THE GRIEF, LOSS, AND COPING ASSOCIATED WITH CHRONIC ILLNESS

A KRÓNIKUS BETEGSÉGEKKEL JÁRÓ GYÁSZ, VESZTESÉG, ÉS AZ EZEKKEL VALÓ MEGKÜZDÉS

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Abstract

The epidemic of chronic illness in society completely changes how health care systems deliver services and this has considerable implications for social workers (Auslander & Freedenthal, 2006). Patients and caregivers living with the grief, and loss associated with chronic illness, rely on health care social workers for biopsychosocial support.

The consequences for social work education include the need to teach and learn about the bereavement issues associated with a chronic illness diagnosis. Professional practice requires familiarity with the psychosocial issues related to chronic illnesses and preparation to interact with patients, families, caregivers, and the health care team. Being informed about chronic illnesses calls for social workers to know as much about a chronic condition as the well-informed patient living with the diagnosis and to recognize how biological changes influence psychological and social changes.

Keywords: social work – biopsychosocial – chronic illness – grief – health care

Összefoglaló

A krónikus megbetegedések elterjedése a társadalomban mára teljes mértékben megváltoztatta az egészségügyi ellátó rendszerek szolgáltatási rendjét, és ez a változás következményekkel jár a szociális munkások tevékenységére nézve is. (Auslander, Freedanthal, 2006) A krónikus megbetegedésekkel együttjáró fájdalmak és veszteségek miatt a betegek és gondozóik az egészségügyi szociális munkástól várnak biopszichoszociális támogatást.

A szociális munkás képzések számára mindebből az következik, hogy tanítani és tanulni kell a krónikus betegség diagnózisával együttjáró gyászfolyamatokról. A jó szakmai gyakorlat megköveteli, hogy a szakember ismerje a krónikus betegségekkel kapcsolatos pszichoszociális kérdéseket, és felkészüljön a páciensekkel, családokkal, gondoskodó személyekkel, valamint az egészségügyi stábbal történő interakciókra. A krónikus megbetegedésről legalább annyit kell tudnia, mint az adott betegségben szenvedő jól tájékozott betegnek, és fel kell ismernie, miképpen hatnak a biológiai változások a pszichológiai és társas folyamatokra.

Kulcsszavak: szociális munka – biopszichoszociális – krónikus betegség – gyászfolyamat – egészségügyi ellátás

The epidemic of chronic illness in society completely changes how health care systems deliver services and this has considerable implications for social workers (Auslander & Freedenthal, 2006). Patients and caregivers living with the grief, and loss associated with chronic illness, rely on health care social workers for biopsychosocial support.

The consequences for social work education include the need to teach and learn about the bereavement issues associated with a chronic illness diagnosis. Professional practice requires familiarity with the psychosocial issues related to chronic illnesses and preparation to interact with patients, families, caregivers, and the health care team. Being informed about chronic illnesses calls for social workers to know as much about a chronic condition as the well-informed patient living with the diagnosis and to recognize how biological changes influence psychological and social changes.

Social workers are trained to offer many supportive roles in patient care (Auslander & Freedenthal, 2006). They engage and encourage patients and caregivers to adhere to treatment plans that help prevent or successfully manage chronic illness. Patients are assisted in problem-solving through identification of their strengths to confront obstacles that improve adaptation to their diagnosis. In addition, social workers offer psychosocial support as individuals experience the emotional and social symptoms related to grief and loss.

Social workers require skills in treating the emotions and reactions related to grief and loss as a result of chronic illness. Despite effective treatments to improve quality of life by delay or palliation of advanced chronic health conditions, an extended life span often results in the grief associated with the loss of physical, emotional, and social resources.

