Emotional Trauma Associated with Renal Disease and Natural Disasters

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Emotional trauma frequently follows any disaster such as fire, flood, earthquake, accidents, war, bombings, and life-threatening disease. One such disease is end stage renal disease (ESRD), an irreversible, progressive loss of renal function (Lancaster, 1995). Since this is a "do or die" situation, it requires artificial methods of hemodialysis, peritoneal dialysis, or transplant, which require learned coping skills. Emotional trauma may occur pre or postdisaster and may include flashbacks when events trigger suppressed memories or unresolved emotions. Aftercare of disasters requires dedicated professionals to guide patients toward essential lifelines.

Disasters are occurrences that interrupt status quo and threaten basic needs for air, water, food, shelter, and security. Disasters come in many forms. Natural disasters include fires, floods, hurricanes, tornadoes, earthquakes, and disease. Man-made disasters include situations such as wars, bombings, explosions, shootings, and transportation accidents.

Floods, tornadoes, earthquakes, and fires strike with little or no warning. Explosions, bombings, shootings, and vehicle crashes are sudden impacts and allow no time to prepare. War has not been experienced for many years on American soil, but the devastation and aftermath are essentially the same. Results of many such occurrences involve interruption of electricity, contaminated water supply, implementation of emergency procedures, property devastation, congestion, and gridlock. Some diseases occur with ample time to prepare. Others strike with little or no warning. When basic needs are threatened there is a natural instinct to aggressively seek homeostasis.

In today's society all facets of existence are interdependent. No longer are people equipped to survive entirely on their own. Goods are readily available as long as there is transportation. Businesses are operative as long as there is a constant supply of energy and goods. Communication is imperative. Life-threatening illness requires health professionals to prescribe, treat, and often provide routine maintenance such as direct care or guidance. Whenever wide-spread disasters strike, the transfer of goods, resources, availability, and communications are interrupted impacting everything across the board.

Disasters create an environment for survivors to experience emotional distress. Whether acute or chronic, many diseases require patients to make significant lifestyle changes. A plethora of emotions may be present and need attention before patients can function appropriately. People with disease often need to learn new coping techniques. Diseases such as cancer, HIV, and ESRD produce similar emotional reactions. Only one life-threatening disease, renal failure, will be addressed.

Coping With End Stage Renal Disease

End stage renal disease (ESRD), an insidious, progressive loss of renal function, is irreversible (Lancaster, 1995). Kidney failure may be due to trauma, any condition that impairs the flow of blood to the kidneys, certain toxic substances, bacterial toxins, glomerulonephritis, or acute obstructions of the urinary tract (Thomas, 1993). Hypertension, diabetes, kidney infections, and inherited disease are some of the main medical reasons for kidney failure. Normal healthy kidneys act as the body's filtering or cleansing system. When kidneys fail, the established modes of treatment are dialysis and transplantation (Chatterjee, 2001). The dialysis care regimen is complex and demanding, extending into nearly all aspects of patients' lives (Kimmel et al., 2000). This means severe, strict lifestyle changes requiring lifelong treatment. The medication/treatment schedule is complex. Reasons for some therapies may be difficult to understand.

Whenever early detection is evident and diagnosis can be made prior to complete kidney failure, patients can be afforded time to prepare and adjust. Sudden onset may be traumatic. Patients must contend with changes that include dietary restrictions, fluid restrictions, frequent infections, access difficulties, changes in daily routine, and activity restrictions.

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They must constantly monitor food and fluid intake. Emotions – the mental state or feeling such as fear, hate, love, anger, grief, or joy arising as a subjective rather than a conscious mental effort – constitute the drive that brings about the emotional or mental adjustment necessary to satisfy instinctive needs (Thomas, 1993). Consequently, emotions related to lifestyle changes run rampant and follow a process similar to the stages of grief described by Kubler-Ross (1997). First there is shock and denial, followed by anger and, possibly, depression moving through memory toward acceptance.

