



FAITH THAT GOD CARES: THE EXPERIENCE OF SPIRITUALITY

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Abstract: *Given the high prevalence of End Stage Renal Disease (ESRD) amongst African Americans, this article will explore the significance of faith, spirituality, and coping in the management of mental health concerns with African Americans receiving hemodialysis. The findings of the study from which this article is drawn points to the identification and use of spiritual assessment tools as a guide for clinical social work practice. Spiritual assessments may help identify the strengths of spirituality in the development of positive coping skills in patients diagnosed with chronic or end stage illness within populations for whom spirituality may be a significant factor.*

Key Words: faith, spirituality, coping, spiritual assessment, prayer, chronic illness

Introduction

Given the high prevalence of End Stage Renal Disease (ESRD) among African American populations, this study expands the existing literature regarding the treatment of African Americans experiencing ESRD by exploring the meaning of spirituality as a component in mental health treatment for clients with this disease.

Chronic kidney disease (CKD) is a public health problem of increasing importance, consuming a growing proportion of health care resources. It is estimated that in the United States there are 19.2 million individuals with CKD, and this figure is expected to increase in parallel to the rising prevalence of hypertension and diabetes, the most common causes of ESRD (United States Renal Data System, 2013). While renal disease may persist for years, at its end stage kidneys are not able to function at a level necessary for daily life. A few of the symptoms indicating the kidneys are no longer functioning include poor appetite, vomiting, bone pain, headache, insomnia, persistent itching, and change in mental status.

Considering the devastating physiological impact of ESRD, individuals with this disease must also come to terms with key psychological issues related to loss of health, hopelessness, and increasing mortality. The bio-psychosocial impacts of the symptoms caused by ESRD are frequently the precursor for depression. Depression has long been identified as the primary mental health problem of patients with ESRD (Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008). According to Cukor, Peterson, Cohen, and Kimmel (2006), life on dialysis is an ongoing challenge and often leads to frequent occurrences of depression and/or depressive symptoms; findings indicate that over half of the patients in their study met the DSM criteria for depression. With depression further

reducing the quality of life and creating a negative clinical impact on persons with chronic illnesses such as CKD and ESRD, acknowledgement of the significant physiological and psychological effects of ESRD on the individual, and ultimately on his/her family, creates an imperative to find treatment and sources of strength and support of coping strategies for individuals experiencing this illness.

Spirituality as a Coping Mechanism

Due to the high rate of African Americans diagnosed with diabetes, CKD, and ESRD it is necessary for mental health clinicians and social workers to learn much more about how best to treat and support African American ESRD clients and their families utilizing culturally relevant strength based approaches. Stewart (2004) states that to produce positive outcomes for any client, it is necessary for human service professionals to develop some understanding of the sociocultural context of the clients with whom they work. Stewart further states that when working with African American clients, a basic understanding of Afrocentric thought can help to contextualize the experiences and behavior of the client. For many African Americans, one vital aspect of making sense of severe illness is spirituality (Smith, 1999). Clinicians may find that spirituality provides a vehicle for helping African American clients cope with and make sense of the challenges posed by ESRD. Individuals faced with the distress, struggle, and conflict created by chronic illness may search for relevant meaning and purpose in life through spirituality.

For numerous clients diagnosed with chronic and life limiting illnesses, spirituality has had a deep and meaningful effect on and in their lives. What is distinctive about the spirituality of African Americans is that its roots are African, which denotes a historical tie to a rich heritage of spiritual beliefs and practices, and its anchor is in American

slavery, the spirituals, and continued creative responses to suffering (Smith, 1999). Spirituality has served as a conduit of hope, a stress reducer, and supportive element. This is particularly relevant to African Americans whose world view stipulates that all things are interconnected; human beings are spiritual; individuals cannot be understood separately from their collective identity; mind, body, and spirit are one, equal, and interrelated; and spirituality and faith are considered an integral component of all aspects of life (Graham, 2002).

Scholars such as Rowe and Allen (2004) indicate that individuals faced with the distress, struggle, and conflict created by chronic illness may search for relevant meaning and purpose in life through spirituality, particularly if these conflicts are unresolved. Folkman and Lazarus (1988) indicate that how individuals cope with chronic illness is quite important to functioning and quality of life. Pargament and Ano (2006) state that when persons are faced with medical illness, many turn first to their faith for hope, comfort, strength, meaning, and a sense of control, social support, and spiritual support. A number of other scholars (Albaugh, 2003; Greenstreet, 2006; Mattison, 2006; Morgan, Gaston-Johansson, & Mock, 2006; Nichols & Hunt, 2011; Pargament, 1997; Pargament, Koenig, & Perez, 2000) have noted the significance of spiritual wellbeing in the lives of those facing chronic and debilitating illnesses as a positive coping mechanism. In the author's work with numerous clients diagnosed with chronic and life limiting illnesses, the observations are that during these challenging times spirituality has had a deep and meaningful effect on and in their lives. Moreover, the author has observed the struggles clients experience with the effects of their various illnesses, and has often become the

sounding board for the deeply reflective questions to find meaning in the struggles and suffering they experience.

Concern about the impact of chronic illness on and in a person's life includes more than the effects of socioeconomic status, the patient's social situation, or perceptions and responses to the diagnosis and treatment of diseases. It also includes concern about the client's response to the deleterious effects of chronic illness that may spark the interest of researchers to gain a greater understanding about the relationship of the psychosocial-spiritual aspects of chronic illness to gain a more holistic approach to care. This approach may be of significant interest to practitioners working with populations for whom illnesses such as CKD and ESRD are most prevalent. To that end the basic biopsychosocial assessment may be inadequate. The inclusion of a spiritual assessment may aid the social work clinician in helping the client to not only identify the genesis of the concerns related to the chronic illness, but to also reflect on how their beliefs, values, and spirituality assist in confronting their concerns.

