears of future losses (Cincotta 2004). Being present means tolerating one's own anxiety about death (Rando 1984) in order to be able to help clients and families to tolerate their own. Psycho social work with the dying, then, requires being in a relationship with a client and family, located with their culture, religion and beliefs in which the clinician is able to tolerate a range of affects, including her own anxiety. This work is not for faint of heart. Sometimes, providing end-of-care is also narrative work. Often very sick patients or their families need to tell their stories, sometimes again and again in order to make meaning out their circumstances (Browning 2004). As is true in working with clients who are traumatized, the clinician who works with the dying may be vicariously traumatized by the cumulative losses that are part of the work. Often the clinician becomes the container for the fear or helplessness that client's can't bear (Ogden, 1996). Professionals who work with the dying may experience counter transference feelings such as aversion, shame, anger, sorrow and the wish for those feeling to go away (Arore et al 2006). These counter-transference reactions must be surfaced. Yet, if these countertransference responses can be shared, in supervision and or in peer led groups, the fears, anxieties, dread, and hate can be demystified, tolerated, and held and the clinician can return to the work, less burdened and with less compassion fatigue. The work requires staying present and tolerating suffering. The work requires staying with present and tolerating suffering. In order to stay with client's narrative, the social worker needs to find some coherent meaning in the story and allow it to become a part of a larger narrative of the social worker's professional experience.

4.2. What do social workers need to know to provide better psychosocial care?

The social workers in end of life care need to be well versed in bio-psycho-social assessment. They need to be able to assess ego functions, defenses, judgment, reality testing, mastery, depression, anxiety, trauma, and underplaying mental illness. They need to know the course of their client's illness and the effects of medication. They need to be able to examine the how the dying person and family adopt to their environments, be they hospital or hospices, home care or nursing homes, and the degree to which the environment does or does not adapt to them (Hartmann, 1939). They also often to work on mobilizing resources on behalf of a patient or family. Sometimes the work is helping patients and families mobilize on their own behalf.

4.3. Family Care:

Clinicians who work with dying are always working in systems family systems, institutional systems, cultural and spiritual systems. Sometimes, the work is facilitative: helping a team to hear a patient; enlisting the help of families in end of life care decision; helping patients, families, and staff to concur in

team meetings. In medical setting that are more hierarchical, the work is often slightly more subversive. In such settings, the social workers may engage family members as co-teachers and co-learners, thus helping them to deconstruct the authoritarian medical model so that they can be a part of shared decision making (Browning and Solomon 2006). The social worker also needs to be able to facilitate difficult conversations between physicians and patients. Not every patient is ready to know his or her prognosis. Helping staff take the family's cue and assessing patient and family readiness are essential to good psychosocial care.

There are several ways that mental health professionals can be involved in situations when people are facing the end of life and decisions are being made. This section reviews the six possible roles: advocate, counselor, educator, evaluator, team members, and researcher.

4.4. Advocate

Social workers who know the dying person or significant other can serve as powerful advocates within a health care system by helping to improve communication between health care team members and patients or significant others (Goold et al., 2000) or between patient and loved ones, and by assisting in mediating conflicts that arise among any of the people who are providing care for the dying person (Block & Billings, 1998).

4.5. Counselor

An experienced social worker can be of invaluable assistance in helping dying individuals and their loved ones as they struggle with any of the said issues in this paper as well as many unique issues that may arise for a particular person and his or her loved ones. By assisting people through the dying process, the social worker can help improve the quality of life of the terminally ill individuals and his or her intimate network (Block, 2001).

4.6. Educator

Providing information and resources to answer questions, alleviate fears, and reduce confusion should be a part of the role of each member of the interdisciplinary team. However, because of scheduling and competing demands the social worker may be the team member who is in the best position to be able to devote the time and attention to the educative aspects of patient care (Doka, 1993).