The introduction of chronic illness

Human history traces the role of health, illness, and healing and the attempts by societies to control or treat sudden, accidental, and fatal conditions (Porter, 1999). Historically, people did not develop and live with the chronic illnesses that are prevalent today. Instead contagious diseases, infections, malnutrition, wars, and natural disasters killed large communities of people, often in single events (Porter, 1999). Individuals worked in unsafe and unsanitary conditions and infection was commonly complicated and compromised recovery. The absence of antibiotics and a shortage of expertise and personnel in health care contributed to the likelihood that accidents or changes in physical health would be life-threatening. Infants were more likely to die and life expectancy was what today is considered "middle age". Diseases such as tuberculosis, pneumonia, influenza, and diphtheria were the leading causes of death at the beginning of the 20th century (Porter, 1999; Tarlov, 1996).

The emergence of chronic illness is relatively new in societies and is the result of two developmental changes. First, the development of medicine, medications, understanding of environmental and industrial effects on health, access to immunizations, and improved quality food has increased life expectancy for most (Auslander & Freedenthal, 2006; Sidell, 1997). Second, due to poor nutritional choices and inactivity, both clearly symptoms of the Westernization of culture, people are very likely to develop a chronic illness, and often live with more than one disease (Auslander & Freedenthal, 2006). Common chronic long-term conditions and diseases include Alzheimer's, cancers, acquired immunodeficiency syndrome (AIDS), heart disease, or diabetes.

Defining chronic illness

Chronic illness is disease that interferes with the healthy functioning of the body, is not curable, and is frequently progressively more symptomatic (de Ridder, et al., 2008). Life with chronic illness interferes with physical performance and is likely to influence emotional and social functioning (Auslander & Freedenthal, 2006; de Ridder, et al., 2008; Kelly & Field, 1996). Symptoms and severity between and within diagnostic categories of chronic disease can vary significantly (Walsh-Burke, 2006). Individuals diagnosed with a chronic illness typically require some form of treatment to control or delay the progression of the disease and many require long-term medical treatment, care, or support. Depending on the unique health factors of the patient, the diagnosis, and the stage of the disease, people can live productively with chronic illness for an extended period of time (Rothman & Wagner, 2003). The trajectory of the disease influences the need for changes in lifestyle, issues related to emotional and social functioning, quality of life, and symptom control (Auslander & Freedenthal, 2006).

Current care

A growing number of people require treatments for chronic illness and compel health care systems to adjust (Auslander & Freedenthal, 2006). Although chronic illness is not considered curable, health care providers must continue to offer treatment. In medical systems trained to seek curative results, treatment plans may fail to acknowledge the chronic nature of a patient's diagnosis and miss vital opportunities to educate and empower patients to improve health and prevent additional health care needs (de Ridder, et al., 2008).

Specialists in chronic illness understand the need to encourage and support people to modify lifestyles and to accommodate alterations caused by the disease. Some diagnoses call for radical modifications, but success with achieving healthy goals can lead to many benefits. It produces a sense of well-being, creativity, and productivity and it may slow down disease progression. Some forms of chronic illness benefit less, if at all, from lifestyle modification, but health providers are an important link for patients as they seek to control symptoms and pain (Auslander & Freedenthal, 2006; Curtin & Lubkin, 1990).

Grief and loss due to chronic illness

Living with chronic illness results in a loss of health and patient and caregivers grieve the demise of familiar routines of living (Waldrop, 2007). The emotion most commonly linked with loss is grief, the experience of intense sadness or great sorrow.

Most individuals experience the emotions associated with loss in their lives. Grief is a common life experience and is often experienced when individuals experience positive or negative changes (Waldrop, 2007; Walsh-Burke, 2006). Changes due to chronic illness however, are particularly challenging, negative, and unwelcome.

Grief associated with chronic illness is first experienced when an event occurs that leads to the recognition of disease related change (Walsh-Burke, 2006). The onset of grief is often unpredictable to the patient, the caregiver, and health providers. Patients may experience overwhelming sadness at what appears to be a rather common or benign everyday experience, yet the individual meaning of the event and the loss it represents leads to significant feelings of grief. The first time the patient needs help getting up from a chair, drops a dish, or cannot negotiate stairs, may be experienced as devastating. The event breaks through a layer of denial and in that moment, the patient faces the power of the disease. These are personal and private moments and others may not always recognize when these moments occur. The same is true for caregivers; their moments of loss are often associated with the end of routine due to the growing significance of disease (Waldorp, 2007). When significant biological, psychological or social changes occur due to chronic illness, people frequently acknowledge feeling scared, helpless, panic, or depressed (Walsh-Burke, 2006).