Methodology

A qualitative phenomenological study was conducted with a purposive sample of 12 African American End Stage Renal Disease patients to elicit their use of spirituality in the midst of this life limiting illness. The study participants elucidated the significance of spirituality in their lived experience as a way to cope with the vicissitudes of ESRD and hemodialysis.

Findings

Three overarching themes and seven subthemes emerged from the data. The overarching themes were (1) Faith that God Cares; (2) Finding Meaning in Ailment/Pain; and (3) Support of Family and Others. Faith that God Cares is the primary focus of this

article. Faith that God Cares indicates the importance of spirituality as inter-connective with both external and internal factors. The four subthemes which emerged from the overarching theme include:

- a. Prayer develops faith and strength,
- b. Faith nurtures spirituality,
- c. Faith develops strength through prayer,
- d. Faith supports coping and hope.

Faith that God Cares is best understood by considering the concept of faith as expressed by the aggregate of study participants. The faith expressed by 10 of the study participants seemed to grow out of a conviction based on past experiences. These are experiences they had with God, which helped them to believe God could be trusted to fulfill His promises even if the promises did not look like what they may have wanted. The faith of these 10 participants seemed to transform them from the inside and helped them to see themselves as survivors and not victims. Examples of discovering and living their faith are shared by three of the study participants. One participant indicated “My faith as far as trusting God everyday becomes a little bit easier because I know that it is God that gets me through this”, whereas another participant stated “I thank God and I pray to God every day to help build my faith because without His help and guidance I would not have gotten this far.” A third participant expressed that “I sit and wonder sometimes on where I could be and where I’m at today, and I thank God.”

For these study participants, the foundation of their faith appears to emanate from the belief that God or the divine would bring them through whatever challenge they faced. The issue then becomes the strength of one’s foundation, and 11 of the study

participants expressed the belief that there is no foundation stronger than faith in God or a divine being. This belief is expressed by seven of the 11 participants. One participant indicated “It’s (faith) the only way I make it through with dialysis or anything, any illnesses, problems that I have or whatever.” Another participant believed that if you “put your faith in God, he’ll do everything.” Still another participant professed “If you just have the faith and belief, God can do anything. But you got to trust Him,” and this participant declared “I put my faith in Him before I put it (faith) in another person. And so I have strong belief in faith”. Three participants proclaimed their belief regarding faith in the following terms: “Having faith, having faith gives me strength”, “You just got to have faith; He’s going to bring you through it,” and “If you have faith the size of a mustard seed; a mustard seed is real small, and that little bit of faith will get you through.”

Another aspect of Faith that God Cares is the concept of being cared for. Caring will endear people to one another, and in the face of adversity and struggle, being cared for is necessary and in many instances life sustaining. Being cared for and cared about is described by study participants as a relational process that includes trust, faith, and a core belief that God cares. God’s personal care for people who are confronted with adverse life experiences is expressed through statements made by six study participants. For two of these participants, the knowledge of God’s care is expressed in these words: “I know that God cares about me, because I could have been gone,” and “God is there for me, 24/7. Seven days a week, He’s there.” Another participant voiced God’s caring in relationship to his physical experience, “If it wasn’t for God, I would not be able to deal with these needles the way that I do.” Another participant spoke to her lifelong

experience with the care of God, “This disease brings many challenges to your life; age does not have anything to do with it. I have had this illness as a child; through prayer, help from friends and family and God I have made it to this point.” A male study participant expressed his gratitude for the provision of God’s caring, “I just appreciate the day that God has given me. I do not focus on the dialysis. I am just thankful,” and he said “I put my trust in God and stop all this worrying because in the good book (Bible) it says He cares.”

For many of the participants, trusting in God helps them in not becoming anxious about their illness and what the future may hold, which has helped them to experience the care of God. Thus, the essence of the lived experience by these study participants is that faith is not about what I know, but about who God is. Their belief and faith in a God who cares indicates that although they may not see the physical evidence of their faith through a healed body, the substance of what they have hoped for is present in their ability to function in spite of the difficulties of the disease. Ultimately the belief and faith that God cares becomes the foundation through which strength through prayer emerges

Sub-Theme 1: Strength through Prayer

Eleven study participants expressed their need for prayer as a way to face the diagnosis of ESRD, along with the challenges one must confront in making decisions about dialysis. The following statements by six of the participants demonstrate that decisions about dialysis required an inner strength they felt could only be accessed through prayer. The first participant shared his decision making process, “When he (doctor) first told me about my choices, I stayed up all night. I prayed, I read the Bible; I talked to God all night until 5 in the morning. I finally felt strong enough to make a

decision.” Another participant expressed his feelings this way; “So again it is my prayer life that gets me through this.” The study participants expressed a sense of tenacity with the decision to do dialysis as well as the experience of dialysis: “And I pray, but I just bear it too.” “I sit down and I had to pray a lot, because I want to live, this was not an easy decision to make.” “You know praying, it helps a lot, praying helps to give me the strength I need to go through this process (hemodialysis).” Another participant shared her concern about the process of dialysis, “There’s another thing, praying, because when I come to renal dialysis I hope there’s not a human error that would disrupt my treatment and cause me to be an inpatient or death.”

