

#### BIOGRAPHICAL EXPLORATION

# Spirituality in the Lives of Patients with End-Stage Renal Disease: A Systematic Review

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Published online: 18 April 2018

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**Abstract** The aim of this systematic review was to answer these questions: What does spirituality means to patients with end-stage renal disease (ESRD)? And are there associations between spirituality and the health outcomes and general well-being of patients with ESRD? Thirty-three studies met the review criteria. Meaning of spirituality for patients with ESRD and spirituality in the lives of patients with ESRD were the main themes emerged. There is growing evidence that suggests a positive relationship between spirituality and the health outcomes and well-being of ESRD patients. However, the evidence is incomplete and there is a need for further research to enhance our understanding

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of the role of spirituality in improving the health outcomes and well-being of ESRD patients.

**Keywords** Spirituality · Religion · End-stage renal disease · Health outcomes · Quality of life

#### Introduction

The concepts of spirituality and religion and their connection to health are gaining more attention in nursing (Cruz et al. 2016d), especially in patients diagnosed with end-stage renal disease (ESRD). They have been shown to have a positive influence on patients' health and longevity, specifically to psychological, social and health behaviours (Koenig et al. 2012). Consequently, healthcare providers should take them into consideration when assessing, planning and implementing care for every patient and evaluating their effectiveness in terms of positive health outcomes. Despite all previous research about the importance of spirituality in health and the evolution of the healthcare paradigm, in terms of patient-centred care or the World Health Organization definition of health, patients' spiritual dimension and needs are often neglected in the care process by healthcare providers, including nurses (Baldacchino and Buhagiar 2003; Cruz et al. 2016b). The provision of ESRD spiritual care was addressed as a key dimension (Egan et al. 2015). However, in spite of this increasing force, the term spirituality remains somewhat difficult to conceptualize (McBrien 2006). Estanek (2006) argues that spirituality is included by religion, but some see religion as only one dimension of spirituality.

According to Murray and Zentner (1989, p. 259) spirituality is "a quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in any God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite and comes into focus when a person faces emotional stress, physical illness or death". In contrast, religion is described as a formalized set of beliefs, customs and practices. Religion reflects an individual's ostensible identification with a particular religious denomination (Baker 2003; McBrien 2006). However, these very rigid beliefs, customs and values of any formal religion operate against the principles of individuality (Henery 2003).

## Background

## Challenges Defining Spirituality

Research has focused on defining and conceptualizing the concept of spirituality (Pargament 1999b) and the measurement of spirituality (Miller 2004; Levenson et al. 2005) and explored the role of spirituality within a range of contexts such as the relationship between spirituality and health outcomes (Rippentrop et al. 2005; Tsuang et al. 2007; Schlundt et al. 2008; Park et al. 2009).

How spirituality relates to religion is one of the challenges associated with determining a uniform definition. The blurring boundaries in the literature between spirituality and other related constructs are another challenge in determining a uniform definition such as psychological well-being, social and subjective well-being (Keyes et al. 2002). This is an area that needs further exploration. A universal definition also remains difficult because of



the different perspectives relating to the right path or practice for exploring spirituality, including Dharmic (e.g. Buddhism), Monotheistic (e.g. Christianity or Islam), Indigenous (e.g. Celtic or Shamanism), agnostic and atheist. Considering the many paths available, it is possible that people's definition of spirituality might be influenced by their own experience or practice of the spiritual (Stifoss-Hanssen 1999; Nasel et al. 2005). Researchers also debate whether all spiritual experiences can be considered equal. This is another challenge in finding a universal definition of spirituality. It is arguable whether the spiritual experiences of historical figures such as Mohammed, Jesus, Buddha can be considered the same as those the "every-day" person experiences on his or her spiritual journey. Research proposes that all spiritual experiences cannot be considered equal with this premise based on varying depths of "consciousness" (Rosado 2000).

Lastly, for spirituality to be considered a universal phenomenon, an important question needs to be answered. That is, does spirituality need to be culture, socio-economic, gender, age or value neutral? Considerable research suggests that it is none of these things (Mansfield et al. 2008). Hence, a definition for operationalizing spirituality must account for the subjective, individual and personal explanation of one's spiritual experiences. Given the previous challenges, it remains no surprise that the identification of a uniform and operational definition of spirituality has proven difficult and challenging (Pargament 1999b; Miller 2004).

