

A Single-Participant Qualitative Case Study: Holism, Healing, and Health-Related Quality of Life in Hemodialysis— Reflections of a Long-Term Survivor

Claudie J. Thomas, PhD, Morgan State University, School of Social Work, Baltimore, MD

The author, a 28-year survivor of hemodialysis treatments, tells a story of his longevity through some of the precepts of holism. These include emphasizing individual growth and change, healing the whole person, and the role that individuals play in self-healing. The author recounts the roles that social, cultural, religious, and educational institutions played in his healing and his transformation from someone devastated emotionally, physically, and spiritually at first, into someone who feels more complete and vigorous at present. The author also derives practice, policy, and research implications from this narrative, for nephrology social workers helping patients to heal and live full lives.

INTRODUCTION

I had my first hemodialysis treatment on September 10, 1983, and have been receiving hemodialysis treatments since, with the exception of a 6-month hiatus due to a failed transplant. I was diagnosed with end-stage renal disease due to complications from polycystic kidney disease, and since that time, my life's journey has taken innumerable twists and turns. Surviving all of those challenges from being a hemodialysis patient has been both difficult and joyful. In reflecting on my life, I can view my longevity through the lens of holism. Thus, the focus of this essay is to examine how the concepts of holism have helped me survive and enhance my quality of life.

Holism is a concept that is central to health-related quality of life (Brown, Renwick, & Nagler, 1996). The term "holism" derives from the Greek word "holos" or "whole." It is defined as systems or organisms that are greater than and different from the sum of their parts (Hemphill-Pearson & Hunter, 1997; Baum, 2010), and explains nature's tendency to generate wholes from an aggregation of single, solitary parts (Baum, 2010). The concept, applied to health, focuses on the balance and interconnectedness of physical, social, psychological, and spiritual aspects (Levin, 2009; Patterson, 1998). Consequently, the main principle in holism is wholeness, or the unity and oneness of mind, body, and spirit. Therefore, in holism, all aspects influence each other while working in concert (Davis-Floyd & St. John, 1998; Hemphill-Pearson & Hunter, 1997; Levin, 2009; Mattson, 1982; Thornton & Gold, 1999).

This concept of holism is quite different from the mechanistic/technocratic model of health and medicine (Brouse, 1992; Davis-Floyd & St. John, 1998; Levin, 2009). In the mechanistic/technocratic model, there is a distinct segmentation and separation among mind, body, and spirit (Davis-Floyd & St. John, 1998; Levin, 2009; Mattson, 1982; Thornton & Gold, 1999). However, the concept of holism focuses on individual growth and change (Brouse, 1992; Patterson, 1998); healing the whole person with balance among the physical, social, emotional, and spiritual selves (Brouse, 1992; Checkland et al., 2008; Davis-Floyd & St.

John, 1998; Hemphill-Pearson & Hunter, 1997; Mattson, 1982; Patterson, 1998; Thornton & Gold, 1999, Thorpe, 2008); and also emphasizes the role that individuals, as opposed to health care providers, play in healing themselves (Davis-Floyd & St. John, 1998; Epstein, Senzon, & Lemberger, 2009; Jobst, Shostak, & Whitehouse, 1999; Mattson, 1982; Thornton & Gold, 1999).

INDIVIDUAL GROWTH AND CHANGE

When faced with renal failure that September of 1983, I was not concerned with individual growth and change. This became an especially challenging time of my life. Anger, depression, and sadness were the predominant emotions that I experienced at the time, due to the realization that I would have to rely on hemodialysis in order to live. To say the least, my spirit was broken. To compound these feelings, I lost my father, my job and my apartment, and my same-gender partner and I separated, all within a year of being diagnosed with kidney failure. It seemed that life could not get any worse.

However, I gradually began to recover from this trauma as I began doing volunteer counseling at a local city agency. This part-time volunteer work actually gave me a sense of purpose, and was the springboard to greater employment opportunities. My small family was supportive of my efforts without being overbearing, and I was beginning to be embraced by a nucleus of fictive "kin" (network of friends) who were concerned about my well-being. At this time, social support was crucial in my quest to survive and have a relatively good quality of life (Kimmel, Emont, Newmann, Danko, & Moss, 2003; Patel, Shah, Peterson, & Kimmel, 2002).

Additionally, I was also deeply involved with my religious institution at this particular time. Seminal research by Hill (1971, 2003) posits that religion and kinship networks have helped African-Americans cope with a myriad of deleterious situations in society. Park (2005, 2007) and Pargament (1997) posit that religion can help individuals find comfort, solace, peace, and strength in the face of health crises. Thus, my involvement in the religious institution, to a certain degree, helped me cope with my renal failure.

However, there were two pivotal moments in this journey that fostered tremendous individual growth and change. First, I left the religious institution that was my denomination from birth because the minister's teachings on sexual identity were causing me great distress. This led me to a more progressive religious institution where I was accepted, enabling me to grow spiritually.