Advancing disease requires changes. It alters the physical and functional abilities of the individual, emotional stamina and ability to cope, and might change the patient and caregiver environment and interactions with society (de Ridder, et al., 2008; Waldorp, 2007). Adaptation to radical change is best supported by interventions based on a holistic biopsychosocial model. This model of care assumes the integration of the biological, psychological, and social (including environmental issues) of patients in treatment of disease.

Physical Losses

When chronic illness is first diagnosed, few symptoms may be noticed. Life goes on relatively the same as it did before the diagnosis. If it is early heart disease, there is an introduction of medications, routine testing and medical advice for lifestyle changes. Sometimes an HIV diagnosis calls for medications and occasional blood tests to determine viral activity. In these two examples, the changes demanded are seemingly simple. Some diagnoses, like breast cancer, may require treatments to be immediate and radical. There may be recommendations for swift action and invasive treatment methods. Breast cancer in very early stages is treated with forms of chemotherapy that might cause hair loss; with some breast cancer diagnoses, health care providers urge a form of surgical treatment as soon as possible. Eventually all patients realize chronic disease has an irrevocable influence on their bodies calling for emotional and social adjustments (Waldorp, 2007).

Emotional Losses

No one totally understands the unique experience of an individual living with chronic illness, even individuals living with the same diagnosis. Social workers can empathize and imagine the reality of patients, often because of repeated interactions with many who share similar experiences. However, because of the subjectivity of feelings, it is difficult to predict exactly how chronic illness affects the patient. This is part of the loneliness people experience when they live with chronic illness (Orfali & Anderson-Shaw, 2005). People respond to this sense of aloneness in a variety of ways. Some may attempt to share how they feel, and acknowledge feeling better. Others state how they feel, but after recognizing no one understands, they avoid talking about their emotions. This is particularly true when they tell people who love them, perhaps a spouse, parent, or child, and it results in a painful reaction such as sadness or grief. The patient may attempt to protect their caregivers and spend time reassuring others that they are fine.

Chronic illness can exact great physical and emotional energy from patients. When the body is fighting disease the exhaustion from medications, treatments, appointments, and disease it taxes emotional strength and powerful feelings of hopelessness, helplessness, entrapment, and frustration can lead to changes in personality (Orfali & Anderson-Shaw, 2005).

Social Losses

Chronic illness redefines social environments in many ways but minimally losses include the patient's personal, social, and community space.

Personal Space

As disease progresses, patients may experience changes in physical functioning that impairs use of personal space, such as within rooms or homes, in the way they did in the past. For instance, stairs may be challenging or impossible or perhaps there is a need for a specialized bed or a portable toilet. Using showers and bathtubs are frequently difficult for people with reduced physical strength so perhaps handrails are installed or the patient requires equipment for bathing.

Frequently, room is needed for the array of medications the patient may be prescribed. Directions for treatments and doctors' appointments may now cover a desk or fill a calendar. If patients are unable to sit at a table, they are now fed while in bed or while sitting on a couch. Trays and dishes are brought to different places within the house. Loss of personal space occurs when required support equipment, such as canes, walkers, and wheelchairs, now occupy room.

Socialization

Social interactions change as chronic illness advances. People living with advanced illness interact with others differently due to weakness, pain, discomfort, and reduced energy. When someone feels sick, they are less likely to enjoy the company of others, or are less likely to display pleasure. Friends and family, once part of the patient's social group, make adjustments to the biopsychosocial losses by engaging in shorter visits. Patients spend more time in their homes and make fewer social contacts. Everyone makes social accommodations to increase or maintain the comfort of the patient. These changes occur in subtle and obvious ways but old patterns of socialization, for patients and their social circles, take on a new look. Patients are often aware of their loss of desire or ability to socialize with spontaneity during outwardly directed interactions.