Strength through prayer presents as an integral connection to Faith that God Cares and may be exemplified through the scriptural reference to strength found in Isaiah 40:29-31: “He gives power to the weak. And to those who have no might He increases strength” (Life Application Bible, p. 1242). One participant indicated that his ability to traverse the illness would not have been possible without his dependence on God: “I had to depend on God more because of this illness that I have, but I realized that with God all things are possible and I am able to make it even with this disease, I am able to make it.”

ESRD is a physically, emotionally, and psychologically debilitating illness which for many study participants created a feeling of weariness. The weariness of the illness has at one time or another caused each of the study participants to feel as though they could not take another step. However, this did not hold true for every participant. One participant who did not identify spirituality as a significant experience for him focused on his capacity to be self-reliant and kindness toward others as the key to his ability to live with ESRD. He stated, “When you do right, something good happens to you, not always

the way you want but something good will happen for you, so I believe that I have to rely on myself and hope for the best.” Another participant vocalized a rather unambiguous perception of spirituality,

Spirituality is a belief in someone you should serve. My wife, entire family are involved in church. My background is in the church as is my wife's, she has gotten our family involved in the church. I am not as involved as she is; I feel like my wife's involvement places me on display. I often read the material she reads, unbeknownst to her. I just do not want her to force me into what I am not ready for. My use of spirituality involves being around my wife and family, I try to keep prayers at the dinner table, we read spiritual books. I attend some of the programs at the church. I try not to curse, and try to live my life in a better way. I try to be less argumentative, and have my children grow up with structure. I try to cope with my illness from a spiritual perspective by praying in private and believing that HE (God) hears me.

With the exception of two participants, the belief that prayer provided the strength to sustain these participants through the weariness of the illness is exemplified in their words. This study participant spoke directly to the strength and ability to cope gained through prayer, “Faith gives you strength, through prayer you can cope through the day. Strength is how I get through. Prayer helps me to keep the faith I have through this process. Prayer helps me to make sure that the techs are in a good mood and have a good spirit that will take care of me during this process. Prayer and hope are the keys to my coping.” Another participant testified to her dependence on spirituality this way, “I use my spirituality as a crutch, hmmm, you know if some people might say I am a Jesus freak or whatever, but I don't care cause I been on the other side you know. Last year this time I was considered gone, but I know He (God) is for real and I see what He (God) can do. So I pray and use it (spirituality) as a crutch and lean on it every day.” The need to incorporate prayer on a daily basis is expressed by this participant, “I pray all the time asking God to give me the strength to deal with what I have to go through in a day.

Because every day is something, just seems like anything could happen so in this world we live in now. I always pray for myself and my family to get me through the day, I take it day by day”. Yet another participant spoke to the strength gained through his spirituality as the only way he could cope, “Well just having the spiritual strength that I have, because there was a time when I wouldn’t be able to deal with this. So that’s why I know there is a God because I would not have been able to do this thing (hemodialysis) three times a week,” and this participant gave expression to how he is able to now accept what he must face on a daily basis, “I pray often and ask the Lord to give me strength. I think over the years I just know, seen myself go through so much and I just accepted it now, I mean, well it is what it is and I ask the Lord to help me deal with it and He (God) has. I don’t like it but I’ve accepted it and through God, through the strength of my spiritualness, it gets me through”.

How prayer was useful in helping the participants to adapt to their illness was another part of this subtheme. The frequent need to adapt to the changes ESRD causes can create a drain on one’s emotional, physical, and psychological strength, thus the use of prayer by participants has proven to be both supportive and strengthening. Prayer was the method most used by study participants to assist them in making the necessary modifications in and throughout the lived experience of the illness. Comments made by four of the study participants addressed prayer as a way to adapt to the challenges of the illness. For instance, one participant expressed, “Prayer is very helpful. It calms me, and gives me peace,” whereas another participant indicated, “You got to pray, first and foremost. Praying is a natural thing in my household; it is what helps me and them to face these problems that this sickness brings”. Yet another participant stated, “My prayer life

is important to me because that's the communication that I have between this great God of mine, so that's why it is important to me." Lastly a participant emphasized, "So again it's my prayer life that gets me through this."

In Christianity, as well as other faiths, believers may ask God/Divine being to act in the natural world in any number of ways. Numerous biblical examples of petitionary prayer and instruction regarding prayer include the faithful asking God to work in mechanistic, biological, and psychological ways. It seems that as long as the petition is offered in faith and in accordance with the will of God, any mode of divine action is potentially acceptable. One study participant shared her experience with asking God to provide a home for her when she had to move from a building that was in disrepair and could not accommodate her wheelchair. The participant stated,

I was going through the worst time in January. My house was falling in and I didn't know where to turn. I couldn't tell you what I was going to do. Now I remind you I have a 9 year old, a 13 year old, and a 15 year old. But I had nowhere to live. And I prayed about it and I talked to God about it, and low and behold, it wasn't in my time, but it was done. I got a brand new house. So God is good to me and I give Him the praise and the glory. I have a brand new house, a new location, a better house than what I had. The man (God) is awesome. You just got to have faith; He's going to pull you through it. And just when you feel like it's a hole coming down to swallow you up, there he (God) comes, and I've been in my house now for six months. Not only have I been in it, I own it. God is awesome".

Thus for these participants when God is understood as caring and strengthening, prayer then becomes the vehicle by which they accessed the faith that helped to support their ability to cope with the harshest realities of their illness.