# **Different Definitions of Spirituality**

Maher and Hunt (1993, p. 22) propose that "what makes the process of defining spirituality so elusive is the nature of the term itself. It is value laden and seemingly so culturally, religiously and ethnically bound, that any meaningful definition appears to be an exercise in futility". However, the challenges associated with defining spirituality have not prevented an explosion in the development of spirituality measures. Hill and Hood (1999) carried out an extensive review of the literature and identified more than 120 definitions of spirituality. Yet, how spirituality is defined in the studies identified by Hill and Hood is a question that still needs to be answered. Unruh et al. (2002) also carried out another review of the literature to look into different meanings of spirituality and religiosity and identified seven themes highlighting how spirituality is defined in the health literature, including (1) transcendence or connectedness to a belief or higher being; (2) existential, not of the material world; (3) relationship to God, a spiritual being, a higher power, or a reality greater than oneself; (4) not of the self; (5) a life force of the person, integrating aspect of the person; (6) meaning and purpose in life; and (7) summative, including definitions that included many of the above-mentioned themes, as well as values and motivations.

The National Interfaith Coalition on Ageing in the USA (NICA 1975) identified four sets of relationships/principles as the components of a person's spiritual well-being. These principles allow for an individual, multidimensional and subjective operationalization of spirituality and are summarized as follows: (1) spirituality as grounded in a belief in a higher being (i.e. God), which considers spirituality to be relevant to the thoughts and practices that underpins theologies either broadly or narrowly defined; (2) spirituality as grounded in self-fulfilment, a conceptualization of spirituality that focuses on human achievement or potential; (3) spirituality as grounded in the relationship with oneself and (4) spirituality as grounded in the connection of oneself to a larger "system", which focuses on one's relationships with the broader reference group, nature or ecology. A number of definitions of spirituality were identified and evaluated against the NICA principles.



The first principle states that spirituality is grounded in a belief in a higher being and thus considers spirituality to be relevant to the thoughts and practices that underpins theologies either broadly or narrowly defined. Pargament (1999a) describes spirituality as, "a search for the sacred (p. 12)", whereas religion is described as "a search for significance in ways related to the sacred (p. 12)". The "sacred" is an entity (e.g. God or Ultimate Being), object, principle or concept that transcends the self, that is set apart from the ordinary and is worthy of worship (Hill et al. 2000). Pargament suggests that the self transcends through searching for the sacred, which may not include an intermediate, "sacred" acts, such as the pursuit of academic excellence, or the like as worthy of worship, or self-fulfilment and personal satisfaction (Pargament 1999b). As can be seen from Pargament's definition, spirituality is placed within the broader domain of religion suggesting that it can be influenced by the beliefs, values and principles of a specific religion. However, this is challenging and asserts the difficulty in determining a universal definition of spirituality considering that there is no one universal religion practiced throughout the world. The fact that different religious doctrines have adopted diverse and often competing religiosities may, therefore, make it impossible to identify a universal definition of spirituality. Moreover, placing spirituality within the domain of religion restricts research to a narrower and more traditional conceptualization of "God" (Stifoss-Hanssen 1999).

Therefore, the first principle/definition of spirituality as highlighted above might not be applicable to people following Islam, or people of Dharmic (e.g. Buddhism) origins, for instance (McSherry and Cash 2004). Hence, the ongoing use of Pargament's definition of spirituality could be argued as limited.

The second principle defines spirituality as grounded in self-fulfilment which suggests that spirituality focuses on human achievement or potential and relationship with oneself. To reflect this principle, Stifoss-Hanssen (1999) proposed that "spirituality is people's search for meaning, in relation to the big existential questions (p. 28)". Therefore, spirituality includes different characteristics that are not in line with Pargament's definition of spirituality. These characteristics include connectedness, authenticity, existentialism, meaning in life, holism and self and community, which are considered as aspects of an individual's spirituality indicating that spirituality must be considered a broader, not a narrower, concept of religion. As can be seen from Stifoss-Hansen's definition of spirituality, it seems broader than that provided by Pargament and goes beyond the possibly narrow limitations of traditional religion. However, there remains a question as to whether searching for existentialism can result in one living a spiritual life. Pargament (1999a) debates whether it may or may not and asserts that finding meaning in life, which might be considered as part of existentialism, is not spiritual in nature or complexity. Further consideration of Stifoss-Hansen's definition of existentialist spirituality suggests that one seeks to know the self, free from beliefs, feelings and identities or labels created upon fear of losing one's physical and psychological identities (Ho and Ho 2007). Seeking the self has a higher degree of complexity and may therefore require a lifetime dedication and selfdiscipline to master (if mastering the pursuit is, truly, possible) (Hamel et al. 2003).