Coping With Natural Disasters

All natural disasters can have similar outcomes. The Low Country of South Carolina is faced with natural phenomena each year in the form of hurricanes. This is one disaster that allows time to prepare. Usually a hurricane forms over time and follows a somewhat predictable path before it makes landfall. In the aftermath, there is a host of conditions that require attention.

Following Hurricane Hugo in 1989, medical facilities operated with skeleton staffing where only critical emergencies were treated. Utilities at those facilities were on back-up generators and in short supply. Communication was almost nonexistent. There was no television or radio unless one was equipped with generators or battery power. Word of mouth was most often the only link to civilization. For many that lived in remote areas, isolation was apparent.

Travel was restricted by fallen trees, debris, damaged or destroyed vehicles, and limited personnel. Because of power loss, service stations could not pump gas. Traffic lights were out. Any emergency staff on duty for the duration became seriously fatigued. Danger was omnipresent. Airborne particles containing foreign germs, bacteria, and viruses were likely deposited with the debris. Charleston, SC, was likened to a war zone, littered with pink insulation, trees, limbs, roofing and other building materials, demolished vehicles, and personal belongings. Boats were perilously moored inside buildings and perched in the middle of highways. Homes were askew, wobbling precariously on damaged foundations.

Fortunately, human goodness emerged. The community banded together, getting to know each other and sharing resources. Charleston in the year 2001 bears little resemblance to the sights, sounds, smells, tastes, and feelings from September 1989. That is, until those who experienced Hugo hear wind, rain, thunder, the constant hum of generators, and the incessant buzz of chain saws; smell and taste the same canned food forced upon them; or see reports on television of other disasters. These triggers often cause resurgent feelings of panic, fear, and loss. It stands to reason that all disaster survivors experience similar reactions, flashbacks, or emotional trauma associated with their specific event.

This trauma impacted Charleston residents for a long time. Restoration of utilities required weeks. Clean up required months. Not only were people displaced but animals were displaced as well. Some residents lost their furry companions. This compounded their grief. Many of us who survived this experience watch every media weather bulletin with flowing adrenalin and sweaty palms, ready for fight or flight.

Hurricane Floyd in September of 1999 presented the southeast coast with other unusual events. Because of that storm's enormity and strength, mandatory evacuation was ordered. Highways were clogged. Travel was severely impeded causing deprivation of food, water, and facilities as the storm approached. People had nowhere to go. At the last minute the storm veered away only to cause flooding in portions of upper South and North Carolina. For the people trapped in their homes or isolated with rising water surrounding them, they were required to muster all ingenuity possible to cope.

Coping With Emotional Trauma

Shock unfolds as renal patients as well as hurricane survivors cope with their dilemma. Emotional or psychological shock may produce disordered feelings of behavior (Thomas, 1993). Psychic trauma, a painful emotional experience, may cause anxiety. Frustration is normally associated with displeasure and intensification of perception of personal need. Physiological changes invariably accompany alteration in the emotions but such change may not be apparent to either the person experiencing the emotion or the observer (Thomas, 1993). Onset of disease, any disease, may cause posttraumatic stress syndrome or flashbacks in emotions associated with previous trauma. For example, familiarity with disaster may limit panic if a person has developed good coping skills. For others whose coping skills are poor, inappropriate responses may recur (Clark, 1996). Often these emotions are free-floating and cause further painful memories or unresolved anguish to surface, hence, another compounding factor in dealing with the reality of ones situation and needs.

With the tremendous onslaught of information, change, and expectations, renal patients may be overwhelmed. Questions arise such as, "Why is this happening to me?" "How long will I need these treatments?" "What did I do to cause this?" "Who's going to pay for all this?" Or, statements like, "This is not really happening to me," "My kidneys are going to start working again soon," "The doctors have made a mistake," or "Everything's going to be all right," are made. If the patient is religious, references to a higher power are frequently interspersed into these ideas such as, "God will take care of me." "God will provide." "God does not fail so my kidneys haven't really failed." "Why me, God?"