Sub-Theme 2: Faith Supports Coping

The manner in which a chronically ill person copes with the consequences of his/her illness plays a major role in his or her adjustment to the illness. Ten of the study

participants spoke of their faith as a supportive mechanism for coping and their ability to adjust to the changes created by ESRD and the experience of hemodialysis. Faith is conveyed as a relational process that includes church, prayer, self-control, and reliance on God and others. The active engagement in church is expressed by one participant this way, "I try to cope with my illness, my health, and sometimes I pray two or three times, with people from the church." Five participants' use of faith as a mechanism in self-control was expressed through the following practices. The first participant spoke to the issue of keeping her mind focused so as not to dwell on negative thoughts, "I have had to guard my mind on a regular basis because if I don't, I can dwell on what's wrong, my faith helps me to keep my mind focused." Another participant addressed the issue of remaining consistent with dialysis treatments, "I actually had to pray and say, God, I need you to reset my mind on dialysis." Yet another participant conveyed the importance of prayer as a way to not feel self-pity, "I can't complain because when you complain you have to think that somebody is worse off than you, I always keep that in mind." Another participant spoke to how the use of spirituality along with reading the Bible assisted him with making the changes he needed to make in his life, "I use it (spirituality) because like I said at one time I was doing a lot of things and I mean a lot of things I should not do until I started to pick up the book (Bible) and started to read it, and from that point on it was like all of the mayhem and mischief that I was doing slowly left my mind and my body." A participant used gospel music to cope with the dialysis treatment, "I keep my head busy by listening to my gospel music while I'm sitting in that chair (dialysis) rather than just sitting there and going to sleep, listening to my music and reading my Bible helps me to not focus on what I have to go through," but for another participant, hearing

the songs of the birds in the morning provided him with the motivation to get up and move into the day, “Listening to the birds early in the morning helps me to get up and appreciate the God that has kept me here one more day, listening to the birds.”

Participants spoke to their ability to incorporate their faith as a coping mechanism through their dependence on God and others. “I began to stop doing what I wanted to do and began getting some information and learning some stuff and talking to some people,” and “If I didn’t believe in everything that my God tells me, lets me believe, and not just what they (doctors) tell me, then I would have probably not gone to dialysis. I would have given up and just let it go and probably wouldn’t even worry about it. I probably would have been out there doing whatever, that’s what my spirituality means to me.”

For the following three participants the strength of their belief is a significant factor in their ability to cope with the challenges of ESRD. They conveyed their beliefs in these comments, “I think if you don’t have it (spirituality), you can’t cope with it (illness).” “If it weren’t for God none of this (dialysis) would be possible, I wouldn’t be sitting here, and I wouldn’t be able to deal (cope) with my illness the way I do.” The third participant stated, “Dialysis makes you strive to live longer and harder so that you do what you have to do to want to be here. If you cope with them (illness and dialysis) on a spiritual basis you can go far”.

For 10 study participants, the spiritual practices of hearing the word of God through music, the Bible, and nature have become the coping mechanisms by which they have been empowered to make the necessary and demanding adjustments in their lives. For 11 study participants whose coping strategies emanate from within a spiritual context, it appears to speak to a trust that God will always meet their needs, even if it is

the need for courage to face death. Although they were not asked about how they felt about death and dying, the ability to face the ultimate end was addressed rather candidly by three participants. The first participant stated, "My belief in a God helps me; it also helps me to face my end." The second participant who addressed his death made this rather succinct remark, "If it's my time to go, it's my time to go. I said, just like I told them (doctors) I put my faith in Him (God)." The third participant conveyed his gratitude for the life he was able to live with dialysis, "I thank God for the dialysis and the staff that he gave me to do what need to be done, and I just live life as much as I can to the best I can."

One study participant who did not express a belief in the concept of spirituality made this statement regarding his preparation for dying, "I don't want to die; I'm not ready to go nowhere. I need a little bit more sit down time with me and the Lord and ask for forgiveness and maybe start to be involved with the church a little bit more so that I can at least have some friends at my little funeral." Even in his ambivalence regarding spirituality, he conceded that perhaps there is some comfort in knowing that by becoming involved with an entity that could provide forgiveness; he might find peace in his life. It is the desire of all people to feel good and avoid discomfort or pain, but for many people - particularly those whose lives are impacted by the vicissitudes of a devastating illness such as ESRD - living a life without pain and discomfort may not be an option. Thus the ability to trust in God or a Divine being whom they believe can supply all their essential requirements and meet them at their level of need is a crucial element in the development of empowering their coping skills.

Sub-Theme 3: Faith Nurtures Spirituality

To nurture is to care for, to nourish, to educate, all of which can support physical, emotional, psychological, and spiritual growth. Eleven of the 12 study participants indicated that their trust and faith that God cares has nurtured their spirituality. The process of spiritual instruction and nurturing for the 11 study participants frequently occurred at home and within the church. Attending church, listening to sermons that emphasize hope and faith in a caring God, along with participation in Bible studies that teach the importance of learning and applying the word of God to life's challenging situations, has for them provided the foundational nourishment which develops their spirituality. Remarks made by four study participants are presented in an effort to share their experience about their interaction with the church and its influence on their concept of spirituality. The first participant spoke to the transformative experience he had with the church once he overcame his initial reluctance, "I wasn't into spirituality at first. After this (ESRD and dialysis) happened, it took me a while to start going to church, but my nephew and my sister, they're very religious and afterward they kept saying come to my church. This is his church as a matter of fact that we all start going to. I started to go to church and listening to the preacher, I felt better, although I wasn't better I began to think different and feel different so I felt different." Another participant shared the positive impact of how being taught to read her Bible and going to church has provided comfort for her through life's challenging situations, and how she is transferring that knowledge to her grandchildren, "When I get up in the morning some people want to know why I am so jolly, why I'm smiling all the time. Yeah, there are illnesses and all that, my daughter tells me, you ain't never had no attitude, you're always smiling. I tell her I read my Bible

