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# CHALLENGES AT THE END OF LIFE

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## Absztrakt

Minden ember közös abban, hogy megtapasztalja a születést, az életet, majd a halált. Az első kettőt sokféle módon élik át az emberek és a nyugati kultúrákban mindkettő gyakori beszédtémának számít. A halálról, és különösképpen a halálra való felkészülésről ellenben legtöbbször nem szívesen beszélnek az emberek. Ez több okból alakult így, az egyik ok az ilyen jellegű beszélgetésekkel együtt járó fájdalom. Kerülik a témát, mert a halállal kapcsolatos tervek és beszélgetések gyakran járnak együtt a visszafordíthatatlan veszteség érzésével.

Az előrehaladott krónikus betegségben szenvedők és családtagjaik halállal kapcsolatos beszélgetései rendkívül sok érzelemhez, szomorúsághoz, keserűséghez és félelemhez kapcsolódnak. Az ilyenkor előtörő érzelmek sokakat arra ösztönöznek, hogy újraértékeljék az életüket.

Az orvosok, az egészségügyi személyzet, a betegek és az ápolók esetenként nem szívesen foglalkoznak a halállal és igyekeznek elkerülni az ezzel, valamint a halálig hátralévő időszakkal kapcsolatos beszélgetéseket. Ez a viselkedés megfelel a kulturális elvárásoknak, amelyek az orvostudomány céljának a betegségek és a halál legyőzését tekintik. A betegség sikeres kezelésében reménykedik mindenki, de az életfunkciók csökkenése, végül pedig a halál is része az egészségügyi ellátásban dolgozók tapasztalatainak. Mindenki, aki részese a halál és a veszteség megtapasztalásának sokféle támogatásban részesül és fontos annak tudatosítása is, hogy a bánatot mindenki egyéni módon éli meg.

**Kulcsszavak:** felkészülés a halálra, szociális munka, interdiszciplináris segítő csapat, hospice, kulturális kompetencia

## End of Life Preparation

All human beings share three experiences: birth, life, and death. The first two occurrences, birth and life, are experienced in a wide variety of ways and are frequently discussed in great detail within our westernized culture. Death, however, is not often an experience most people enjoy talking about, particularly in preparation for the event. This is true for many reasons, but one of the reasons is the pain associated with these conversations. They are avoided because planning and discussing death often presents issues associated with irreversible loss.

For individuals living with later stage chronic illnesses and their families, discussing end-of-life brings up many feelings, including sadness, grief, and fear.

The variety of emotions people experience as they consider end of life may challenge some to consider or reconsider the meaning of their life.

With the increase of the successful treatments and the result of prolonged life for people living with chronic illnesses individuals and their families often use physical indicators to predict the trajectory of the disease. Signs of decline in health measures as indicated by blood tests and functionality are often used to estimate quality and length of remaining life. However, there are many examples of people who live far beyond the expectations regarding the duration of their lives. Sometimes health indicators plummet one week and the next there are signs of remission. Our society seems challenged to find a balance between hope of continuing to live and accepting the fact that life may be nearing the end (Back, et al., 2003; Clark, 2002).

### *End of life discussions and decisions*

As people age, thoughts about end of life begin to occur more frequently. If someone is in relatively good health, their thoughts are perhaps not really about the end-of life, but perhaps instead about retirement and what they desire when they are no longer earning a paycheck. After retirement, most begin to see a more significant amount of health loss, both personally and with friends. Health conversations by the young are often very different than the conversations people 55 and older are having, and the time spent talking about health problems differs quite significantly. As people near retirement age they are more likely to be diagnosed with chronic illness or see the progression of chronic illness in others. Diseases like cancer and heart disease take lives more frequently as we age and end-of-life is no longer an exceptional event.

Although we know death can occur at any age and for a variety of reasons, the most common time death occurs is late middle age to late age. There is much to learn about preparing for loss and end-of life by examination of the literature regarding the process of aging (Galambos, 1989). Similar to the advancement of chronic illness, aging often brings many forms of loss. Changes occur in friends and family, and a decline of functioning that result in feelings of grief.

People living with advanced disease frequently experience decreased functioning, personal losses and an increase in health problems. These changes result in a sense of personal powerlessness and loss of control. Life events no longer develop or occur due to planning and implementation but instead are the result of the unexpected or unpredicted. Loss of control, fears of the unknown and a fear of eventual dependence on others becomes overwhelming (Galambos, 1989; Rubinow, 2005).

Potentially there are many fears for people facing end-or life. Rubinow (2005) suggests some of the most common fears include: 1) living dependent on technology, 2) physicians and family will not respect their final wishes or advanced directives, 3) their physician will abandon them, 4) their lives will end in a hospital or other institution, 5) their death will bring stress and anguish to their family and friends, and 6) their illness and death will bring financial burdens to their family.