Reference to God is not meant to embrace only the Judeo-Christian concept of belief in a higher power. Any other recognized higher power such as Allah, Jehovah, or Yahweh may be substituted for God. Esteemed philosophers such as Confucius or pagan reference to Mother Earth may be reference points for some people. Whatever entity is addressed, this is intended to represent a source outside of oneself to place responsibility and sometimes blame. It is not meant to be all-inclusive. The point is that in the real world disasters strike, and people look for something or someone to blame.

After a period of time, people living with disease begin to understand their needs. Their disease is permanent. Anger may surface, sometimes directly or indirectly. Anger can paralyze one's ability to function. Anger and blaming stem from increased awareness of loss, physical fatigue, and emotional stress (Cohen & Ahern, 1980). Symptoms include chronic attitude problems, negativity, and acting out. Patients may lash out at anything or anyone in their proximity, especially toward the health care professional on whom they depend for their care. Dialysis patients may fail to show up for treatment, be late, or cut their treatment time. Compliance is the degree to which patients' behavior corresponds to the recommendation of a health care provider (Elixhauser, Eisen, Romeis, & Homan, 1990). Kimmel et al. (2000) cited in *Renal Rehab Report* that short-term consequences of noncompliance might not be obvious. One recent study of 295 dialysis patients showed that frequent skipping and/or shortening of dialysis treatments was associated with poor survival. Another study reported that skipping even one dialysis session per month is associated with an increased risk. Active self-management of renal disease and its treatment is the key to living long and well (Leggat et al., 2000). It is the responsibility of health care professionals to encourage compliance by gently reminding patients to follow prescribed treatment regimens.

Deeply enmeshed in anger is fear: fear of death, the unknown, isolation, rejection, and total loss of control. Imagine for a moment what it must feel like to have been totally active, independent, employed, self-sufficient, and generally healthy. What must it feel like to be plunged into inactivity? How does one deal with having to depend on a machine? How does one deal with devastation, debris, and inconvenience? What does one do when they cannot work as before? What happens when one is no longer able to function spontaneously? Disaster interferes with one's aspirations, dreams, and goals. Concern for financial well-being, interpersonal relationships, social activities, and security adds stress. Questions may surface such as, "What's the use?" or "Why bother with all this?" One's emotional state can significantly affect health, medical treatment, and progress (Moiger, 1997). One such emotion is anxiety – a feeling of apprehension, worry, uneasiness, or dread, especially of the future (Thomas, 1993) – and may be manifested by hyper-alertness, trembling, palpitations, and tenseness.

Some people may experience depression demonstrated by frequent crying, insomnia, decreased interests in relationships, loneliness, and feelings of worthlessness. Other common psychological reactions include sadness, phobias, guilt, and irritability. Some people may have difficulty concentrating or making decisions. Psychosomatic complaints and mental illness are other responses to disaster and may have long-term effects (Smith & Maurer, 1995). Patients who follow prescribed treatment regimens may feel well enough to resume activities adapted to their special needs. Many resume employment and lead active, independent lives. As long as an established routine is maintained, dialysis patients fare very well. Any interruption in routine, however, may create difficulty for people to return to their normal routines and relationship patterns.

From a mental health perspective, Farberow and Gordon (1986) suggested four phases of emotional reactions that accompany disasters: *heroic* – excitement that has to do with situational novelty; *honeymoon* – optimism where plans are made; *disillusionment* – frustration with bureaucracy; and *reconstruction* – individual and community effort to reestablish normalcy. How one deals with emotional reactions is directly related to one's ability to cope with disaster. According to Demi and Miles (1983), psychological reactions may be mild to severe, normal to pathological, or immediate to delayed. All disaster victims and workers may need referral and follow-up with mental health professionals to restore them to predisaster mental health.

Major concerns of dialysis patients during natural or man-made disasters are the same as for the general populous plus their critical, immediate need for treatment. During a state of emergency requiring evacuation, the clinic staff must adjust schedules and accommodate patients needs as rapidly as possible, providing information about facilities in other cities. Patients are concerned about where they must go and what they must do for safety's sake. They need information about facilities in other areas that will receive them on short notice. They want to know the procedures while away and what to expect when they return home. Patients must assume responsibility and seek treatment wherever they go. If they choose to remain, they are encouraged to seek shelter and contact the clinic for emergency plans as soon as feasible following the storm.