Social change occurs within intimate relationships, too. Chronic illness can influence sexual intimacy and perhaps impair sexual functioning (Claiborne & Rizzo, 2006; Nusbaum, Hamilton, & Lenahan, 2003). Sexual functioning is altered by many things in life, including physical, social, and emotional health. Physical changes occur due to disease, various medications, and other treatments and these factors influence the exchange of social and emotional attention of loved ones and ultimately shape the patient's potential to experience sexual desire and arousal (Nusbaum, et al., 2003). Disinterest or an inability to participate in familiar and intimate relationships at a time when this form of closeness to others could comfort them, adds to the sense of grief and loss.

Community Mobility

Community space changes for individuals living with chronic illness as dependence grows. Loss of mobility is often due to a reduction in strength and endurance. In some cases, people with advanced disease are unable to change physical positions without assistance or need help to move from being seated to standing. When significant mobility limitations exist, the constraints affect where people go and how they physically get there. It also interferes with autonomy and as mobility losses occur, levels of independence deteriorate.

Increased dependency leads to other significant losses for both patients and caregivers. For instance, for older couples and those who are single, functional decline may raise questions about continued independent living. Caregivers are not always able to accommodate the increase in care needs and sometimes support systems must look at alternative care options. Both families and patients frequently deny the need for patients to lose their personal residence and even under the best of circumstances, families experience guilt for relocating patients. For some patients, the decision to move is not their own and the final choice of residence is not their choice (Kao, Travis, & Acton, 2004).

All forms of relocation are stressful for patients and caregivers. Moving to another location alters patients' physical and emotional health. In some instances, patients' perception of hope declines when they move from their home and they experience abandonment or depression. All forms of loss influence the experience of quality of life.

Quality of life

Quality of life is a standard of living uniquely perceived and influenced by multiple factors (de Ridder, et al., 2008). It is influenced by variables such as the stage or severity of the illness, age and gender of the individual, pre-diagnosis health, and the support needed to live within the community. Healthy people often take personal independence for granted, yet, in the face of illness independence may be the ultimate value. In some cultures, dependence due to illness is a severe assault to one's integrity and quality of living, while other cultures support and honor the concept of dependence on social networks. There are striking differences between cultures in attitudes regarding issues of chronic illness and the role of family and community support (Curtin & Lubkin, 1990; Hooyman & Kiyak, 2008). In all cultures, to varying degrees, quality of life is influenced by 1) the ability to control pain or palliative care, 2) the meaning attached to life or spirituality, and 3) the psychosocial support of family and caregivers.

Palliative Care

Palliative care refers to the active medical treatment of pain and symptoms when recovery and cure are no longer the expectation (Goldstein & Fischberg, 2008). This form of care no longer prescribes to the assertive measures used to treat and cure disease (Davis, 2005). Although treatment continues, the sole goal is to minimize the negative effects of the symptoms produced by the disease.

The movement toward palliative and end of life care is a response to the medicalization of death. Due to the advancements in health technology, death has become the foe. Most medical treatment is designed to destroy and treat disease for as long as possible. But as disease advances, physicians, families, and patients realize that longer life is not necessarily the only way to measure successful health care. Instead, focus can shift to indicators of quality such as an ability to interact with others in meaningful ways (Goldstein & Fischberg, 2008). For instance, although some chemo-therapies are beneficial, sometimes the symptoms of the treatment outweigh the benefits and offer little or no hope of improved health. While continued treatment is one way the patient continues to experience hope, the result of the treatment does not necessarily add to quality life (Ballard & Elston, 2005; Davis, 2005).

Palliative care is an attempt to merge the common end-of life struggle between two strong feelings; hope and acceptance (Clark, 2002). It changes the goal of health care from curative medical strategies to facing the inevitability of death. Acceptance of death need not replace hope. Palliative care changes hopes of cure to hopes for pain management and other quality of life issues (Thorne, Oglov, Armstrong & Hislop, 2007).