Clearly these fears influence the feelings of loss of control at the end-of-life and the stress they bring to this phase of life. Particularly for aging members of society who are newly diagnosed with chronic illness, it is important to remember the health care system they remember or interacted with in their youth is likely to no longer exist in their community. In the last few decades, even some of the most remote and isolated communities in the United States experienced significant changes in delivery of health care, particularly in the areas of diagnostics, testing, treatments, and pharmacological interventions. The new world of health care is immense and is often experienced as impersonal and frightening.

Research suggests what people want when death approaches is a “good death” (Clark 2002; Kieffer & Wakefield, 1986; Rubinow, 2005; Smith, 2000). Literature regarding the “good death” suggests that instead of futile treatment of disease, people with advanced chronic illness want end-of-life to provide dignity and meaning. The “good death” is described by Clark (2002), as composed of the following elements; 1) pain-free death, 2) open acknowledgement of the imminence of death, 3) death at home, surrounded by family and friends, 4) an “aware” death- in which personal conflicts and unfinished business are resolved, 5) death as personal growth, and 6) death according to personal preference and in a manner that resonates with the person’s individuality. Social workers can work with patients to find ways to regain a sense of personal control by asking questions about their desires regarding the death experience.

Many cultures do not encourage discussions about death and many people are oblivious to the fact that they have choices and decisions to make at the end of life (Rubinow, 2005). When a patient believes there is nothing more they can do, social workers point out some of the important discussions and decisions that are necessary. Patients continue to encounter opportunities to influence pain and symptom improvement, resolve their underlying fears and concerns, explore their understanding of end-of-life, and resolve and deepen relationships (Back et al., 2003). Although decisions made by people facing end-of life do not necessarily improve their health or remove disease, they do influence the future. End-of life discussions and decisions include some of the following issues; 1) acceptance, 2) preparation of durable power of attorney documentation, 3) preparation of a living will, 4) end of life communication to family and friends, 5) decisions about palliative care and 6) understanding the role of hospice care.

### *Acceptance*

Acceptance is not a requirement for the end-of life. End of life occurs regardless of whether people accept the inevitability of death or not. The reason the discussion is included in this section is because the complicated process of acceptance is a challenge, sometimes for the patient and sometimes for the patient’s intimate community of support. For instance, if the patient and most of the support system of the patient accepts of the inevitability of the patient’s death, those who are not accepting and are not preparing for this event, will feel left out and isolated from the process.

*Bob is dying from AIDS. He has lived for 20 years with HIV, and given his tenacity, the advent of new medications, and his compliance with medication, diet and exercise, he has beat the odds of dying much earlier in his life. But given the reoccurrence of a severe form of cancer, things are looking bleak. Despite his conversations with his partner about his readiness to die, his partner, Dan, does not accept that Bob is facing death soon. Perhaps on some level, his partner knows medically things are very critical, but his language and efforts are all driven by looking for medical treatment options. Bob agrees to a high-risk surgery as a possible “cure” for the cancer, and although Bob survives the surgery, he still has*

*AIDS, and when laboratory tests are done soon after the surgery, there is still evidence of the cancer. Dan's voice and actions are distinctly out-of tune with the rest of the Bob's support group. Bob patiently waits for Dan to accept the end-of-life issues that Bob, his sisters, friends, minister, and health staff are preparing for. When the physician meets with Bob and Dan in the hospital room, he tells them it is time to think about hospice. It is not until this conversation that Dan allows himself to outwardly accept the fact that there is no medical treatment that will cure Bob.*
*Review the details of Bob and Dan's experiences with end of life. Do you think Dan completely denied Bob's health problems? Dan probably knew more about Bob's challenges than Bob's family members and other care givers. So it is unfair to say Dan did not accept the fact that Bob's disease state was critical, but Dan did not accept that it was time to stop treatment when Bob did and needed to keep trying to find a solution. To stop trying represented giving up for Dan and he wanted Bob to keep trying. Understand this desire to attempt to find a cure is a desire for everyone in the orchestra of Bob's life. Yet, at some point, eventually everyone in Bob's group of support, including Bob, came to the understanding that Bob's journey with the disease had reached the end-of-life phase; Dan was simply the last one to get there. When Dan ultimately joined Bob for the end-of-life discussions and decisions, together they started some of the planning and emotional exchanges that bring quality to this phase of life.*

Someone is always last to understand the end-of-life phase has arrived. At times it is the patient, it can also be a parent, spouse or partner and sometimes it is the physician. Rubinow (2005) suggests that physicians are challenged when it comes to dealing with issues of death. Traditional medical training teaches confrontation of death with medicine and the role of the physician is to lead the charge. Some physicians may resist, avoid and postpone acknowledging the approach of the patient's death. When acceptance is delayed, support system members resist engaging in end-of-life tasks and miss out on some important ways to take control, experience hope, and accept support; all while expecting death. Dissonance in the patient's support group regarding end of life may interfere with the patient's journey to varying degrees. Some patients, like Bob, chose to support the needs of his partner to continue to speak in terms of healing and cure. Supporting Dan, Bob continues to care for the needs of his loving care giver. Some patients ask others in their support group to help articulate their need to live their last days with the freedom to talk about death to the rest of their care givers.