Hill et al. (2000) offered another definition of spirituality highlighting that it is the "thoughts, feelings and behaviours that arise from a search for the sacred (p. 66)". They even developed a criterion for considering Pargament's definition of spirituality. In opposing Pargament's definition, Hill et al. suggest that even though an individual's spirituality can be expressed through religion, it does not essentially need the institution of religion. Hill et al. (2000) consider the role of a Being or Purpose that is superior to the individual, namely the Transcendent which might or might not involve God as the Higher Being. One's Higher Being or Purpose may be placed within or beyond the individual. The



transcendent may be external to the individual or recognition of something superior to the individual (Mahoney and Pargament 2004).

The third and fourth principles identified by the NICA in the USA (1975) highlight that spirituality is grounded in the connecting of oneself to a larger system or with oneself. To reflect this principle, Reed (1992) offered a definition of spirituality that focuses more on the individual relationships with self, others, nature and a power greater than the self. According to Reed, "spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced through connectedness with oneself, through connectedness with others and the natural environment and through relatedness to the unseen, God, or power greater than the self and ordinary source (p. 350)". As can be seen from Reed's definition, it appears that spirituality is firmly centred on interpersonal relationships and the community, where nature or the environment has a central role in one's experience of spirituality. Contrary to some other definitions of spirituality offered, the one offered by Reed suggests that one can only know who they are after they have achieved connectedness with self, others, and the environment, and God or higher power. Considering Reed's definition further, by its very nature, it appears to be holistic. It demonstrates that spirituality means an awareness of oneself and our relationships with everything that is not the self (Meehan 2002). It highlights that individuals seeking spirituality must identify, understand and value the essential socio-spiritual structure connecting them with all others and nature (Fraser and Grootenboer 2004).

While no one definition of spirituality is possible, this systematic review was conducted to answer the following two questions:

- What does spirituality means to patients with ESRD?
- Are there associations between spirituality and the health outcomes and general wellbeing of patients with ESRD?

# Methodology

## Search Strategy

The following databases were searched: CINAHL, MEDLINE, PsycINFO, ATLA, AMED, The Cochrane Library, PubMed, British Nursing Index, Web of Knowledge, ScienceDirect, Google Scholar, and Index to Theses of Great Britain and Ireland which was used to access British and international PhD theses related to the search criteria when possible. The following keywords were used for searching: Spirituality, Religion, End stage renal disease, health outcomes and quality of life. Email alerts using Zetoc, Medscape, EBSCO (EPNET alerts) and NCBI-PubMed were set and received either weekly or monthly to ensure that we were abreast of the new literature as it was published.

#### **Inclusion and Exclusion Criteria**

Studies were included if they focused on the following: spirituality in the lives of patients with chronic kidney disease (CKD), ESRD, or in people receiving haemodialysis (HD) treatment; explored or examined the relationship between spirituality and the quality of life (QOL), health outcomes and general well-being of patients with ESRD; and were



published in English between 1999 and 2017. A limited number of studies were retrieved, and therefore all retrieved studies were included in the review.

Studies were excluded if they were focusing on children with ESRD, caregivers of patients with ESRD, physiological outcomes or interventions. Studies were also excluded if they were commentary letters to editors or not reporting original research results.

#### Results

#### **Data Extraction**

Abstracts of all retrieved studies were screened initially, and all relevant studies were exported to RefWorks (version 2.0) to be read in full. The search strategy retrieved 480 papers, 410 were excluded (n = 397 did not meet the inclusion criteria, and n = 13 were duplicates). In total, 70 studies were exported to RefWorks. After thorough reading, 33 studies were included in the final review. Figure 1 highlights the process for study selection.