Second, I was given the opportunity to study doctoral-level social work. Daniels (2001) and Williams (2008) both believe that, in order for an individual with a chronic illness to thrive, life-enhancing opportunities must be made available to them. As an African-American gay male with a chronic illness, I lived with society's bigotry toward vulnerable and marginalized groups. Pursuing my doctoral degree boosted my confidence, self-esteem, and sense of purpose. After 8 years of intense study and a couple of health-related setbacks, I received my PhD in 2003. I have subsequently taught full-time at two universities in their departments of social work, while still undergoing thrice-weekly hemodialysis.

HEALING THE WHOLE PERSON

Healing the whole person is a hallmark of holistic health and has been central to my longevity on hemodialysis. This concept involves striking a balance among the various aspects of human existence (Checkland et al., 2008; Thorpe, 2008). There has to be harmony among physical, social, emotional, and spiritual realms. I gave equal attention to all of those entities. Although I try to keep myself physically well by engaging in health-promoting activities, such as exercise, eating nutritious meals (within the confines of the renal diet), and refraining from injurious lifestyle actions, I also try to surround myself with persons who have positive attitudes. Additionally, I try to enjoy myself at various social and cultural events, including concerts, plays, and parties. These events lift my spirits. Some of these events also have spiritual dimensions, fostering connectedness to others (Park, 2005, 2007). Being around positive, life-affirming persons, while enjoying social and cultural events, helps me maintain a more harmonious emotional state. Physical, social, and emotional care have played equal parts in helping to improve my health-related quality of life, with no part overshadowing the other.

For me, healing the whole person also involved affirmation of my sexual orientation. My life as an African-American gay man was fraught with anxiety at times. Even though I had come out as a gay man in the early 1970s, being diagnosed with kidney failure in 1983 added another challenge to my existence. Egan and Kadushan (2007) speak about the multiple layers of oppression African-American lesbian, gay, bisexual, and transgender individuals face. In order to counteract those negative influences, I had to pursue life-affirming strategies to enhance my quality of life. These strategies included reading gay and African-American literature, attending African-American and gay pride events,

and becoming a member of a gay-affirming religious institution, which also had a history of supporting equal rights for African Americans and other persons of color. This certainly gave me a more positive sense of self, and helped restore a sense of wellness to my whole being.

HEAL THYSELF

As for the role individuals play in helping to heal themselves, Epstein, Senzon, and Lemberger (2009) identify a healing paradigm that they term "reorganizational healing." In this model, they propose that disease can be viewed as an impetus for growth, enhanced awareness and, ultimately, an opportunity to become "stronger, healthier and wiser" (p. 475). Certainly, confronting the vicissitudes of hemodialysis for the past 28 years has helped me to become emotionally stronger, and perhaps wiser. Through these years, I may have declined physically somewhat, but I do feel stronger emotionally. Having to deal with venipunctures 3 times a week, sitting for treatments 3.5 to 4 hours at each session, and disciplining myself to a renal diet have given me an emotional toughness that I did not possess before.

Additionally, Jobst, Shostak, and Whitehouse (1999) aver that individuals can bring different perspectives to illness that totally reconfigure the patient/health care worker relationship. Over the years, I have developed an equal relationship to my health care workers. I view them as equals, rather than "superior" health care professionals. I feel that my knowledge of what it takes to live well as a dialysis patient is just as important as their technical expertise. I also emphasize to my health care providers that I am the most important person in the relationship. I assert my rights in the decision-making process. Initially, this may cause some strain in the relationship, but when providers see that I am serious about taking care of my health, they usually assent.

IMPLICATIONS FOR NEPHROLOGY SOCIAL WORKERS

In this narrative, I have attempted to illuminate how certain concepts embedded in holism have informed my journey as a hemodialysis patient. Specific narratives and life stories cannot be used to generalize beyond each situation (Neuman, 2009). However, I believe that my story does have broader implications for those in nephrology practice. Certainly, holism constructs would not seem to be foreign to nephrology social workers. Most social workers are trained to embrace theoretical constructs, such as the ecological, social systems, and strengths perspectives. The conceptual foundation of these theories and constructs certainly dovetails with holism (Dominelli, 2002; Ungar, 2002).

In order to use holism in the dialysis unit, nephrology social workers should be adept at urging dialysis patients to become more vocal about their own care. This means that social workers will have to become cognizant of and divest themselves of any paternalistic feelings they may have about their patients. They, and the other health care

providers in the dialysis unit, must begin to view dialysis patients as partners in the health care delivery system who, together, can make effective decisions about their own care (Johnson, Slusar, Chaatre, & Johnsen, 2006; Ungar, 2002). Thus, nephrology social workers should view dialysis patients as partners in the decision-making process, not as clients with little or no control over their situation. This would help to engender a sense of empowerment that would help dialysis patients navigate this complex health care process with a sense of self-determination.