Social workers witness these attempts of intimate groups of people to experience end of life. Understanding, patience and gentle caring for all, patients and their teams of support, is the most effective way to proceed. Latimer, (1998) states the emotional tension and fatigue due to the exhausting process of chronic illness often makes it difficult for patients' and their families to hear, think and absorb the reality of the future they worked to avoid. Taking the time to listen offers an outlet, decreasing feelings of fear and isolation and increasing feelings of security (Latimer, 1998).

Kübler-Ross (1997, 1987) suggests people who are dying go through many phases as they adjust to loss; denial and isolation, anger, bargaining, depression and acceptance. Note acceptance may be the last step people experience. The literature (Back, et al., 2003; Walsh-Burke, 2006) suggests not all steps are experienced by all patients, the steps of grief are not necessarily experienced linearly, and many of these steps are experienced by family members as well as the patient. Regardless of the stages of anticipatory grief, many of the emotions noted by Kübler-Ross are part of the journey toward the end-of-life. Some patients die and never publicly accept the inevitability of their death, but acceptance often allows time for tasks to be accomplished that offer patients and their support group an opportunity to plan a good death.

### *Communicating good-bye*

At some point in the social worker's relationship with the patient the discussion about end-of-life occurs. This discussion is frequently emotionally charged and sometimes leads to a broader discussion about endings. The end of a relationship with a social worker is frequently referred to as termination; a very powerful word. Many people find the end of relationships difficult, even under the best of circumstances and chose to avoid the experience of saying good-bye. However, end of life presents a final opportunity for people to communicate and despite the emotional pain many find this step vital in recovering from hurt of grief.

The end of a clinical relationship between a social worker and a client is guided by certain steps such as reflection of the relationship, reviewing the relationship and emphasizing the positive events, expressing positive emotions and saying goodbye (LeBow, 1995). These are helpful suggestions to patients and families as they progress toward the end of life. Reassure patients and families that there are no magic words or a right way to say good bye. In fact sometimes words are unnecessary and good bye can be communicated through other emotionally charged ways, holding hands, embracing, or hugs. Sometimes patient care givers sing, read meaningful excerpts, pray or meditate at the end of life good byes. Some keep long vigils or family members take turns staying with the patient, while still others stay with the patient 24 hours a day.

Good byes are uniquely personal to the patient and the care givers and social workers are helpful when they provide opportunities for privacy, space, or time for this communication to occur. Advocate for support within the health care team for the resources necessary for the family to end the relationship. For instance, if the patient is inpatient, can the family bring in the patient's dog? Would the family like a spiritual or religious guide present? There are respectful ways a social worker supports the cultural expressions of good byes and helps create a positive moment despite the grief.

### *Palliative Care*

Palliative care refers to the active medical treatment provided when recovery and cure are no longer the expectation. The symptoms of the disease are treated, particularly pain, but this is much different than the assertive measures used to treat and cure disease (Davis, 2005). Treatment continues, but the goal is minimizing the negative effects of the symptoms produced by the disease.

The movement toward palliative care and hospice is a response to the medicalization of death. Due to the advancements in health technology after WWII, death became the foe, or at least the enemy to attempt to conquer. All treatment is designed to destroy and treat the disease for as long as possible. But over time, physicians, families and patients realize that longer life is not necessarily the way to measure successful medical care. Instead, focus began to shift to measuring the patient’s ability to interact with others in meaningful ways and quality of life. For instance, although some chemo-therapies temporarily extend life, the symptoms of the treatment often outweigh the benefits and offer little or no hope of lasting success. While continued treatment is a way the patient continues to fight disease, the result of the treatment does not add quality life (Davis, 2005).

Palliative care is an attempt to merge the common end-of life struggle between two important feelings; hope and acceptance (Clark, 2002). Palliative care changes the goal of health care from continued medical treatment to facing the inevitability of death. Acceptance of death however, does not mean there is no room for hope. This is very important for social workers to understand. When palliative care begins, the goals a patient and their care givers hope for changes. Instead of treating the disease and hoping for cure, the hope moves towards providing comfort by minimizing any form of pain associated with death. Palliative care is a great example of the biopsychosocial model at work because the method treats the biological needs of the patient, but also treats psychological and social needs of the patient and their care givers.

### *The role of Hospice*

The most prominent form of palliative end-of-life-care is hospice. Palliative care is end of life care provided most frequently in an inpatient setting with health care providers in attendance; hospice care recognizes the same goals as palliative care but is frequently provided in patient homes or in hospice or long term care centers. In the United States, about 80% of hospice care is offered in home settings and 20% is offered to patients in long-term care facilities. Hospice care offers palliative care for the patient, but it also recognizes the family and care givers as needing care as well (Luptak, 2004).

The philosophy of hospice, in general, includes keeping the patient comfortable, ending extraordinary treatment measures and using the final stages of their life to focus on quality of living for the dying and support for the care givers (Bretscher, et al., 1999; Johnson & Slaninka, 1999; Torrens, 1985; Waldrop, 2006). Wallace (1995) suggests hospice places itself in service to the patient and family unit, but recognizes their expertise in determining their needs. Social workers recognize the patient’s right to self-determination and know the strengths of the patient, family, and care givers assist them to meet their needs while facing death.