# **Quality Appraisal**

The quality of the reviewed studies was assessed using the quality appraisal checklist that was developed based on the Critical Appraisal Skills Programme (CASP 2013). Also, we developed a literature review matrix for ease of referral and summation of retrieved studies. The matrix included the following headings: author/s, year of publication, country, studies' research questions and aims, methodology (i.e. design, sampling methods, participants' characteristics, inclusion and exclusion criteria, and data analysis methods), key findings and strengths and limitations. Due to the limited number of studies exploring spirituality in the lives of patients with ESRD, no study was excluded based on its quality.

# **Selected Studies**

The literature review underlined a shortage of literature that explored and examined spirituality and its role in the lives of patients with ESRD receiving HD treatment. Four of the seven qualitative studies retrieved explicitly explored spirituality in the HD population (Walton 2002, 2007; Tanyi and Werner 2008b; Molzahn et al. 2012). However, the main aim of the other three studies was not to explore spirituality. Only six quantitative studies examined the relationship between spirituality and QOL or HRQOL of patients receiving HD treatment. Noticeably, there were methodological limitations within the studies. In general, these studies highlighted that spirituality is important in the lives of patients with ESRD and almost all studies emphasized the need for further research to explore this important concept amongst patients with ESRD.

#### The Main Themes Identified in this Study

The main themes that emerged from the literature review were as follows: meaning of spirituality for patients with ESRD and spirituality in the lives of patients with ESRD. The latter theme comprises three sub-themes: spirituality and QOL, spirituality and psychological adjustment, and spirituality and satisfaction with care and treatment preferences.



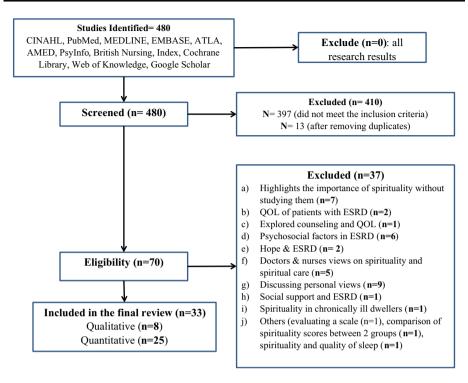


Fig. 1 Study selection process

## Meaning of Spirituality for Patients with End-Stage Renal Disease

Two studies explicitly explored the meaning of spirituality in patients receiving HD treatment (Walton 2002, Walton 2007). Both studies were carried out in the USA, conducted by the same researcher and adopted a grounded theory approach. Walton (2002) was amongst the first to study spirituality in patients with ESRD, and her findings initiated theory development and provided a theoretical underpinning for understanding spirituality in the dialysis population. Walton's (2002) study, using semi-structured interviews with 11 patients receiving HD treatment, suggests that spirituality is a life-giving force that inspires one to strive for balance in life and is nurtured by connecting with people, God and the environment. On the other hand, Walton (2007) carried out another study with 21 patients in the USA and found that spirituality means "being in the world" and involves all aspects of living for those under investigation. Connection with the family, community, belonging and helping others emerged as other meanings of spirituality. In Walton's report (2007) praying was identified as a core category. However, it was not clear whether participants identified connection with God as a meaning of spirituality or not.

## Spirituality in the Lives of Patients with End-Stage Renal Disease

Out of the 33 reviewed studies, four studies used a qualitative approach and explicitly explored spirituality in patients receiving HD treatment. The other three studies also used a qualitative approach; however, their main focus was not to explore spirituality in patients receiving HD treatment. These studies were included because they highlight that



spirituality is an important coping strategy amongst their study participants. Findings from the qualitative studies are presented first.

# Spirituality and Quality of Life

Evidence suggests that the way in which spirituality affects patients' lives is by encouraging them to search for meaning and purpose in life which empowers and enables them to feel stronger in the face of a challenging disease. For example, Walton (2002) illustrated this in a grounded theory study with 11 patients receiving HD treatment in the USA. Similarly, in Canada, patients identified that spirituality is important in patients' lives and helps them to find meaning in illness, which empowers them to come to terms with their disease (Molzahn et al. 2012; Al-Ghabeesh and Suleiman 2014). Further evidence from three studies also suggests that the way in which spirituality affects patients' lives is by facilitating coping which gives patients the ability to adapt and manage their daily lives. For instance, Walton (2007) carried out a grounded theory study in the USA which shows that spirituality and, in particular, praying is a powerful way to cope with the stress of HD treatment. Prayer nourishes inner strength and helps patients cope with hardships, and offers hope and inner strength. Tanyi and Werner (2008b) found similar findings from a phenomenological study with 16 dialysis patients in the USA. They found that spirituality is essential in buffering against and reducing anger, depression, anxiety and bitterness, and thereby fosters coping. Correspondingly, in Thailand, patients also reported that spirituality helps them to adapt to HD treatment and to maintain role function and interdependence as well as coping with the mental challenges of HD (Yodchai et al. 2011).