Spirituality

Often the role of spirituality in health care is minimized because of the nonscientific nature of the concept or because spirituality is perceived as the same as religiosity (DuBois & Miley, 2008). Yet research suggests a positive relationship between concepts of religiosity /spirituality and health and well-being (Cattrich & Knudson-Martin, 2009; Gall & Grant, 2005; Rowe & Allen, 2004). It is appropriate that social workers thoughtfully engage in conversations with patients about their religious and spiritual practices (Cattrich & Knudson-Martin, 2009).

The definition of spirituality defies a concise description because it is uniquely personal and encompasses multiple human dimensions (Chu-Hui-Lin Chi, 2007; DuBois & Miley, 2008; O'Neill & Kenny, 1998). Spirituality refers to the fundamental issues addressed by most religions, including views of life, ethical values, emotional preparation for dealing with pain and tragedy, and how to make meaning of experiences (Leifer, 1996). The characteristics of spirituality include belief in a higher power, prayer, a sense of inner strength, and relationships with others and nature (Burkhardt, 1993; Gall & Grant, 2005). Spirituality is considered as giving meaning to one's existence, pervading all aspects of being, and experienced in caring connections with self, others, nature, and God or Higher Power (O'Neill & Kenny, 1998). It is identified as a key element in hope for people experiencing the diagnosis and advancement of chronic illness and for people who are dying or bereaved (Chu-Hui-Lin Chi, 2007; O'Neill & Kenny, 1998). Spirituality also serves as a means to improve the ability to cope with stress (O'Neill & Kenny, 1998). Clearly, understanding how patients experience spirituality is a way to better understand how they experience life and loss.

Diagnosis of a chronic illness is a major life assault and often causes individuals to question themselves, their purpose, and their meaning of life (Pulchalski & Sandoval, 2003). These are existential and spiritual questions. Illness disrupts a life journey by altering careers, relationships, and future plans. In addition, a diagnosis affects how a person experiences joy; these issues are the fundamentals of life.

Many patients recognize how interactions about life and the meaning of life enrich them or cause them to stop and see events in a richer and fuller way (Kaye & Raghvan, 2002). People rely on the medical system for cure from a disease, but many look to spirituality for meaning, purpose, and understanding (Chu-Hui-Lin Chi, 2007). Biopsychosocial and spiritual care offer a valuable combination for working with individuals living with chronic illness (Bingham & Habermann, 2006).

Family and caregivers

It is challenging to capture the many forms of supportive roles that develop when an individual is faced with the losses associated with advanced chronic illness. After possibly years of managing chronic illness independently, individuals must often turn to their families and caregivers to find assistance. Supporters commonly step up in a variety of ways to offer care to the patient and in doing so improve the patient's quality of life. Caregivers attempt to assist the patient to face the advancement of disease, and in some cases, the end of life.

Caregivers, people who provide biological, emotional or social care for someone, are frequently the heroes in providing health related care (Fox & Chesla, 2008). Often caregivers are connected to the patient through a variety of relationships: family, friend, partner, spouse, sibling, neighbor, coworker, volunteer, and child. As chronic illness advances, the daily living chores of ambulation, toileting, eating, and dressing are frequently impossible to accomplish independently. Provision of these services by caregivers, to someone who is relatively unable to assist, is essential to the patient's quality of life.

Often at great personal sacrifice of time, energy and money, caregivers offer love and care in ways that are unavailable from others. Patients experiencing pain, discomfort, or fear at their losses benefit from the attention and affection of their support systems (Waldrop, 2007). While families attempt to meet patient needs, they also deal with their own feelings of exhaustion, inadequacy and grief. They helplessly witness changes and losses and try to maintain hope for recovery (Waldrop, 2007).

Roles for social work in chronic illness care

Patients living with chronic illness experience more than a biomedical problem. It is essential that support in all areas of patient life, including the emotional and social aspects, be available (Waldrop, 2007; Weinert, Cudney, & Spring, 2008). The most common responsibilities for health care social workers in chronic illness treatment include 1) working toward prevention, 2) supporting for adherence to treatment, 3) assisting to identify strengths and potential barriers, 4) providing psychosocial care by offering support to patients and caregivers, and 5) offering effective techniques to help patients and caregivers utilize effective coping skills.