Hospice care is not a new concept in the world and it can be traced back to the 5th century. The roots of the concept of hospice are traced to Western Europe where the first hospice care facilities were established during the Middle Ages. The first hospice centers were designed to give charity health care to travelers and the sick and dying. In 1879, Sister Mary Aikenhead, founder of the Irish Sisters of Charity, established “Our Lady’s Hospice for the Dying” in Dublin, Ireland. It became the first hospice facility in the English speaking population and it was developed distinctly to care for the dying (Bishop, Gores, Stempel, Torrington, Tynan, Jaskar, & Garewal, 2000; Luptak, 2004; Kerr, 1993). The practice of hospice care in England and Ireland was designed to improve the care of the dying (Bishop, et al., 2000; Torrens, 1985). Today, hospice is available to people experiencing the end of life in many countries throughout the world.

Hospice provides many different services in support of end-of-life services. Those services include paying for medical equipment, medical and nursing services, social work services, spiritual services, bereavement services, home health aide services and volunteer services. The services are designed to be holistic, treating the pain and comfort needs of the body, but also attending to the emotional concerns of the patient and their care-giving group. This is frequently an exceptional situation to witness the concept of biopsychosocial service delivery.

Hospice services can take place in a variety of settings. The most common setting is the patient's home or the home of a family member, but hospice services are also available through nursing homes, hospitals, and hospice centers. Rarely do patients or their support persons visit a hospice office, but when they do it is most likely for information about services, the admission visit for the patient, or perhaps for a support group offered on-site.

Hospice assessments are done with the patient at the first visit if this is possible. Sometimes the referral for services comes late in the disease. There are a variety of reasons for this. Many patients want to pursue all treatment options and are not ready to agree to discontinue aggressive treatment. The delay to initiate hospice services is frequently because people, both patients and family caregivers, perceive being admitted to hospice means they are dying. It is true that people who receive hospice services die, but of course they do not die because of hospice. It is also true that people admitted to hospice are in some way giving up the need to continue to treat a disease that will be their cause of death.

The advancement of medical technologies in the United States influences how we live with chronic illness and impending death. The advancement of life-extending medical treatments contributes to hopes of cure and despite small chances of healing, people may choose to continue to put hope in treatments. It is difficult to prepare for death when attempts to actively treat continue. The two goals, fighting disease and preparing to die, are difficult to fuse. Health care providers, patients and support systems all work to sustain life, but when life is limited, the provision of hospice services enables the family and patient to talk openly about the future and to communicate about the past in ways that confirm the patient's life.

The hospice assessment is done with the goal of listening to the biopsychosocial aspects of the patient's life, both strengths and needs. A hospice team member, often a social worker, asks the patient about their life; family, education, work history, emotional and social needs, caregiver issues, mental health issues and risk factors. The assessment also covers questions about funeral and burial plans, advance directives and referrals to other agencies or services. Discussing this material with a patient and their family is emotionally loaded and must be completed by a skilled social worker who displays compassion, respect, and patience. The information collected during this assessment is necessary for a social worker and the interdisciplinary hospice team to provide patients and families with informed holistic care. The process should seek to gather an understanding of the patient and their wishes as they approach end-of-life.

It is important to be empathic during the assessment. Consider the circumstances of this conversation from the perspective of the patient and the support system. Questions like, "What is your favorite activity?" seem innocuous, but if the patient was an avid golfer, they are, in this moment, faced with the fact they will never golf again; the grief issues can be overwhelming. Asking questions about funeral plans and end of life plans can also be overwhelming for the patient and family. Rely on clinical skills and the patient's leadership to decide if all answers to all questions are necessary during the first visit. If there is no engagement or relationship building prior to the first visit, these questions can easily be perceived as insensitive or invasive.

The first visit from hospice is often significant due to the emotional step of being admitted to hospice services and the initial assessment, but also because of the new information given to the patient and care givers. The patient likely receives a folder filled with information about medical insurance, services offered by hospice, and the patient's rights. Remember when people are in crisis, it is often difficult for new information to be absorbed or integrated. Patients' and their families are often exhausted and overwhelmed by the treatment issues of the disease. Do not expect the patient or care giver to prioritize reading information in a folder, despite the neat packaging. But many do read the information eventually. Skilled social workers assess the ability of the family to absorb new information and prioritize and highlight the most important information for the family to consider.

The assessment is frequently done in the patient's home, although this varies due to specific circumstances; assessments are completed in hospitals and nursing homes as well. It bears repeating that this initial visit is often overwhelming for the patient and support group and it is important to remember to be considerate, empathetic, and to use clinical skills to advance the assessment. If two members of a team are both talking, or interrupting each other, or lose sight of the patient's role, the goals of the visit are lost and the interaction is unsuccessful.