4.7. Evaluator:

The social worker as an evaluator plays an obvious role that properly trained in evaluating the narrow issue of the dying person's decision making capacity and more broadly evaluating whether the person's judgment is impaired and if so at what degree (Sullivan & Youngner, 1994) and a comprehensive assessment should be entail reviewing the psychosocial issues discussed above.

5. Multidisciplinary team member

The social worker can be a valuable member of multidisciplinary treatment teams, which are becoming the

standard of care for providing services to terminally ill individuals (Quill & Byock, 2000). Social workers can help patients, significant others, and experience about the various psychosocial issues. Further, they can bring important skills and perspectives to pain treatment (Simon & Folen, 2001). Ongoing involvement would allow informal counseling and evaluation to be continuous and would make a transition to more formal assessment process and interventions easier for all parties if they become indicated.

5.1. Social workers as researchers

The dearth of research on many aspects of end of life care has been noted. Many social workers are ideally suited to design and conduct investigations of the care of dying people and develop appropriate interventions (Quill et al., 1998).

5.2. Ethics at the End of life care

Social workers in palliative care often face complex ethical conflicts. Some patients want the most aggressive treatment despite a terminal prognosis, and the social worker must advocate for their wishes. In interdisciplinary team work, ethical dilemmas abound. There may be issues of a client's right choose a self determined death, which may conflict with a family's needs or values to prolong life. There may be ethical dilemmas in the decision to remove life supports, which a hospital may support but a family may not. Social workers may take up the central role of mediator. Hence, psychosocial care with the dying patients requires a relationship in which the social worker can accurately assess what the family does and does not want to know in terms of prognosis. Some patients' want to know the truth: others do not. Respecting individual differences is crucial. Social workers who work with the dying patients need to be vigilant about the cultural differences that help clients and families to maintain their dignity and integrity without intrusion.

5.3. Self care measures at End of Life Care

Working with the dying requires self care. It is very difficult to stay engaged with those whose existence is threatened, who suffers psychosocial, spiritual or physical pain, or who may be depressed or despondent without replenishing the self. Social worker who is called into 'make' the patient or family 'behave' less angry or less difficult. Practitioners describe isolation in this work; the tears shed alone, the suffering experienced alone. It is hard to face cumulative grief, day in and day out, and to tolerate suffering without suffering oneself (Figly1994). Rezenbrink (2004) writes of the need for social workers to engage in

relentless self care. This can come in the form of supervision and peer learning. It can be come with debriefing and collaboration with doctors and nurses and other working colleagues. Practitioners may exercise, meditates, and practice yoga as a ways of dealing with secondary trauma. Good colleagues with whom they can share their counter transference help them to use themselves more consciously and with this more flexibility. As a result, they may be empowered more and this leads back to better psychosocial care.

5.4. The limits of the Social Work Education in the End of Life Care

The social work training to deal the end of life care issues are limited. Social work covers dealing grief, bereavement and shock but training is limited on long term of care of end of life. It should be noted that end of life care does not just take place in palliative care, hospice care, nursing homes, and on medical floors. All clinical social workers encounter death, dying, and bereavement whichever set-up they work. We may die young or old, or from a dreaded disease or accident or from a chronic illness condition or by an act of violence by another or against the self. Yet how to work psychosocially with the dying has been relegated to on the job training. Many social workers in end of life care describe learning on the 'fly' or teaching themselves. Without masters or post masters training themselves identifies their native knowledge and grounds it in clinical theories that are narrative, psychodynamic, existential, system oriented and spiritual, many social workers and health care professionals do not see what they do as legitimate and valuable (Barnard 1995).

6. Conclusion

The work of end of life care then requires standing in the intimate places, alleviating pain, and tolerating sufferings, responding to psychological, spiritual, and cultural needs. It requires assessment, and appropriate interventions. It is also necessary being open to colleagues, commitment, connection and the capacity to live with the uncertainty. It takes the willingness to help to patients and families make meaning out of misfortune. It takes considerable common sense and capacity to face the unknown. Most of all, it requires self care and courage.