In order for nephrology social workers to begin to see dialysis patients as partners, they must also be culturally sensitive and culturally competent (Spector, 2009). They must realize that all patients, regardless of their education, race, gender, sexual orientation, disability, and socioeconomic status, bring some strengths to the situation. This means going beyond the usual required online course modules. Nephrology social workers, in order to work skillfully and effectively with patients of different backgrounds, may have to leave their comfort zones and learn about other races and cultures through personal experiences, respectful curiosity, and self-education. Most of the social workers whom I have encountered in my 28 years on dialysis have been white females. For the most part, they were compassionate, caring, and understanding. However, I did encounter one who was seemingly not that empathic and appeared to be insensitive to the plight of African-American men and the challenges they face. This social worker seemed so indifferent to the plight of African Americans on dialysis that she neglected to cover the evening shift, which was composed of many African-American men. Subsequently, the patients complained to the Renal Network and she did begin to see the evening shift patients, although seemingly reluctantly. Consequently, when African-American men constitute the largest racial and gender group receiving hemodialysis (United States Renal Data System, 2009), one has to ask what can the profession do to encourage more African-American males and other people of color to join the field?

Also, for patients to live well and holistically on hemodialysis, nephrology social workers must ask patients questions regarding the overall meaning of hemodialysis in their lives. The Kidney Disease Quality of Life (KDQOL) survey helps social workers ask patients about the changes they would make to improve their lives. It not only involves social workers asking about patients' social situations, but also how their physical and spiritual lives connect with the other parts of their beings. Social workers also determine from patients whether they want to live healthier and more enjoyable lives, and what it would take, from the patients' perspectives, to achieve that goal. Furthermore, nephrology social workers ascertain from patients the extent to which they wish to be involved in and participate in their own treatment decisions. Regarding implications for policy from my narrative, Epstein et al. (2009) and Williams (2008) assert that opportunities and resources must be made available to individuals with chronic health conditions in order for them to live full

lives. These include educational and training opportunities, safe and affordable housing, and access to preventive health services.

Additionally, Epstein et al. (2009) assert that these individuals must also be resourceful in seeking out the best courses of action for their well-being. Admittedly, I may have had an advantage in this regard as opposed to many other hemodialysis patients.

When diagnosed with kidney failure in 1983, I already had my master's of social work degree, having obtained it in 1975. Because of my educational background in social work, I may have also had more insight into how to navigate the resource network in order to sustain myself. Relative to opportunities, I was given the chance to teach as an adjunct professor in a school of social work, to work as a research assistant in a university-sponsored research project, and to supervise research assistants in a medical school research project. However, my greatest opportunity came when I was admitted to a doctoral program in a school of social work. Matriculation in a doctoral program in social work had been a goal since I had begun teaching as an adjunct professor in social work. However, it had seemed unattainable since I was on hemodialysis. Fortunately, I came to realize that placing limitations on my aspirations was self-defeating. Overcoming limitations was what ultimately led me to become successful in my quest.

Thus, nephrology social workers and other practitioners involved in the care of people on hemodialysis should continue to advocate for more enlightened policies that will assist them in their pursuit of life-affirming activities. This means that social workers must continue to advocate for the rights of patients to pursue employment or educational undertakings without being penalized financially by governmental agencies trying to assist persons with disabilities (Tremblay, Smith, Porter, & Weathers, 2011). These authors assert that receiving Social Security Disability Insurance benefits for a period of time and then losing those benefits after a trial work period has ended is a powerful disincentive to work for many recipients. This may be especially pertinent for younger people on hemodialysis who have not yet established a solid employment history or who wish to begin or complete an educational endeavor.

This narrative falls within the vein of single-participant qualitative research. As such, I believe that more qualitative research studies should be performed with hemodialysis patients. Most studies I have read of hemodialysis patients are quantitative in nature and may not capture the full breadth and depth of the lived experiences of hemodialysis patients. There are many ways of knowing and the various fields of qualitative research also contribute to this knowledge base (Neuman, 2009). Stories and narratives of hemodialysis patients can be powerful documentation as to their strength and resiliency.

CONCLUSION

In summary, I have attempted to tell my story through the lens of holism (Epstein et al., 2009). Through holism, I have intertwined the precepts of individual growth and change, healing the whole person, and the role individuals play in healing themselves. This has been *my* story; not all hemodialysis patients will make progress in the same way. Some have been too scarred emotionally and physically to recover from the devastating effects of end-stage renal disease, along with discrimination, lack of understanding, and other societal problems. However, there will be some with this illness who will want to live full and vibrant lives. It is with these patients that nephrology social workers will be most successful. I hope my story further enlightens and educates nephrology social workers and other professionals on how to assist patients who wish to live holistically while overcoming obstacles.

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