Six studies explicitly examined the relationships between spirituality or spiritual beliefs and the QOL/HRQOL of patients receiving HD treatment (Kimmel et al. 2003; Finkelstein et al. 2007; Ko et al. 2007; Kao et al. 2009; Davison and Jhangri 2010; Saffari et al. 2013), whereas eleven more studies examined the relationship between religious factors or religious coping and the QOL/HRQOL of patients with ESRD (Patel et al. 2002; Finkelstein et al. 2007; Thomas and Washington 2012; Ibrahim et al. 2012; Lucchetti et al. 2012; Ramirez et al. 2012; Davison and Jhangri 2013; Saffari et al. 2013; Taheri-Kharameh et al. 2016; Cruz et al. 2016; Cruz et al. 2017). Of the 15 studies, five were carried out in the USA, two in Canada, two in Brazil, two in Iran, two in Saudi Arabia, one from Malaysia and one from Taiwan. Sample sizes ranged from as low as 53 (Patel et al. 2002) to as high as 633 (Kao et al. 2009). Twenty of the studies specifically indicated the use of a crosssectional design, whereas five studies did not specify a specific design although they seemed cross-sectional in nature. All used valid measures to assess spirituality and QOL such as the Free Interview for Spiritual and Religious Beliefs Scale (Kao et al. 2009) and the Spiritual Perspective Scale and the Spiritual Well-Being Scale (Davison and Jhangri 2010), McGill QOL Questionnaire (Patel et al. 2002) and the Medical Outcomes Study Social Support Survey (SF-36) (Thomas and Washington 2012).

ESRD introduces many physical and psychological challenges into patients' lives that may negatively affect their QOL. Patients receiving HD treatment must adjust on a daily basis to their treatment schedule, dietary limitations and other potential complications (Tanyi and Werner 2003). Evidence from cross-sectional studies suggests that spirituality is important in the lives of patients with ESRD and may have a positive association with their QOL. For example, Kimmel et al. (2003) illustrated in a relatively large cross-sectional survey with 165 HD patients in the USA that spirituality is a determinant of QOL. Spiritual beliefs were positively associated with QOL (p = .005) and satisfaction with life (p = .01) and negatively associated with the number of reported symptoms (p < .01).



Finkelstein et al. (2007) found in another study that scores on the Spiritual Well-Being Questionnaire (SWBQ) were associated with several QOL domains of the SF-36 questionnaire, with a caution that none of these values were reported to highlight the strength or direction of the association. Likewise, Kao et al. (2009) carried out a large cross-sectional study (n = 633) in Taiwan and found that patients with no or with strong beliefs had higher role physical (p = .001) and social functioning (p = .001) scores than patients with weak beliefs. Even after adjusting for gender, time on dialysis, age, marital status, education and co-morbidities, patients with no or with strong spiritual beliefs still had a higher social functioning scores (p = .02) than patients with weak beliefs.

In contrast, evidence from two studies suggests that spirituality has insignificant associations with QOL in patients with ESRD (Ko et al. 2007; Davison and Jhangri 2010). In Davison and Jhangri's (2010) study, the findings may be affected by the fact that the Spirituality Well-Being Scale (SWBS) used to assess spirituality mainly focuses on assessing religion rather than spirituality and that there were difficulties to distinguish between religion and spirituality in the ESRD Spiritual Beliefs Scale. Similarly, in Ko et al.'s (2007) study, a limitation was that the study was carried out in one dialysis unit and recruited predominantly African American participants. Therefore, these studies need to be replicated to confirm whether spirituality influences QOL or not.