For the ESRD patient, heightened emotions and physiology may be compounded by physical distress from improper personal care and inadequate dialysis, especially if no treatment has been available for several days. Typically, the renal patient experiences fluid buildup, shortness of breath, fatigue, and possible malaise when treatment is delayed. This can be extremely painful and frightening. After Hurricane Hugo dialysis clinics had no power, water, or communication, and had sustained damage. Some locations in the Charleston area were equipped with generators and operated around the clock to meet patient needs until more appropriate care was available. Not only were patients concerned with meeting their medical requirements, but they had the added burden of restoring their property or seeking alternative living arrangements.

Renal patients must be taught proper emergency and self-care from the beginning of their illness. They need to have food on hand to meet their dietary needs (Sukolsky, 1999). They need to know where to go for treatment. They need to know how to disconnect from machines if disaster occurs during treatment. This knowledge provides tools and skills to call forth when other natural or man-made disasters strike.

Role of Social Workers and Counselors

People involved in disasters need encouragement and empathy.

Survivors need to express their fears and concerns and find appropriate ways to cope. Social workers as well as mental health counselors are trained to intervene in psychosocial issues and encourage survivors to persevere and participate in the process (Callahan, 1998). Six major services of the nephrology social worker as mandated by Medicare Conditions of Coverage for End Stage Renal Disease from the Code of Federal Regulations include: (a) psychosocial evaluations, (b) participating in a team review of patient progress, (c) recommending changes in treatment based on the patient's current psychosocial evaluation, (d) providing casework and group-work services to patients and their families in dealing with the special problems associated with ESRD, (e) identifying community social agencies and other resources, and (f) assisting patients and their families to utilize them (Rice, 1999). These services are designed to promote interpersonal relationships and coping with stress related illness.

Mizzoni (1998-99) suggests that social workers provide assistance and advocacy for patients to regain control and live healthy. This enhances patients' autonomy. Patients want to be treated with respect. They want to be informed. They need to participate in their health care. Each incidence of patient participation allows for a teachable moment and promotes independence.

Personal responsibility cannot be overemphasized. While counseling professionals are helpers, they cannot be expected to assume tasks that survivors can and must do for themselves. Thus, social workers are able to do what they do well – provide resources. For example, social workers refer people to other professionals with specialized expertise. While social workers usually have a vast amount of information available, they do not have all the answers. It may be necessary for the survivor and social worker to pursue information and learn together. Above all, survivors must remain flexible and be willing to do whatever it takes to meet their own needs.

Conclusion

Aftercare following disasters requires as much energy on the part of the counseling professional as it does at onset. Some of the ways to deal with such situations include: listening to concerns, providing information, relating to people with respect, giving clear concise instructions, educating survivors in safety, refraining from arguments, finding humor in experiences, and remaining professional in demeanor and presentation. During pre-disaster preparation staff must be available to disseminate emergency information. Knowledge can significantly minimize patients' anxiety. All procedures must be followed with the utmost care. Workers must be team players and demonstrate confidence and reliability. Survivors depend on that. Some post disaster stabilization techniques include debriefing sessions, information hotlines, and partnerships to provide mutual support and assistance (Stanley, 1990).

Finally, counseling professionals must take care of themselves first so they can assist others in emotional distress. It is crucial for professionals to take appropriate time away from their work to rest and play. They must find creative ways to divert their attention from demanding schedules and workload, eat right, and exercise. There is often something magical that transpires with a solitary walk, a relaxing bath, a time for meditation, or participating in a favorite activity. Minds clear, energy rejuvenates, bodies relax, and purpose resurfaces. Life, death, disease, and disasters go on. But when professionals have cared for themselves they are far more effective in providing care, encouragement, and services.

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