Prevention

Prevention is the ultimate tool to affect the consequences chronic illness for a minimum of two reasons. First, prevention is far less expensive than actual treatment of disease. The cost of chronic illness management for all systems is overwhelming. Second, poor access to health care is common but less necessary when there is absence of disease. Prevention of chronic illness is ideal and allows for the best quality of living, increasing opportunities for long life.

Many types of chronic disease are developed due to lifestyle habits and behaviors that put people at risk. If individuals are aware of the risks of disease, and actually change behaviors, there is a real chance that long-term disease is delayed or avoided. Although behavioral changes are difficult to maintain prevention is still the best course of quality living (Auslander & Freedenthal, 2006).

Social workers teach different forms of prevention: primary, secondary, and tertiary (Wheeler, 2000). Primary prevention emphasizes stopping something before it happens. For instance, educating people about the risk behaviors associated with forms of chronic illness so that behaviors change and disease diagnosis is averted. Secondary prevention is slowing down the advancement or stopping the disease from inflicting further damage. An example is support for the lifestyle changes associated with heart disease such as weight loss, exercise, and medication. Tertiary prevention is the treatment of disease in a way that improves quality and quantity of life. This is done through medical treatments or socially supportive roles. Most social workers in health care are involved in some or all forms of disease prevention (Wheeler, 2000).

Adherence to Treatment

Individuals with a diagnosis of chronic illness can plan on changes in many areas of life (Auslander & Freedenthal, 2006; de Ridder, et al., 2008). The two most common areas include alteration in daily living habits, and a new relationship with the health care system. Social workers are instrumental in assisting individuals in adjusting to these changes.

Patients with a new diagnosis are often assigned new and important health-related tasks and must rely significantly on self-motivation. Unfortunately, despite real desire and sincere efforts, changes in daily habits are difficult to achieve. However, because many forms of chronic illness benefit by some types of change in behaviors such as losing weight, starting an exercise program, abstaining from alcohol and drugs, and improving levels of stress, sleep, and nutrition, it is essential for patients to attempt these changes. Achieving successful change varies individually and is frequently associated with patients' belief that the effort will help them reduce their chance of more advanced disease. New personal responsibilities for tasks such as taking medications, exercises or following through on medical tests and appointments can be emotionally and physically exhausting.

Social workers teach and support patients to adhere to health programs and medical treatment plans (Auslander & Freedenthal, 2006; de Ridder, et al., 2008). Support is necessary as these changes are often accompanied by feelings of significant grief and loss as patients recall days before diagnosis, when perhaps life seemed simpler. Social workers assist patients to identify their goals and encourage and promote steps toward accommodating and eventually achieving positive change. This role of encouragement recognizes attempts to change and helps to identify resources for support. Although personal discipline is an important factor for change, having someone from outside the family or support system to honestly share defeats and frustrations with offers a sense of collaboration and partnership.

Strengths and Barriers

Living with chronic illness is stressful because it affects all aspects of life (de Ridder, et al., 2008). The health care system is often solely focused on the medical course and treatment of the disease, but the social worker understands the need for emotional and social treatment as well.

For instance, it is common to wish the course of chronic illness be predictable, yet frequently health providers must respond with uncertainty. This elusiveness is maddening because it interferes with the patient's desire to control or manage life. The symptoms, trajectory, length of time, pain, and other variables are unique for every chronic illness and vary by individual leading to feelings of powerlessness (Sidell, 1997; Thorne, et al., 2007).

When individuals are diagnosed with a chronic disease, they begin to redefine ways of coping with the news, changes, and treatments, that include living with disease (de Ridder, 2008). Pollin and Golant (1994) suggest that a person diagnosed with a chronic illness is likely to experience "a wide range of powerful and painful emotions such as anxiety, terror, denial, anger, depression, helplessness, frustration, and even shame" (p. 8). These emotions are normal and expected, but can camouflage the personal strengths of the patient. There are many moments when patients living with a chronic illness feel particularly vulnerable: at the time of diagnosis, during significant changes in the illness, and after hospitalization (Pollin & Golant, 1994).