every night. I read the 23rd Psalm and I pray it every day. My grandmother taught me and I tried to teach them. I teach my grandchildren. In fact my grandson reads it from the Bible in church. I try to teach them that learning the word of God and going to church is good.” A third participant is a beneficiary of his wife’s involvement with church and his spiritual interest and growth can be attributed to her, “Being around my wife and her family, we say our prayers at the table and we’ll sit there and read the spiritual books, I want to learn about the God she talks about all the time.” Lastly, a participant conveyed the significance of the hymns she learned at church and the comfort they provide for her as she goes through the dialysis treatments, “I hum hymns all the time, they call me the hummer. I hum the songs, hymns I learned in church. They help me to go through this dialysis. Old hymns from the church, you know the ones I mean, Rock of Ages, and Come Ye Oh Disconsolate (laughs), those old hymns and hearing them helps me and they help the others too.” Thus, the significance of the role of church, spiritual music, and Bible reading as experienced by these African Americans faced with the life-limiting diagnosis of ESRD are indicative of strengths accessed in times of stress.

If life results in growth, then it would also be true that spiritual life results in spiritual growth. For at least four of the study participants, spiritual growth is a result of understanding and practicing the foundational principles that are given in the word of God. These four study participants believe the word of God is not simply a collection of words in the Bible from God, but a vehicle for communicating ideas. They describe what they learn from the word of God as life changing and dynamic as it works in them, penetrating the core of their family, moral, and spiritual lives.

The first participant expressed how learning the word of God has helped to decrease domestic tension in his home. This is significant because the mercurial hormonal shifts caused by ESRD do in effect impact one's emotional stability. "Learning about the word of God has helped to decrease the arguments in my home, it also provides some structure for our kids, and we had structure when we were kids, so I guess it is working out for us." Another participant realized that he perhaps could not make the journey through this illness on his own and offers this insight, "I had to start getting connected to with somebody greater than myself and I found it in God". For two other study participants, relationship with God was of great significance, and that relationship was developed through reading the Bible, "Just reading the word, it just builds on your relationship with Him (God)," and "Spirituality, it means having a relationship with a God who created the universe and just realizing that His love letter to us is in His Bible.

Thus, for these study participants, the relationship developed with God/Divine who cares is garnered through the word of God and is an essential Spiritual process by which a person can grow and learn from both good and bad experiences. However, some life experiences can become so challenging that one may not see if there will ever be light at the end of the tunnel. It is at these times that the concept of hope becomes a reality.

Sub-Theme 4: Faith Develops Hope

Hope is not a static, but a dynamic process that often changes minute by minute and day by day. "Hope is what helps to keep me living," was a statement made by one participant for whom the illness process has made life a struggle. Hope helps us live with a difficult present and an uncertain future. Hope is particularly relevant to the ESRD population because of their need to adhere to inflexible dietary and fluid restrictions that

perhaps less hopeful people would find rather difficult to cope with. In addition to inflexible physiological restrictions, the conflicting demands of dialysis regimen and work/family/social life are a complex and often overwhelming process.

Hope is expressed by four study participants. The first participant referred to how prayer and hope aided her to continue moving forward after dialysis treatments, stating “And so when I walk out of here and go home, though I lay down but I know I can get back up and not be bedridden by any type of other problems that I already have. So by praying and hoping that everything is fine I continue to move forward.” The second participant’s comment is succinct yet filled with hope, “I hope and I pray that I can get a kidney.” A participant who has experienced a failed transplant continues to hope for another chance at a normal life, “I have had a kidney transplant before, but it failed; but I continue to hope that when they do my blood work it is good enough that I will get another call that I can get another transplant, so I can go back home with my daily life which is not spending three days in here.” The final participant made a declarative statement about what hope is to him, “I know there is hope. Hallelujah there is hope, there is hope.”

The things most hoped for by these study participants is a continuation of the health they do have, the hope for a renewed life through kidney transplantation, and, most significantly, that hope exists for them. The diagnosis of ESRD will ultimately bring with it the constraints of dialysis and the inflexibility of lab work, diets, and restricted fluid intake. Thus the significance of spirituality, along with hope, for this population is of preeminence so that it may support them throughout the process of dialysis treatment,

potential declines in health, and the possibility of not receiving a much hoped for transplant.

Three study participants expressed their hope in a God that is always present, especially in the ups and downs of their illness, which provided them with something to hold onto and something to hope for. The first participant spoke to how even in the transitions of the illness God is always there, “We have our ups and downs, but it’s all right as long as God is there”. A second participant addressed how significant holding onto God who holds onto him has been, “This God of ours, when it seemed that all was lost and I had nothing else to hold onto I realized I had God to hold onto”. Lastly a third participant’s hope extends to his ability to return to a productive life, “So I went yesterday and looked at the pickup truck, and it needs a little work, but the guy is fixing the transmission, and he’s going to give me that (truck), so I can start doing the things I used to do with the truck, I could not have hoped for more. I already feel productive again.” The hope of many ESRD patients is kidney transplantation. Even if transplantation is not in their future, the hope of being productive once again provides meaning and offers purpose in their lives.

Objectives: In an effort to empower social work clinicians in their work with African American ESRD clients I would recommend: 1. the use of culturally relevant spiritual assessment tools to identify the significance of spiritual beliefs and values in the life experience of the client. 2. The inclusion of the client’s faith, spiritual beliefs and values in identifying positive coping strategies. 3. The incorporation of the client’s beliefs and values in the process of identifying and developing the key components to authentic empathic therapeutic relationship.

