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Counselors Working with the Terminally Ill

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Counselors provide service in a variety of settings and to diverse individuals with many different challenges. One of the most difficult areas for counselors to work is in hospice settings with individuals who are dying. The needs of the dying are complex and little has been written to guide counselors in providing service.

Needs of the Terminally Ill

A counselor working in a hospice setting works on a multidisciplinary team (Hospice Foundation of America, 1998; Kitch, 1998; National Hospice and Palliative Care Organization, 2001; Parkes, Relf, & Couldrick, 1996;

Rando, 1984; Rhymes, 1990; Stroebe, Hansson, Stroebe, & Schut, 2001). Tasks of counselors include helping the dying individual prepare for the reality of death. This is done through education and supportive therapeutic interventions about the dying process that address the physical, emotional, social, spiritual, and practical needs (Davies, Reimer, Brown, & Martens, 1995; Doka, 1997; Parkes et al.; Rando, 1984; Rando, 2000).

Physical needs. Pain management is one of the most important concerns of hospice care (National Hospice Foundation, 2001). In addition to pain medication, the use of traditional psychological interventions such as biofeedback, hypnosis, relaxation and imagery techniques are used to provide skills that increase the client's awareness and control of pain. (Arnette, 1996; Cook & Oltjenbruns, 1998; Rando, 1984).

Sensitive education about the physical changes and common processes prior to one's death can help alleviate anxiety and diminish erroneous preconceptions about dying (Parkes et al., 1996; Rando, 1984; Rando, 2000). Dying individuals who have preconceived notions from the media may be disillusioned when their notions do not match reality. Counselors can provide information on how the body changes, what changes to expect in the future, and when to contact a physician (Cook & Oltjenbruns 1998;

Rando, 2000). Clients often experience a loss in strength, increased fatigue requiring greater sleep and rest, a decrease in appetite due to nausea, constipation and pain. The loss of functional ability as the illness progresses is important for counselors to address. The client is no longer able to do the things he/she was once able to do and may feel depression or feel they are a burden to caregivers. As the illness progresses, the body often undergoes changes that are either a normal part of the dying process or a reaction to treatment; these changes can affect body integrity, the ability of the body to function normally (Viney, 1984). In her study of 484 seriously-ill patients, Viney found that the loss or threat of loss to body integrity affected the individuals' emotional state, producing feelings of sadness, anger, helplessness, and hopelessness. Reconciling the loss of body parts or changes from treatment (e.g., hair loss) with the individual's identity is important for emotional health (Cook & Oltjenbruns).

Emotional needs. Dying individuals cope with intense emotions such as anger, fear, guilt, and grief (Doka, 1997; Rando, 1984). Dying individuals benefit from counseling as much as anyone and these emotions are both a normal part of the process of dying and can be alleviated by sensitive intervention (Doka; Rando; Shneidman, 1978). Addressing the anticipatory grief of the individual is critical for counselors (Parkes et al., 1996; Rando,

2000; Shneidman). Issues of anticipatory grief include helping clients redefine life as it currently is, facilitating communication about feelings of being a burden, supporting clients as they struggle with change, encouraging the search for meaning, and allowing the client to live day-by-day (Davies et al, 1995). Open communication within the family must be developed or supported during this stressful time (Rando; Shneidman).

Social needs. The dying individual needs social involvement as much as he or she did before the illness (Davies et al., 1995; Parkes et al., 1996). Interventions by a counselor can facilitate the ability of friends and family to enable the dying individual to maintain a social life in the face of physical limitations (Davies et. al.; Kubler-Ross, 1969; Rando, 1984; Shneidman, 1978). The process of finishing business is an important part of this social realm. Tasks such as interacting with important others to resolve old disagreements, connecting with long-term friends, and asking forgiveness are all important to the dying individuals' peace of mind (Davies et al.; Rando; Shneidman). Counselors working with dying children need to be aware of the unique social needs of children to provide developmentally appropriate care (Stevens & Dunsmore, 1996). Play therapy, art therapy, peer support and support groups are common forms of

intervention that allow children with serious illness to live as normally as possible (Cook & Oltjenbruns, 1998).

Spiritual needs. Spirituality has been defined by the Spiritual Care Work Group of the International Work Group on Death, Dying and Bereavement as "…concerned with the transcendental, inspirational, and existential way to live one's life as well as, in a fundamental and profound sense, with the person as a human being. ….spirituality may be heightened as one confronts death" (Doka & Morgan, 1993, p. 11). The Spiritual Care Work Group continues by providing a 31-item statement of general assumptions and principles that describe the spiritual needs of the dying individual and appropriate responses by caregivers. They state that these assumptions and principles must be implemented within the individual's spiritual life and society (Corless et al. 1990).