Hospice services are always provided using a team approach. The interdisciplinary team is frequently made up of a number of people from a variety of disciplines and includes social workers, chaplains, the volunteer coordinator, the bereavement counselor, the nursing staff, the dietician, and physicians. Social workers are an integral part of the hospice team (Csikai, 2004). This team meets about the needs and issues of the current patients and families, but also spends time talking about the recent deaths of other hospice patients. A team takes time to remember and celebrate the life and death of their patients and this also helps members experiencing their own bereavement issues and secondary trauma; a healthy way to avoid burn-out in a potentially difficult job.

Discharge from hospice services is not always because of death. Some patients, thought to have a shortened lifespan due to disease, actually get better. Sometimes patients experience improved health or respond to a treatment after their admission to the hospice program. Resigning from hospice services is often a delightful surprise for a patient. The ability of our medical system to predict end of life is based on educated guesses and cannot possibly be correct in all cases.

## Losses Due to Bereavement

Bereavement is often associated with someone who is grieving over the death of a loved one, but in addition to the loss of a person they loved, there are many additional kinds of loss. People experiencing bereavement are challenged to cope, readjust, reorganize and resemble without the presence of the person they loved (van Baarsen, 2002).

The dying process and eventual death is experienced by the person with the terminal condition, but the grief and loss of the dying and death of a family member or loved one is also experienced by their family members and others who cared for them. The systems theory provides a way to understand that change in one part of the individual's system leads to changes within other parts of the system. For instance, the advanced illness and eventual death of someone did not affect just the person who died. The changes caused by the death of an individual affect the family and the patient's larger community. Death causes changes, experienced as grief for family and many others experiencing the change involved in moving forward without this individual.

Sometimes death is unexpected due to accident or swift progression of an acute health event. This form of death occurs to anyone at any age and to people who are in good health. Traumatic and unpredictable forms of death are particularly difficult to adapt to. Reed (1998), states the death of a family member is one of the most disruptive of all life events, particularly deaths experienced through sudden loss. "Sudden bereavement is a complex, multidimensional process involving physical, psychological and sociological domains" (p. 285).

In addition, people die due to the progression of chronic illness. This form of death is often predicted and there is a certain amount of time for planning and care giving that can and must take place. Regardless of the reasons for the death, the end result is the same, people suffer from loss. Grief over the death of a loved one is the most common and challenging issues for social workers to face with clients. People grieve physically, emotionally and spiritually (Muller & Thompson, 2003). This is why the biopsychosocial integration of care is so appropriate.

What is the difference between grief and bereavement? The traumatic and important changes due to loss often result in emotional responses such as grief. Scannell-Deush (2003) defines the terms grief, bereavement and mourning as unique yet related experiences; grief is a profound, intense and personal emotional reaction to the death of an individual. Bereavement is the process of integrating the deprivation due to death, and mourning is the unique way people express and show their grief.

Cultures shape all of our responses, including grief, bereavement and mourning. All emotions and experiences associated with death are complex but a universal human experience and are shaped primarily by the culture of the patient and family (Scannell-Deush, 2003). Although a universal experience, loss is experienced in many unique ways for every individual.

Muller and Thompson (2003) suggest the bereavement experience is influenced by a number of factors including; 1) the relationship to the deceased, 2) the type of death, 3) historical approaches to bereavement, 4) societal influences, 5) cultural norms, 6) the quality of the relationship with the deceased, 7) the age of the deceased, and 8) personal aspects of the bereaved such as personality, vulnerability, age, social behavior, and family history with grief. Some of these factors are a stronger influence on bereavement than others, but the variety of factors that influence reactions to loss clarifies why bereavement is very complicated and unique; depending on the circumstances (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Muller & Thompson, 2003).

### *Coping with grief*

The death of someone we love is one of the most difficult emotional experiences we face. Social workers in health care, regardless of their work environment, must be prepared to support patients who face death, families and loved ones who experience the death of someone they love, or perhaps the death of someone the patient loves. Grief is experienced by everyone at some point in their life and this means it is essential for social workers to develop expertise and provide a safe and comfortable resource to discuss the issues associated with the loss experienced due to death.

People all grieve in their own unique way and this influences the time it takes to recover from loss. The steps of adjustment after loss is experienced at different rates of speed and it is a myth to think people are at different points of strength at certain times (van Baarsen, 2002). Social workers must also use caution and not to expect reactions to death to be predictable; some experience the death of a loved one as emotionally distressing, and some family members experience relief or perhaps joy after the death of someone they loved who had suffered with advanced chronic illness (Aneshensel, et al., 2004).

The signs of grief are unique and as diverse as every culture. Tears and crying are common forms of expression for many cultures and in some cultures are appropriate expressions of sorrow for by both men and women. Crying is not the only way people express their grief, so lack of tears must not be perceived as lack of profound sorrow. Some cultures or specific circumstances within a culture, support a less visible or emotional means to grieve. Some cultures grieve through clicks of the tongue or wailing or self-mutilation. Cultures also use a variety of other ways to express their pain: prayers, rituals, parties or wakes remembering the dead, church services, memorials, wearing black, women wearing veils, social isolation and social withdrawal.