Evidence from fourteen studies suggests that religion or religious coping strategies can have an impact on the QOL of patients receiving HD treatment. This was illustrated in a cross-sectional study in Brazil by Lucchetti et al. (2012). According to Lucchetti and his colleagues, reading religious literature was inversely associated with depressive symptoms (p < .001). The psychological domain of QOL was positively associated with increasing religiosity (p = .030) and negative depression scores (p < .001). In addition, increasing importance of religion was positively associated with the social domain of QOL (p = .032), with a caveat that the sample recruited was on HD for < 6 months and, therefore, patients may have not experienced the full impact of ESRD and HD treatment on their lives. It has been reported in the literature that patients experience an improved QOL during the first 6 months after commencing HD treatment (Kring and Crane 2009). Therefore, findings from Lucchetti et al.'s study should be treated with caution because it was not clear whether their study participants reported better QOL as a result of religion or as a result of receiving HD treatment.

Ramirez et al. (2012) carried out another cross-sectional study in Brazil with patients receiving HD treatment (n = 170) and found that positive religious coping was associated with better overall HRQOL (p = .02), better mental health and social relations (p < .001), while religious struggle had a negative impact on all dimensions of HRQOL: physical, mental and social (p < .001, p < .001, p < .01, respectively). Yet, the findings may be limited by the inclusion of predominantly Christian participants who have a Roman Catholic affiliation. Likewise, Davison and Jhangri (2013) found that in Canadian patients receiving HD treatment, existential well-being (EWB) was associated with higher overall HRQOL, mental and physical domains (p < .001), with a caveat that the sample was predominantly white. Even in a small sample of 53 dialysis patients in the USA, similar findings emerged (Patel et al. 2002; Kharame et al. 2014; Taheri-Kharameh et al. 2016; Cruz et al. 2016; Cruz et al. 2017). Patel and his colleagues found that religion as a coping mechanism correlated with higher functional status (p = .007), higher satisfaction with life (p = .01) and lower depression (p = .01). However, Patel et al.'s study was limited by the small sample, was carried out in one dialysis unit and recruited predominantly African Americans. In contrast, Thomas and Washington (2012) carried out a cross-sectional study (n = 176) in the USA to show that there were inconclusive findings as to whether religion



was associated with better or worse HRQOL of patients receiving HD treatment, with a limitation that the study included only African Americans which may limit the generalizability of the findings.

Spirituality and Psychosocial Adjustment and Coping

Patients with ESRD experience many psychological problems such as depression, anxiety, uncertainty and dependency on the dialysis machine and the nursing staff (White and Grenyer 1999; Kimmel et al. 2003; Patel et al. 2005; Cukor et al. 2007; Cengic and Resic 2010; Babamohadi et al. 2015).

Evidence from five studies suggests that the way in which spirituality/religion positively impacts on patients' lives is by helping them cope with and adjust to their psychological problems and by empowering them to accept their treatment and feel stronger in the face of illness. Spirituality may affect patients' lives by acting as a buffer against depression and a wide variety of stressful events encountered by patients with ESRD. For example, Patel et al. (2002) illustrated this in a study conducted in the USA (n = 53). In their study, spirituality and religious involvement were associated with lower depression scores (p = .05 and p = .001, respectively). Tanyi and Werner (2003) demonstrated in another cross-sectional study in the USA (n = 65) that spiritual well-being was positively associated with overall psychosocial and psychological adjustment in women receiving HD treatment (p = .01), with a caveat that the study included women only and that the convenience sampling approach means that only those who met the inclusion criteria or those who could address the area of interest were recruited, which can introduce researcher bias. In another study from Brazil (n = 150), Martinez and Custodio (2014) found that spirituality was significantly associated with better mental health (p = .001) and that spiritual well-being was the strongest predictor of mental health (p = .003), psychological stress (p = .006), sleep disturbance (p = .002) and psychosomatic complaints (p = .0003), with a limitation that the study was carried out in one dialysis unit. In contrast, Ramirez et al. (2012) carried out a cross-sectional study in Brazil (n = 170) which showed that using religion did not correlate with depressive or anxiety symptoms, whereas religious struggle (i.e. tension, question and conflict about spiritual issues within oneself, with other people and with the Divine) correlated positively and significantly with both depressive (p < .0001) and anxiety (p < .0001) symptoms.