The next step in an effort to empower social workers and mental health workers in this area of assessment I would recommend: 1. the inclusion of spiritual assessment tools in social work curriculums to expand the knowledge base of prospective clinicians. 2. The training of social work clinicians in the use of spiritual assessment tools in an effort to complete a more comprehensive bio-psycho-spiritual assessment of client needs. 3. Along with imparting the necessary knowledge about the importance of assessments in the establishment of adequate measurement tools to effectively gauge the outcomes of the inclusion of spirituality in the therapeutic process.

The last step in further empowering social work practitioners in their work with African American ESRD clients is to 1. Train social workers and mental health clinicians in the practice of presence through contemplative practices. 2. Assist social workers and mental health clinician's to employ the practice of presence in the development of spiritually sensitive therapeutic relationships. 3. To incorporate the practice of presence as a way to effectively engage and service clients from an authentically empathic perspective.

In review, the three specific aims of this research study were to (1) Describe how African American ESRD patients who are on dialysis experience spirituality in the management of their illness; (2) Increase the understanding about the role and meaning of spirituality when African American ESRD patients face the multiplicity of challenges which are a part of this chronic illness; and (3) Gain information which may help guide future clinical interventions that incorporate a patient's use of spirituality in their treatment process. Information gained from this research study is important because of the higher incidence of chronic illnesses such as diabetes, hypertension, and Chronic Kidney disease which are the leading causes of End Stage Renal Disease (ESRD) among

African Americans. African Americans are four times more likely to require hemodialysis as a long term treatment approach for ESRD than are whites (Barbour, Schacter, Lee, Djurdjev, & Levin, 2010). Current statistics offered by the United States Renal Data System (2013) annual report indicate the incidence of ESRD in the African American population has finally started to decline overall and for ESRD due to diabetes. Among those ages 20-39, however, differences between whites and African Americans continue to be dramatic, with rates among the latter up to 3.8 times greater. Rates are also considerably higher for African Americans age 60 and older than for their white counterparts, though the gap is narrowing. Given this factual information, it becomes imperative for clinical practitioners who treat African Americans with ESRD to understand their lived experience and the aspects of their experience which empowers their capacity to endure. The recognition and inclusion of spirituality in research may serve to create a more holistic and supportive approach to the provision of services for this population, which may prove beneficial in their overall care and treatment.

Faith that God Cares

Faith that God Cares nurtured the participants' spirituality by helping them to develop hope, which supported their ability to cope with the many physiological and psychological challenges and changes of ESRD and thrice weekly hemodialysis treatments. For the 10 study participants, the transformative nature of spirituality led to the development of an affirmed sense of self and an altruistic approach to life. For seven of the 10 study participants, the challenges and changes they faced throughout their experience with ESRD spoke of how their spiritual relationship with God affirmed them as functional and productive versus disabled and debilitated. One of the most significant

concepts from this research study is the influence of faith on many of the study participants. For 10 of the study participants, faith that God cares was not necessarily grounded in a particular faith tradition, but in a belief fostered through a relationship with God/divine. For four of the study participants, their relationship with God began with grandparents or elders who introduced stories about God and taught them to read the Bible and how to pray. Each of the 10 study participants talked about their relationship with God, which seemed to evolve from experiences with God, creating a trust that - no matter the circumstance - God would bring them through. In a concept analysis on faith posited by Dyess (2011), faith is an evolving pattern of believing which grounds and guides authentic living and gives meaning in the present moment of interrelating. Interrelating with a God that cares will increase one's faith and develop hope.

Faith that develops hope and support coping are two of the sub-themes identified under the major theme Faith that God Cares and as such are highlighted as integral elements in the study participants' coping strategies. Wright (2007) conjectures that spiritual beliefs, which are the basis for the overarching theme Faith that God Cares, are specific though not exclusive to African Americans. Faith in a God that cares is believed to be the foundation of hope that undergirded the ancestors of African Americans through the middle passage, through slavery, Jim Crowism, segregation, the civil rights movement, and the disenfranchisement/marginalization of African Americans within the predominate culture (Noel & Johnson, 2005). If this level of faith in a God who cares could bring African Americans through the sufferings and trials of racial and economic discrimination, these participants seemed to believe they could place the same faith in a God who cares to help persons who are facing a life limiting medical diagnoses such as

ESRD. Although this concept of faith may not apply to every African American, for 10 of the participants in this research study, the belief in Faith that God Cares emerged as a primary theme serving as the rhetorical umbrella or overarching theme from which the concepts of coping and the development of hope emerge.

Hope in the face of struggle, pain, and life challenges can provide one the tenacity to keep moving forward; as one participant noted “hope is what keeps me living”. For the participants of this study who are facing a life limiting and disabling illness such as ESRD, hope can lead to one’s capability to see children grow up, hope may engender the belief that the illness may abate for a time and permit them to attend a loved one’s special event, and hope that tomorrow will be a better day may be life sustaining. The manner by which Rice (2000) conceptualizes hope provides a descriptive metaphor for the way hope may be experienced by those for whom hope may at times seem fleeting:

The rainbow is God’s promise of hope for you and me. And though the clouds hang heavy and the sun we cannot see. We know above the dark clouds that fill the stormy sky, Hopes rainbow will come shining through when the clouds have drifted by.