Social workers remind patients and caregivers that everyone experiences crises differently. They validate the attempts and successes of patients and link the patients' past successes in life with the ability to be successful in the future.

There are a variety of strengths that people utilize to cope with a health crisis but this concept is illusive when the diagnosis and treatment aspects are tied to a "disease concept" model (Rapp, 1997). The strengths model—a model that bases successful interventions in patient strengths —guides social workers to help individuals "recognize past situations when they made good decisions, demonstrated competence, or displayed skills" (Rapp, p. 87). The model does not minimize tough barriers or problems, but promotes the belief that problems are not the sole element of life. Weick and Chamberlain (1997) suggest that despite the condition or disease, social workers acknowledge that "a person is always more than his or her problem" (p. 45).

Adaptation supports

As chronic illness limits and changes routine functioning, patients grieve (Sidell, 1997; Walsh-Burke, 2006). They begin to understand the impossibility of returning to a prediagnosis state. Loss accompanies the patient during the course of the illness, and he or she describes the process as similar to a "roller-coaster ride." Individuals often feel safest when they can predict the future, but people living with chronic illness experience a radical alteration in this form of thinking. As chronic illness symptoms increase, individuals wonder about their likelihood of experiencing future events. For some, the future becomes frightening. Pollin and Golant (1994) suggest fear is a common reaction and name eight unique forms of fear associated with the diagnosis of chronic illness: loss of control, 2) loss of self-image, 3) dependency, 4) stigma, 5) abandonment, 6) expression of anger, 7) isolation, and 8) death.

Social workers offer patients an opportunity to identify their fears and offer empathy. They assist patients and caregivers to physically, emotionally and socially adapt. Every stage of disease progression is accompanied by biopsychosocial change and social workers teach patients and health care teams that most reactions are normal, common, and expected. They encourage all systems to identify strength-based coping skills that enhance an individuals' ability to adapt to their future (Weinert, et al., 2008). Social workers normalize the fears and reactions to diagnosis and disease with the patient, caregivers and medical colleagues and encourage viewing reactions on a continuum, as part of a normal process, not a maladaptive way of functioning.

Social workers in health care practice rarely engage in long-term psychological patient therapy so it is vital for social workers to know counselors in the community who are assessable and have expertise in working with individuals and families experiencing longer-term emotional needs. Understanding the clients' needs and their perceptions of change during the course of illness and treatment provides social workers critical information about how to best support the biopsychosocial adaptation needs of patients and their families (Walsh-Burke, 2006; Weinert et al., 2008). Knowledge of the patients' perceptions is obtained through careful and thoughtful assessments that ask open-ended questions, allowing for honest reflections (Sidell, 1997; Walsh-Burke, 2006).

Psychosocial Coping

Coping with chronic illness relies on the patient developing a wide range of strategies (de Ridder, et al., 2008; Walsh-Burke, 2006; Weinert, et al., 2008). Livneh (2000) suggests that most recognized ways of coping are frequently targeted at three dimensions: emotion-focused, problem-focused, and avoidance or minimizing. Individuals rely on a variety of emotional strategies to minimize or avoid emotional pain because the experience of loss and change vary by stage of disease. The role of psychological defense mechanisms is to reduce emotional distress and assist patients to manage fears of pain, change, weakness, and loss. Coping methods help individuals function and attain some level of problem-solving behaviors and psychological adaptation to disease. Problem solving helps the patient limit experiences with avoidance, passivity, submission, self-blame, and other maladaptive coping styles that contribute to emotional distress. When functional changes occur and concrete evidence of chronic illness is evident, radical alterations in daily routines occur, strengths can emerge, and resilience can develop (de Ridder, et al., 2008; Livneh, 2000; Walsh-Burke, 2006).