Spirituality and Survival, Satisfaction with Care and Treatment Preferences

Only three studies were identified in the review that explored the relationship between spirituality and survival (Spinale et al. 2008), spirituality and satisfaction with care (Berman et al. 2004) and spirituality and treatment preferences (Song and Hansen 2009) in patients with ESRD. All were conducted in the USA and used cross-sectional design and valid measures to assess spirituality and religion. Sample sizes ranged from as low as 51 participants (Song and Hanson 2009) to as high as 166 (Spinale et al. 2008). Perhaps the difficulty assessing spirituality led to these studies only having small sample sizes on which to draw conclusions, which can affect their power to identify significant findings.

Evidence from one paper suggests that spirituality may have a relationship with survival amongst patients with ESRD. Spinale et al. (2008) demonstrated in a cross-sectional study with 166 dialysis patients in the USA that spirituality and religion were important coping mechanisms (p = .0002). Evaluated by mean split in their entire sample, higher spirituality scores were associated with longer survival (hazard ratio [HR] .49; 95% confidence



interval [CI] .27–.88; p = .02). However, for the entire study population there were no associations between spirituality and survival. In addition, there was no association between religion as a coping mechanism and survival. These findings seem to be confusing. The reasons for that might be because, firstly, the study included a predominantly African American male population, 18 participants died during the follow-up, and 19 participants received a kidney transplant which may have affected the final analysis. Had the views of these participants been included in the analysis, the study may have yielded different findings. Secondly, the scale used to assess spirituality mainly focuses on assessing religion and faith rather than assessing spirituality as a multidimensional concept (i.e. there was a lack of variables to measure relationship with self, others and nature) and the fact that the scale has not been subject to validity and test–retest reliability means that more studies are needed to establish if it was appropriate to assess spirituality.

Berman et al. (2004) carried out a survey to examine the relationship between religion and satisfaction with care and adherence to treatment in HD patients (n = 74) which found that religiosity was associated with satisfaction with life and medical care (p = .021), but not with adherence to HD treatment. Furthermore, data from a small cross-sectional study that was carried out in the USA to examine the relationship between religion and end of life preferences in patients (n = 51) receiving HD treatment demonstrated that there were no associations between importance of spirituality and religion with treatment preferences and acceptance of treatment outcomes (Song and Hanson 2009). Both studies recruited mainly African American participants, and the small sample size may have limited the power of these studies to yield significant findings.

# Discussion

This systematic review intended to critique and highlight a dearth of studies specifically exploring and examining the role of spirituality in the lives of patients with ESRD and its influences on their health outcomes and general well-being worldwide. This systematic review was conducted to answer the following two questions: What does spirituality means to patients with ESRD? And are there associations between spirituality and the health outcomes and general well-being of patients with ESRD?

# Meaning of Spirituality for Patients with ESRD

In Walton (2002) and Walton (2007) studies, the use of a grounded theory approach and the fact that the researcher validated the findings by asking patients and nurses who had experience working with dialysis patients to confirm the findings to ensure clarity and application increase our confidence in them. However, these findings must be treated with caution because the first study (Walton 2002) was carried out in one dialysis unit and the second study (Walton 2007) recruited American Indians only. In spite of these limitations, these studies offer an explanation to increase our understanding of the meaning of spirituality in the lives of patients with ESRD though there was no agreement over one meaning of spirituality that can be applied to all dialysis populations. Yet, more qualitative research is required with patients from different dialysis units and different religious and cultural background to gain an in-depth understanding of this important concept in general.



# Spirituality in the Lives of Patients with ESRD

Findings from the reviewed studies offer an explanation that spirituality may be important in patients' lives as it encourages them to find meaning and purpose and offers them an important source of coping. However, these findings must be treated with caution for many reasons. First, samples included in these studies might not be representative of the whole dialysis population. For instance, Tanyi and Werner (2008a, b) recruited women only, Walton (2007) recruited American Indians, and Yodchai et al. (2011) recruited Buddhist patients only. In addition, three of the studies were carried out in one dialysis unit (Walton 2002; Yodchai et al. 2011) or in one geographical area (Molzahn et al. 2012). Second, using self-selection as a sampling method may have introduced some bias as only those who were spiritual may choose to participate. This may also limit the generalizability of the findings. Third, Kimmel et al. (2003) used two questionnaires to measure spirituality that were not validated previously and, therefore, more studies using these questionnaires are required to validate the questionnaires and the study findings. Fourth, using the McGill QOL questionnaire, they asked patients about changes in the past 2 days which might be too short to assess any differences. Fifth, they did not consider ethnic and cultural differences in their study which may limit the generalizability of the findings. Lastly, the use of a cross-sectional design means that it was not possible to reveal the true relationship between spirituality and QOL. Thus, these studies might need to be replicated in order to confirm their findings.