Social workers assist people who grieve. Short term, social workers express empathy and support the family's immediate problem solving efforts after the death. Depending on the setting and the situation, social workers refer individuals and families to appropriate resources for longer term bereavement counseling. Long term bereavement counseling is not typically a part of health care social work. Counseling needs for the bereaved vary from the exploration and resolution of issues regarding their past and the relationship with the loved one who has died or perhaps grappling with how to cope with day-to-day existence due to loss, or perhaps the bereavement needs for someone are similar to the need to debrief after a crisis opportunity.

## Cultural Competence

The cultural influences of a person have significant power over their relationship to issues of death and dying (Searight & Gafford, 2005). All of the cultural variables intersect to create unique perspectives from every individual about the end-of-life and this perspective is affected by patient values and preferences. Assessing your personal issues is an essential step when working in health care, particularly if you work with people with advanced chronic illness and are faced with issues of death and dying. Professionals, social workers and other members of the interdisciplinary care team must be competent to face their own issues of mortality (Goldberg, 2002) and recognize their personal values influence what they think is the right end-of-life. Ignorance of your values and beliefs regarding end-of-life and death risks the patient's right to self-determination. Self-assessment is necessary because patients and families often need some form of leadership in beginning the conversations about their wishes and their impending loss.

Conversations about end-of-life and patient and family wishes are best when they begin before the patient is still relatively well and able to communicate. The input of the patient is vital because it later serves to relieve guilt and doubt from family members about end of life decisions. The conversations are especially important for patients who do not have advanced directives in place (Crane, et al., 2005).

Self-determination is the right of the patient, and the ethical commitment of the social worker. The National Association of Social Workers [NASW] provides social workers with a basis for respecting the right of the patient to make treatment decisions regarding their health and end-of-life care (2007). This is clearly not the license for the health care team to contribute to the death of a patient who wishes to die (Goldberg, 2002). Instead, self-determination trusts that the strengths of the patient and their support system are capable of making the decision about the end of life treatment best for them. Social workers respect the end-of-life treatment preferences of the patient and their family. Sometimes end-of-life discussions are often emotionally charged and intense, but by paying attention to the patient's values, spirituality, and relationship dynamics, the health care team understands and follows the cultural preferences of the patient regarding end-of-life (Searight & Gafford, 2005).

People who struggle with their health often struggle with decisions about their treatments as well. As the United States adjusts to the epidemic of chronic illness diagnoses, the health care system must find ways to respond. Social workers must be prepared to recognize the relationships between body, emotions and the social network as patients experience losses in these systems. As end-of –life approaches for those with advanced illness, social workers are prepared to deliver cultural and spiritually appropriate support and advocacy for the patient and family within the health care system.

## Summary

At times physicians, health teams, patients and care givers are reluctant to focus on end of life and chose to avoid the discussion of end of life and palliative care. This is normal and part of the cultural expectation that medicine can cure the enemy, death. The successful treatment of disease is a hope for all, but the loss of function and ultimately of life is part of the health care professional experience. Everyone involved in the experience of death and the feeling associated with this loss benefits from a variety of supports and the understanding that all grieve in their own way.

## References

Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. Journal of Health and Social Behavior, 45 (4), 422-440.

Aronoff, G. M. (2000). Pain medicine: Hope is a powerful analgesic. Geriatrics, 55 (9), 38-39.

Back, A. L., Arnold, R. M., & Quill, T. E. (2003). Hope for the best, and prepare for the worst. Annals of Internal Medicine, 138 (5), 439-443.

Bretscher, M., Rummans, T., Sloan, J., Kaur, J., Bartlett, A., Borkenhagen, L., & Loprinzi, C. (1999). Quality of life in hospice patients: A pilot study. Psychocomatics, 40 (4), 309-313.

Bishop, M. C., Gores, F. A., Stempel, J., Torrington, P., Tynan, C., Jaskar, D., & Garewal, H. (2000). A collaborative end-of-life care curriculum. American Journal of Hospice & Palliative Care, 17 (2), 137- 140.

Burkhardt, M. A. (1993). Characteristics of spirituality in the lives of women in a rural Appalachian community. Journal of Transcultural Nursing, 4 (2), 12-18.

Crane, M. K., Wittink, M., & Doukas, D. (2005). Respecting end-of-life treatment preferences. American Family Physician, 72 (7), 1263-1269.

Clark, D. (2002). Between hope and acceptance: The medicalisation of dying. British Medical Journal, 324 (7342), 905-907.

Csikai, E. L. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. Health & Social Work, 29 (1), 67-77.

Davis, M.P. (2005). Integrating palliative medicine into and oncology practice. American Journal of Hospice & Palliative Medicine, 22 (6), 447 – 456.

Dunbar, H. T., Mueller, C.W., Medina, C., & Wolf, T. (1998). Psychological and spiritual growth in women living with HIV. Social Work, 43 (2), 144-155.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. Science, 196 (4286), 129-136.

Emanuel, L. (2000). How living wills can help doctors and patients talk about dying. British Medical Journal, 320 (7250), 1618-1618.