Faith that God Cares then becomes the rhetorical umbrella that protects one from the clouds and storms of hopelessness and despair, providing the ability to see the rainbow of hope for tomorrow. A hope which finds its roots in a faith that God cares may help participants live with a difficult present and an uncertain future (Edey & Jevne, 2003). This degree of hope emerged as a coping strategy, empowering study participants to make the day-to-day adjustments created by ESRD and the strict treatment regime which is a part of it. According to Barnard (1995), hope is often expressed by what is called the paradox of chronic illness, which essentially means to “defy limitations in

order to realize greater possibilities and to accept limitations in order to avoid enervating struggles with immutable constraints” (p. 39). The constraints of ESRD are prevalent in the daily lives of anyone experiencing hemodialysis three times a week; constraints that limit food choices, the intake of liquids, and the ability to vacation in places far from home. These constraints frequently lead to illness intrusiveness (Devins, 1997), which exerts a powerful psychosocial impact on those with chronic diseases such as ESRD; in many ways negatively influencing one’s lived experience.

For the vast majority of African American ESRD patients participating in this study, hope rooted in faith that God cares has proven to be an advantageous coping strategy in that it appears to have sustained these study participants in and throughout their treatment process. Paradoxically, the results of this research study indicate hope seems to emerge from the suffering associated with the effects of ESRD. This level of hope for many of the study participants arose from the belief (faith) that God cares and would bring them through whatever challenge they faced in the illness experience. Faith that God cares seemed to help the participants of this study locate an inner strength that empowered them to effectively cope with the illness and continue to move forward even in the face of physical suffering. Faith that God Cares supports coping and develops hope was clearly one of the resilience-related consistencies of the participants in this study. The concept of caring will endear people to one another; in the face of adversity and struggle, however, being cared for is necessary - and in many instances - life sustaining. Faith that God cares appears to be a life sustaining belief for many of the study participants.

Discussion

Within the lived experiences of these 12 African American ESRD study participants, the results of this research study reveal areas of new understanding about spirituality which may be unique to African Americans. For 10 of the 12 study participants who expressed faith that God cares, this belief has helped them to develop strength through prayer as a way to face the vicissitudes of a life limiting illness. Four of the 12 study participants indicated the prayers of family members and others added an additional level of support that provided encouragement and strength. Five of the study participants shared that the debilitating effects of ESRD were such that at some point in their journey they required concrete assistance with tasks of daily living and housing; they believe the prayers they prayed regarding these needs were answered, which fostered the relationship they have with God and seemed to solidify their faith that God cares.

Implications for Clinical Practice

With the increase of ESRD within the African American population as documented by current statistics (United States Renal Data System, 2013), it is imperative for social work clinicians to become more actively engaged in helping patients who are experiencing the damaging effects of this illness to find positive coping strategies. The significance of spirituality should not dissuade social work practitioners from including the beliefs and values of persons who are experiencing such life challenging issues. Although spirituality is a core value of the Council on Social Work Education (CSWE), approaching such a personal topic can be disconcerting for both the clinician and the client. Hodge (2006) states that although the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires the administration of a

spiritual assessment and most practitioners endorse the concept of spiritual assessment, studies suggest that social workers have received little training in conducting spiritual assessments. The results of a national study conducted with social workers in 2001 indicate that “only 17% agreed or strongly agreed that social workers in general possess the knowledge to address religious or spiritual issues” (Furman, 2001, p. 5).

According to Derezotes (2006), in light of the paucity of training it is perhaps unsurprising that many practitioners desire to learn more about spiritual assessment. Perhaps this interest is spurred by the social work practitioner’s understanding that a spiritually oriented practice will help inform a holistic approach to treatment. The training that is offered is primarily through continuing education opportunities, which are not mandated. In spite of the limited training in spiritual assessment processes and the uneasiness this level of inquiry may pose for the practitioner, it is important for the clinician to be open to the patient’s spiritual experience and how that lived experience has manifested in every aspect of their lives. Five recently developed complementary spiritual assessment approaches are reviewed and offered as tools for clinicians to utilize in a given client-practitioner setting (Hodge, 2005).

- 1) Spiritual Histories are oral histories and are analogous to conducting a family history. According to Hodge, this form of spiritual assessment is most accommodating for verbally oriented people. The relatively unstructured frame allows clients to relate their stories in a straight forward manner without having to adapt their narratives to fit a particular diagrammatic format.
- 2) Spiritual Life Maps are more diagrammatic in their format. A spiritual life map is a pictorial delineation of the client’s spiritual journey. The spiritual life map is an

illustrated account of the client's relationship with God over time. The most basic of this process is a pencil drawing which includes the various trials faced, along with the spiritual resources used to overcome those trials.

- 3) Spiritual Genograms provide social workers with a tangible graphic representation of spirituality across at least three generations. As is the case with spiritual life maps, spiritually meaningful events can be incorporated, such as water and spirit baptisms, confirmations, church memberships, and bar mitzvahs (Hodge, 2001).
- 4) Spiritual Ecomaps, in contrast with the previously discussed assessment tools, focus on clients' current spiritual relationships. Spiritual ecomaps focus on that portion of clients' spiritual stories that exist in present space. This assessment approach highlights clients' present, existential relationship to spiritual assets. The heart of the spiritual ecomap is the relationship between the family system and the spiritual systems, which are represented by various types of sketched lines, much like those in the spiritual genogram (Hodge, 2005).
- 5) Spiritual Echograms combine the assessment strengths of spiritual ecomaps and genograms in a single assessment approach. Echograms tap information that exists in the present space and also information that exists across time. Echograms also depict the connection between past and present functioning. Historical influences on current systems can be seen as well as present relationships with historical influences.

An additional assessment option includes the FICA Tool for Spiritual Assessment developed by Puchalski, a physician in a Palliative Care program (Kilpatrick et al., 2005),

and The FACT Spiritual History Tool developed by Larocca-Pitts (2007), a chaplain at the Athens Regional Medical Center in Athens, Georgia.