However, despite these limitations, synthesizing the findings from the aforementioned studies it seems that there is a growing evidence to support that spirituality may be important for the dialysis population. Yet, there remains a need for further research to expand on these findings considering their methodological limitations. Next we are presenting the findings from the 26 quantitative studies that examined spirituality/religion in patients with ESRD.

# Spirituality and Quality of Life

Given the findings from the previous studies, it seems that the relationship, whether positive or negative, between spirituality/religion and the QOL of patients receiving HD treatment is not well understood as highlighted by the inconclusive findings from these studies. Hence, more research is needed to examine these relationships and find out whether they support current research findings or contradict them.

Spirituality and religiosity have been used interchangeably in health and psychological research (Mattis 2002), which indicates a lack of understanding of the possible discriminate nature between the two concepts (Harmer 2009). However, in light of the lack of the research addressing spirituality in patients with ESRD, we included studies that examined the relationships between religion and QOL/HRQOL of patients receiving HD treatment.

Synthesizing the findings from the reviewed studies, it seems that there is evidence to suggest that religion can have an impact on the QOL of patients with ESRD. The use of cross-sectional design makes it difficult to infer causality to reveal the true relationship between religion and QOL. In addition, given the inconclusive findings from these studies about the relationship between religion and QOL, the limited number of studies available and the fact that all studies used quantitative approach suggest that further research is needed using different methodologies to increase our understandings of the role of religion in the dialysis population and increase our confidence in the results already available.



Research relating to spirituality and its role in the dialysis population does not inform nursing practice. This might be due to the difficulty in defining and discriminating between spirituality and religion, which may affect the way that nursing interventions are implemented within dialysis units. Whether spirituality can be accurately measured is questionable, and even though there is a plethora of validated instruments to assess spirituality, there remains a state of inconsistency measuring spirituality (Koenig 2004; Tanyi and Werner 2007). Fisher (2009) reported on nearly 200 spirituality measures which focus on four domains of spiritual well-being, with only about one-third of them containing religious items.

The variations in the scope and focus of the retrieved studies also suggest that there is a need for future research to gain more insight into the role of spirituality in the lives of patients with ESRD. The heterogeneity of the participants and composition of the samples (e.g. recruiting women only, recruiting African Americans) in several studies is problematic, and there are concerns regarding the generalizability of their findings to all dialysis populations. The reasons why the focus of spirituality research has been more on African Americans are not clear. However, research suggests that people from an African background view religion or spirituality to be more important in their lives and that they are more likely to pray privately, practice religious rituals, attend religious services and believe that the Bible is the word of God (Jacobson et al. 1990; Levin et al. 1994). Ultimately, it is questionable whether these studies sufficiently reflect the range of individuals who are affected by ESRD, in terms of different cultures and different backgrounds, and whether it was these characteristics that influenced the findings of the studies. Indeed, this makes it less possible to generalize the findings of most of these studies to other groups of patients and those from other cultural, ethnic and religious backgrounds. Therefore, further research with the inclusion of more diverse samples is also needed.

#### Spirituality and Psychosocial Adjustment and Coping

Despite the limitations of the studies discussed, it seems likely that spirituality may play a role in affecting patients' lives by facilitating the process of coping; however, considering the differences in the findings about the relationship between spirituality and religion and the psychosocial adjustment amongst patients with ESRD, further research is needed to increase confidence in these results.

## Spirituality and Survival, Satisfaction with Care and Treatment Preferences

Despite their limitations, the three studies discussed examined the relationship between spirituality and survival, satisfaction with care and treatment preferences, an area that had not previously been reported. The studies highlighted that although the evidence remains inconclusive, the findings suggest that spirituality may play a role in the lives of dialysis patients in terms of survival, satisfaction with care and treatment preferences. Consequently, there remains a need for more research to establish whether or not spirituality has a relationship with these issues.



## Conclusion

This systematic review shows that there is a growing body of evidence that suggests a positive relationship between spirituality and the health outcomes and well-being of patients with ESRD. However, the evidence is incomplete and there is a need for further research using various research methodologies to enhance our understanding of the role of spirituality in improving the well-being of patients with ESRD.

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