Frankel, V. E. (1959). Man's search for meaning. Boston: Beacon Press.

Galambos, C. (1989). Living wills: A choice for the elderly. Social Work 34 (2), 182-185.

Goldberg, S. (2002). Do-not-resuscitate orders in the OR: Suspend or enforce. Association of Operating Room Nurses Journal, 76 (2), 296-300.

Hickman, S. E., Hammes, B. J., Moss, A. H., & Tolle, S.W. (2005). Hope for the future: Achieving the original intent of advance directives. The Hastings Center Report, Nov/Dec, S26-S31.

Horton, J. K. (2001). Hospice: Care when there is no cure. NCMJ, 62 (2), 86-90.

Johnson, C. B., & Slaninka, S. C. (1999). Barriers to accessing hospice services before a late terminal stage. Death Studies, 23, 225-238.

Kao, H., Travis, S. S., & Acton, G. J. (2004). Relocation to a long-term care facility: Working with patients and families before, during and after. Journal of Pyschosocial Nursing & Mental Health Services, 42(3), 10-16.

Kerr, D. (1993). Mother Mary Aikenhead, the Irish Sisters of Charity and Our Lady's Hospice for the Dying. The American Journal of Hospice & Palliative Care, May/June, 13-20.

Kistner, W.G. (2000). Durable power of attorney: A powerful planning tool. Healthcare Financial Management, 54 (9), 74-75.

Kieffer, S. E., & Wakefield, D. S. (1986). The availability of primary caregivers: An emerging problem. The American Journal of Hospice Care, May/June, 14-18.

Kübler-Ross, E. (1987). AIDS: The ultimate challenge. New York: Collier Books.

Kübler-Ross, E. (1997). On death and dying (reprinted ed.). New York: Scribner.

Latimer, E. J. (1998). Ethical care at the end of life. Canadian Medical Association Journal, 158 (13), 1741-1747.

LeBow, J. (1995). Open-ended therapy: Termination in marital and family therapy. In R.H. Miksell, D. D. Lusterman & S.H. McDaniel (Eds.), Integrating family therapy: Handbook of family psychology and systems theory (pp. 73-86). Washington, DC: American Psychological Association.

Leifer, R. (1996). Psychological and spiritual factors in chronic illness. The American Behavioral Scientist, 39 (6), 752-767.

Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. Health & Social Work, 29 (10), 7-15.

McAuley, W. J., Buchanan, R.J., Travis, S. S., Wang, S., & MyungSuk, K. (2006). Recent trends in advance directives at nursing home admission and one year after admission. The Gerontologist, 46 (3), 377-381.

Muller, E. D., & Thompson, C. L. (2003). The experience of grief after bereavement: A phenomenological study with implications for mental health counseling. Journal of Mental Health Counseling, 25 (3), 183-203.

National Association of Social Work [NASW] (2007). NASW Standards of social work practice in palliative and end of life care. Washington, DC: NASW Press.

Nusbaum, M. R. H., Hamilton, C., & Lenahan, P. (2003). Chronic illness and sexual functioning. American Family Physician, 67 (2), 347 – 354.

O'Neill, D. P., & Kenny, E. K. (1998). Spirituality and chronic illness. Image: The Journal of Nursing Scholarship, 30 (3), 275-281.

Osman, H., & Becker, M. A. (2003). Complexity of decision-making in a nursing home: The impact of advance directives on end-of-life care. Journal of Gerontological Social Work, 42(1), 27-40.

Puchalski, C. M., & Sandoval, C. (2003). Spiritual care. A clinical guide to supportive and palliative care for HIV/AIDS, pp 1-10.

Reed, M. D. (1998). Predicting grief symptomatology among the suddenly bereaved. Suicide & Life-Threatening Behavior, 28 (3), 285 – 300.

Roberts, S. S. (2001). Advance directives, part 1: Living wills. Diabetes Forecast, 54 (5), 99-101.

Rubinow, A. (2005). The physician and the dying patient: A question of control? IMAJ, 6 (7), 3-4.

Rushton, C. H., Spencer, K. L., & Johanson, W. (2004). Bringing end-of-life care out of the shadows. Nursing Management, 35 (3), 34-40.

Saunders, C. (1979). Annual report: St. Christopher's hospice. 1977-1978. Sydenhaum, U.K.: St. Christopher's Hospice.

Scannell-Desch, E. (2003). Women's adjustment to widowhood: Theory, research, and interventions. Journal of Psychosocial Nursing & Mental Health Services, 41 (5), 28-36.

Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. American Family Physician, 71 (3), 515-523.

Smith, R. (2000). A good death: An important aim for health services and for us all. British Medical Journal, 320, 129-130.

Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfoy, V., Wolf, S. M., Nolan, K., Jackson, R., Koch-Wesser, D., & Donnelley, S. (1993). Decisions near the end of life: Professional views on life-sustaining treatments. American Journal of Public Health, 83 (1), 14-23.