Individuals cope with personal crises based on their personal style and the situation but coping is also related to family of origin, ethnicity, and many other cultural components. Some patients are interested in learning new and effective coping measures, particularly if they remain distressed and unable to function or maintain an adequate quality of life. Consistently unresolved symptoms of stress are destructive to health maintenance and health providers recommend patients find ways to decrease the emotional and social symptoms of disease to better treat physical symptoms. Social workers benefit from recognizing reactions to disease and knowing a variety of coping techniques. By understanding the ways patients cope, social workers can help create and enhance ways to integrate strengths. Social workers partner to create positive supportive networks, and challenge and reframe negative thoughts and experiences (Livneh, 2000).

Finding ways to cope is essential for patients living with chronic illness and these strategies are essential in helping patients maintain the greatest quality of life (de Ridder, et al., 2008). Social workers educate the patient and caregivers regarding functional coping strategies that allow movement forward in a way that supports unique physical, emotional and social circumstances (Walsh-Burke, 2006). The social worker offers objectivity to the patient and a place to vent feelings and learn alternative ways to cope. Understanding and teaching coping skills to patients improves problem identification, solution strategies, and positive goal-directed living (Livneh, 2000).

Summary

Chronic illnesses are the leading cause of health problems and frequently reduce quality and quantity of life. Social workers contribute vital psychosocial services to people affected by chronic illness by partnering with them, assisting them to recognize their strengths, reassuring them about their reactions to change, and encouraging healthy coping techniques.

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ASSERTIVE COMMUNITY TREATMENT: A CRITICAL UPDATE

ASSZERTÍV KÖZÖSSÉGI ELLÁTÁS: KRITIKAI ÁTTEKINTÉS

TOMI GOMORY

Abstract

Assertive Community Treatment (ACT) has been identified in the United States as one of only six evidence-based practices for the severely mentally ill by federal, private foundation, and academic mental health experts and is being rapidly implemented throughout the world. This article reexamines the research of the inventors of ACT (the Madison Wisconsin ACT group) regarding two of their claims. First, that ACT reduces homelessness, and second, that it also reduces penal stays, outcomes which have been key empirical claims for the National Alliance of the Mentally Ill's proactive and very successful public relations campaign to institutionalize ACT across the US. The Madison Wisconsin ACT group makes these assertions in the longest study (at least 14-years) ever done on this treatment model. The analysis concludes that there is no ACT specific clinical effect in these domains. The implications of these findings are also discussed.

Keywords: mental disorders – Assertive Community Treatment – evidence-based practice – critical analysis – critical thinking

Összefoglaló

Az Asszertív Közösségi Ellátást (ACT) az Egyesült Államokban a szövetségi, magán- és alapítványi intézmények, akadémiai szakértők úgy ismerték el, mint az összesen hat bizonyítékokon alapuló segítői tevékenység egyikét a súlyos mentális zavarokkal küzdők kezelésében. A módszert világszerte gyorsan kezdték el alkalmazni. A jelen tanulmány áttekinti az ACT kidolgozói (a Madison Wisconsin ACT csoport) kutatásait, két állításukra fókuszálva. Az első, hogy az ACT csökkenti a hajléktalanság veszélyét, a második, hogy mérsékeli a büntetés-végrehajtó intézményekben töltött időt. Ezek azok az empirikus eredmények, amelynek alapján a Mentális Betegek Nemzeti Szövetsége sikeres PR kampányt folytatott le, hogy szerte az Egyesült Államokban intézményesítse az ACT gyakorlatát. A Madison Wisconsin ACT csoport állításait az e modellen valaha lefolytatott leghosszabb, legalább 14 évig tartó kutatásra alapozza. Azonban az elemzésből kiderül, hogy semmilyen, specifikusan az ACT-nek tulajdonítható klinikai hatásról nem beszélhetünk. A tanulmány tárgyalja ennek a kutatási eredménynek a lehetséges implikációit is.

Kulcsszavak: mentális betegségek – Asszertív Közösségi Ellátás – bizonyítékokon alapuló gyakorlat – kritikai elemzés – kritikai gondolkodás