As lifelong learners, information about spiritual assessment tools will expand the abilities of social work clinicians to service patients from a holistic perspective. However, simply learning about the aforementioned tools, albeit important, is not enough. Understanding which tool to use, when to use it, with whom, and how where the foundation of empathic attunement is grounded. If in the process of this study the author decided to utilize a spiritual assessment tool, she would need to consider the amount of time she had with the participants and their interest in engaging in either a structured dialogue or non-structured format. Knowing this information would assist in determining which tool would fulfill the required objective. A Spiritual Echogram or Spiritual Genogram would require a great deal of time and description to employ. If the use of a Spiritual life-map is considered, this spiritual assessment tool would not allow for the open free flow nature of a phenomenological process. Thus the selection of an oral spiritual history provided by the participant in an unstructured manner might create for the participant the willingness to share their spiritual experience, allowing for an in-depth exploration of the participant's spirituality. It might also create the opportunity for the researcher to be fully present in the moment in order to hear on a deeper level what the participant is saying, leading to the development of a more authentic and spiritually sensitive relationship between participant and researcher/clinician.

A spiritually sensitive relationship with clinical providers seems to be the perspective through which work with African American ESRD patients may prove to be most effective. In an effort to achieve such a relationship, the clinician must be open to

the process of examining and discussing the significance of spirituality with the patient even if this is an area in which the clinician may not be well versed. Canda (1988) conducted a series of interviews with 18 social work professionals from which he identified several themes that may help in providing insight relative to spiritual sensitivity in social work practice. The themes he identified indicate (1) spirituality was an integral part of the professionals' practice with their clients; (2) decisions about how to address religious or spiritual issues were dictated by the client; and (3) each of the social work professionals expressed an appreciation for diverse spiritual beliefs and practices while, at the same time, maintaining a strong commitment to her/his own faith and spiritual orientations. Based on these results Canda (1988) suggests "that social workers of various faiths and spiritual orientations can respond to the diverse spiritual needs and modes of expression of clients with sensitivity and affirmation" (p. 245). Therefore the development of spiritual sensitivity on the part of the clinician may be aided with the use of appropriate spiritual assessment tools and create the opportunity for an authentic relationship with the patient.

The authenticity of the relationship with the clinician appears to be a key element in work with African Americans, particularly when faced with medical challenges, such as ESRD, that will impact every aspect of their lives and the lives of those connected to them. It is from an authentic empathically attuned relational perspective that social work clinicians must begin to view the therapeutic work entered into with African American patients for whom spirituality is a significant factor. The multiplicity of issues faced by African American ESRD patients receiving hemodialysis are such that their emotional state, psyche, and sense of self are under attack by the depleting physiological

functioning of their bodies, along with the challenge of not feeling heard or being understood by the predominant medical culture. It becomes an opportunity for the clinician to understand and genuinely empathize with the cultural and spiritual experience of the African American client in order to enter the client's world, assisting him/her to find his/her own voice.

From a practice perspective, if one is to work with African American patients from a holistic and empathic focus, one must take time to learn and understand the present position of the patients in regard to their experience of spirituality. The process of learning about the patient evolves from a holistic perspective which is inclusive of a spiritual assessment. Implementation of a spiritual assessment tool such as the types mentioned earlier serves as a way of gathering information about the patient which would include spiritual beliefs and values. Utilizing a spiritual assessment would help to expand the overall valuation and make inquiring about the patient's spirituality feel less intrusive and a more natural part of the assessment process. The use of a spiritual assessment tool would be inclusive of every patient the social worker encounters, therefore not targeting only African American patients. However the inclusion of a spiritual assessment tool would allow the African American patient to experience the discussion of his/her spirituality as a more organic process and become the basis for an authentic empathic relationship between patient and worker. Canda (1988) indicates "spiritually sensitive social workers address clients as whole persons, applying professional roles, rules, and assessment labels in a flexible way that is responsive to the values of the client and his or her community" (p. 32).

The information gained from a holistic assessment will assist the social work clinician working with African American ESRD patients for whom spirituality is significant in identifying the strengths gained from the client's spirituality. In doing so, the clinician may better assist the patient in applying those strengths in times of overwhelming struggles during the course of his/her illness and dialysis treatment. The use of a spiritual assessment tool would not be indicated with the patient for whom spirituality is not a significant factor. However exploration of the patient's strengths and coping styles continues to be important for and with a patient for whom spirituality is not a significant factor. The exploration of the non-spiritual (or differently spiritual) clients' coping strategies should be a part of the overall bio-psycho-social assessment done by the clinician, and in doing so identifying the strengths of whatever their perspective is in assisting them with facing this illness and other life challenges.

As social work clinicians, we can be viewed as harbingers of hope by those for whom hope may seem transient. Therefore we must understand the importance of providing care from a holistic perspective. For many African Americans, spirituality is the foundation from which their lives are lived. According to Akbar (2004), the African views the person as spirit in his/her essence with the physical and mental components. Spirituality is the basis from which decisions about every aspect of their lives are made (Akbar, 2004). When faced with struggles that are life changing, many study participants referred to the Bible as their go-to guide for the values and principles which emanate from their conviction in faith that God cares. According to the study participants, this belief has more frequently than not been fostered by their past experiences with God. The foundation of this belief was verbalized by several study participants, either directly

or indirectly, throughout the intensive interview sessions. Prayers prayed to God, like personal requests made to someone with whom you are in relationship with, have proven that God cares. It is from this perspective that 10 of the 12 African American ESRD patients in this study have had their lives transformed and have developed an altruistic relationship with others helping to find meaning in the pain and suffering of the illness.

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