Doka (1993) outlined three main spiritual components for counselors to provide for dying individuals. First, it is important to help clients find meaning in their lives and in the illness. This search for the integration of events, experiences, and meaning in life can be precipitated by old age or severe illness. The failure to find meaning in life can create a deep spiritual pain as individuals may feel their life has become empty or meaningless.

Counselors can facilitate the integration of life events and experience to create meaning by providing time for this reflection and encouraging exploration of events that have been witnessed or things the individual has done. These reminiscences can be supported by using the creation of picture albums of life events, journals of history, or tape recordings left for the future. Secondly, Doka discusses helping clients create a personal definition of an appropriate death. Individuals desire to die in a way that is consistent with their self-identity. Individuals who have lived an independent life may feel great distress if all control over their own death is taken from them. Counselors can alleviate some of this distress by listening to what plans the dying individual has for her or his manner of death, care of the body after death, and the disposition of possessions after death. Lastly, Doka describes the need to help clients transcend death, either through religion and an afterlife, or through future generations or work left behind. Doka states that an important spiritual need is transcendental in that we seek assurance that our life has had meaning and we have contributed something of value.

To support the comfort of transcendental continuation, counselors can identify lasting contributions, from modest contributions such as participating in group activities like a Parent Teacher Association to more

noticeable contributions such as building a railroad. Opportunities for intergenerational visitation provide subtle reminders of biological legacy. Many religious and spiritual belief systems provide a theoretical framework for immortality, although even in religious or spiritual belief systems that include God, the counselor needs to be aware of emotions of anger at God, fear that past sins may have caused the illness, and guilt for not having always lived a righteous life (Parry, 1990). It also is important for counselors to recognize that positive psychological growth can occur, such as a new appreciation for others in life, an increased sense of freedom to experience life, or a new unlocking of emotions (Balk, 1999; Davies et al, 1995; Marrone, 1999; Mead & Willemsen, 1995). The use of ritual and symbolism to create meaningful experiences can help the client identify meaning, gain emotional comfort, and gain control over how her/his illness is perceived. For example, some clients create ritual endings before they die by inviting friends and family to an “end of life party” where music is played, the client’s life is discussed, gifts are given, and good byes are said.

Practical problems. Another area where counselors often are involved is helping solve practical problems. Issues such as distribution of possessions,

settling financial affairs, arranging wills and trust funds, and pre-funeral planning are all important topics for discussion, but are ones that family members often are hesitant to approach (Rando, 1984).

Supervision of others. Another potentially important area for counselors is that of supervision. Although this area is not often mentioned in the grief literature, Vacc (1989) found that the single greatest proportion of time for counselors working with oncology patients was spent in supervising volunteers and counselors in training. Even though not all patients on an oncology unit of a hospital are terminal, this study highlighted the potential importance of supervision issues for counselors. Counselors who supervise volunteers may be expected to recruit, assess compatibility of the potential volunteer to such work, train, and provide emotional support for volunteers (J. A. Bryers, personal communication, June 18, 2003). Counselors also may be involved in training other professionals in the emotional, psychosocial, and spiritual needs of the dying individual and their family (Parkes et al., 1996; Shneidman, 1978).

Summary

Counselors working with terminally ill individuals work in a multi-disciplinary team to provide psychological comfort to the dying and their

family. They may normalize emotions during a difficult time, provide spiritual support, educate about normal physical, emotional, and social changes, and assist in managing practical problems. A large part of the counselors' time may be spent in supervising and training volunteers or counselors in training. Finally, the counselor develops relationships with the survivors to provide services after the death.

One last aspect of this work is self care for the counselor. Working in hospice settings can be emotionally taxing and counselors feel grief when their clients die. It is critical for the counselor to take care of themselves to prevent distancing themselves from their own emotions or their clients and to prevent burn-out. Some counselors perform rituals to help themselves process the grief such as lighting candles, keeping a memory journal, attending the funeral, or arraigning a memorial service with other team members. It also is helpful to see a variety of clients, for example working with children on social skills or classroom behavior, to provide balance in the counselors' case load. Working with dying individuals can be challenging and very rewarding for counselors. Many counselors report feeling greater love of life, greater appreciation of friends and family, and a more spiritual life from this rich experience of working with people during

the last dance of life.

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