Strom-Gottfried, K., & Mowbray, N.D. (2006). Who heals the helper? Facilitating the social worker's grief. Families in Society: The Journal of Contemporary Social Services, 87 (1), 9-15.

Torrens, P.R. (1985). Hospice care: What have we learned. Annual Review Public Health, 6, 65-83.

van Baarsen, B. (2002). Theories on coping with loss: The impact of social support and self-esteem on adjustment to emotional and social loneliness following a partner's death in later years. The Journals of Gerontology, 57B (1), S33-S43.

Walsh-Burke, K. (2006). Grief and loss: Theories and skills for helping professionals. Boston: Allyn & Bacon.

Waldrop, D. (2006). At the eleventh hour: Psychosocial dynamics in short hospice stays. The Gerontologist, 46, 106-114.

Wallace, B. (1995). Suffering, meaning, and the goals of hospice care. The American Journal of Hospice & Palliative Care, May/June, 6-9.

# KIHÍVÁSOK A HALÁL KÖZELEDTÉVEL

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## Összefoglalás

A legtöbb ember nem szívesen foglalkozik a halállal, azonban a halálos beteg páciensek esetében ezzel is szembe kell nézni, mivel esetükben az egészségügyi ellátás és a folyamatos gyógykezelés célja többé már nem a gyógyítás, hanem a beteg hátralévő életének a megkönnyítése. Az egészségügyi ellátó személyzet tagjai, a beteg és a család közötti párbeszéd a halálról részét képezi a szakemberek napi munkájának és az egészségügyi dolgozóknak képesnek kell lenni arra, hogy ezzel a helyzettel megbirkózzanak.

Amikor a beteg úgy érzi, hogy nincs mit tenni, a szociális munkások kezdeményezik a fontos beszélgetéseket és segítenek meghozni a fontos döntéseket. A betegek folyamatosan szembesülnek újabb lehetőségekkel a fájdalom vagy a tünetek enyhítésére, a helyzetükkel járó félelmek és aggodalmak feloldására, a halál közeledtével kapcsolatos gondolataik értelmezésére és az emberi kapcsolataik tisztázására és elmélyítésére (Back et al., 2003). A halállal szembesülni kénytelen emberek döntései nagy valószínűséggel már nem javítják egészségi állapotukat vagy szüntetik meg a betegségüket, a jövőt viszont befolyásolják.

A palliatív ellátás célja a betegség tüneteinek enyhítése. Kiváló példája a biopszichoszociális modell működésének, mivel a módszer a beteg biológiai szükségleteinek ellátása mellet a páciens és az ellátó személyzet pszichológiai és társadalmi igényeit is figyelembe veszi.

A végső stádiumban lévő betegek leggyakoribb palliatív ellátási formája a hospice. A szolgálat holisztikus, a test fájdalmának kezelése és jólétének szolgálata mellett a beteg és az ellátást nyújtó szakemberek érzelmeivel is foglalkozik. A hospice szolgálatot mindig interdiszciplináris csapat látja el.

A haldoklást és végül a halált természetesen elsősorban a beteg éli át, de a családtag vagy a szeretett személy haldoklással és halállal járó fájdalomban osztoznak a családtagok és mások is, akik számára a beteg személye fontos. A szeretett személy elhunyta miatti bánat a szociális munkások számára az egyik leggyakoribb és legnagyobb kihívást jelentő feladat.

A szociális munkások segítenek a gyászolóknak. Kifejezik együttérzésüket és támogatják a családot a halált követő tennivalók elvégzésében, a problémák megoldásában, szükség esetén pedig továbbküldik az érintett személyeket vagy

családokat a megfelelő helyre, ahol a gyászesettel kapcsolatban hosszabb távú segítséget kaphatnak.

Az egyént ért kulturális hatások jelentős hatással lehetnek a halálhoz és haldokláshoz való viszonyára. A szakembereknek és az interdiszciplináris csapat tagjainak tisztában kell lenni a halandósággal kapcsolatos saját gondolataikkal és vélekedéseikkel, valamint észre kell venniük, hogy az értékítéletük hatással van a haldokláshoz és halálhoz való viszonyukra. Az ezzel kapcsolatos értékek és vélekedések figyelmen kívül hagyása veszélyezteti a betegek önállósághoz való jogát. Az önértékelés szükséges, mivel a betegek és családjuk gyakran van szükségük arra, hogy a kívánságaikról és a közelgő veszteségről való beszélgetést a szociális munkás kezdeményezze.

A szociális munkásoknak fel kell készülni arra, hogy felismerjék a test, az érzelmek és a társadalmi hálózat közötti kapcsolatokat, mivel a betegek gyakran szenvednek el ezekkel kapcsolatban veszteséget. Ahogy az előrehaladott betegségben szenvedők a halálhoz közelítenek, a szociális munkások készek kulturálisan és lelkileg megfelelő segítséget és támogatást nyújtani az ellátó rendszeren belül a betegnek és a családnak.

**Kulcsszavak:** felkészülés a halálra, szociális munka, interdiszciplináris segítő csapat, hospice, kulturális kompetencia