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The Quality of Life of Patients with End-Stage Renal Disease on Dialysis in South Africa: A Grounded Theory Analysis

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ABSTRACT

Introduction: End-stage renal disease (ESRD) is a global health problem with increasing prevalence worldwide. The number of patients with ESRD will increase to almost 60% by 2020, with the potential to greatly impact patients' quality of life (QOL). This study aimed to explore and analyze QOL in patients with ESRD on dialysis.

Methods: Grounded theory, underpinned by a social constructivism paradigm, was used. Data collection occurred simultaneously in the natural settings of four selected public hospitals. A coding process was used to analyze rich data and generate findings from three focus group discussions.

Results: Results revealed that some participants scheduled for hemodialysis three times a week and others performing peritoneal dialysis four times a day lost their jobs. Young participants in the study worried about changes in body image due to dialysis and reported psychological discomfort. Others felt that they were a burden to their families as they sought transportation assistance at all times for hospital visits and dialysis. Most participants no longer engaged in social activities because of restrictions imposed by their dialysis schedules. However, good social support enabled participants to survive the challenges they encountered on dialysis.

Discussion: Three overarching categories emerged from this study, living in fear causing stress and depression, dependency, and geographical remoteness, which contributed to poor QOL in participants with ESRD.

Keywords: End-stage renal disease, Quality of life, Dialysis, Social support, Financial constraint

INTRODUCTION

Globally, the prevalence of chronic illnesses are on the rise, and the double burden of communicable and non-communicable diseases are escalating the prevalence of end-stage renal disease (ESRD) (Lemos, Rodrigues, & Veiga, 2015). ESRD is a global health challenge leading to poor quality of life (QOL) in patients who receive renal replacement therapy (RRT) in the form of dialysis (Lemos et al., 2015). The World Health Organization defines QOL as "a broad ranging concept affected by the person's complex physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment (Joshi, 2014, p. 306)."

Currently, hemodialysis and peritoneal dialysis are the only treatments for patients with ESRD. Both of these treatment modalities place enormous psychologi-

cal strain on patients, resulting in lower QOL (Hackett & Jardine, 2017; Hou, Li, Yang, Liu, Wu, Xu et al., 2014). Research indicates that the psychological well-being of patients with ESRD is mostly affected by living in fear of dying and experiencing stress due to anxiety about the future and their families, disease outcome, and shortened life span (Xhulia, Gerta, Dajana, Koutelekos, Vasilopoulou, Skopelitou et al., 2016). In particular, depression is one of the most serious comorbidities associated with ESRD, with one estimate suggesting that between 20% and 44% of patients with ESRD suffer from depression (Cukor, Ver Halen, Asher, Coplan, Weedon, Wyka et al., 2014). Studies show that depression in patients with ESRD can be a result of factors ranging from financial constraints, dependency on others, and sudden change of social roles; however, it is unclear if depression has an effect on poor outcomes associated with ESRD (Cukor et al., 2014).

Several forms of renal replacement therapy (RRT) are available including hemodialysis, peritoneal dialysis, and kidney transplantation, which have been shown to improve the QOL and clinical outcomes in patients with ESRD (Makkar, Kumar, Mahajan, & Khaira, 2015; Tannor, Archer, Kapembwa, van Schalkwyk, & Davids, 2017). Although RRT enables patients to live longer than they would without treatment, patients' QOL remains uncertain (Nayana, Balasubramanian, Nathaliya, Hussain, Salim, & Lubab, 2017). Results of a cross-sectional descriptive study, conducted in Sudanese hospitals, found that the leading cause of ESRD affecting productive patients older than 40 years of age was caused by hypertension followed by glomerulonephritis and diabetes mellitus affecting (Banaga, Mohammed, Siddig, Salama, El-bashir, Khojali et al., 2015). In another study, researchers indicated that only 8% of patients with ESRD in Senegal received RRT, and in Ghana, 5% of total ESRD admissions have chronic kidney disease of whom 27% die of ESRD (Banaga et al., 2015).

In a study conducted in the Northern KwaZulu-Natal districts of UThungulu as well as UMkhanyakude, it was discovered that only a few patients could be accepted on the chronic renal program, which gives patients the opportunity to receive RRT (Madala, Thusi, Assounga, & Naicker, 2014). However, to date, little has been documented regarding the challenges that South African patients with ESRD on dialysis encounter as the population in KwaZulu-Natal is mostly from rural areas. Patients travel long distances, almost 300 km, to dialysis centers which are located in urban areas affecting their QOL (Caldwell, Grant, Gaede, & Aldous, 2018; Madala et al., 2014). This study aimed to explore and analyze the QOL of South African patients with ESRD on dialysis.

Research Question

How is the quality of life of patients with end-stage renal disease affected when they are on peritoneal dialysis and hemodialysis?

METHODS

Study Design

A grounded theory approach, underpinned by the social constructivist paradigm, was used to explore the current topic as the phenomena are poorly defined. Grounded theory was selected because it enables researchers to integrate, unify, and refine an emerging theory, verify or validate categories against data and focus literature, leading to the emergence of a cohesive storyline (Corbin, Strauss, & Strauss, 2014).

Setting Description

In grounded theory, data collection is performed in a natural setting, as it is central to the generated meaning (Corbin et al., 2014; Glaser & Strauss, 2017). The natural setting took place in four public health

institutions offering renal replacement therapy to patients with ESRD in KwaZulu-Natal. Three of the four study settings (Hospitals A, B, and D, respectively) were located in the EThekweni district, and the fourth (Hospital C) was located at UMgungundlovu district.

Sampling procedure

Non-probabilistic purposive and theoretical sampling were used to select participants with the goal of generating rich information, leading to a better understanding of the phenomenon under study (Corbin et al., 2014). Purposive sampling was followed by theoretical sampling to guide the participant selection. A total of 18 participants were recruited to provide in-depth information about the concept being explored in the study.

Data collection

Data collection and the initial phase of data analysis took place over a seven months between October 2017 and April 2018. In-depth interviews were performed with patients, each lasting approximately 45-60 minutes in length. A focus group guide formulated by the researcher team was used to ensure that all the objectives of the study were met during discussions. Simultaneously, generous field notes were taken during data collection to provide thick descriptions of the phenomenon under study (Charmaz, 2014; Corbin et al., 2014). New concepts were identified, and existing codes continued to grow until redundancy was reached.

Ethical consideration

Approval for the research was obtained from the University Research Ethics Committee [BE 506/17], and gatekeeper permission was obtained from the Provincial Departments of Health [KZ-201709-72]. Prior to data collection, informed consent was obtained from all participants and ethical principles were adhered to, as stated in the research protocol.

Data analysis

Grounded theory analysis involves the constant comparative method of emerging data analysis where codes are compared to codes and categories, categories compared to categories while continuously reassessing meanings in order to understand what is going on from the perspective of the participants (Corbin et al., 2014; Strauss & Corbin, 1990). Data analysis followed three phases, described by Strauss and Corbin (1990): open coding, axial coding, and selective coding. In the first stage (open coding), researchers used line by line analysis to derive concepts and their properties from data. During this phase, researchers broke down, examined, compared, conceptualized, and grouped data with the same meaning into categories (Corbin & Strauss, 2015; Strauss & Corbin, 1990). In the second stage of data analysis (axial coding), researchers described all the concepts identified during the first step in terms of their properties and dimensions and applied a coding

paradigm to connect categories found during open coding. The process of collapsing related categories under a single category helped us to reduce the number of initial categories by ensuring that they were organized in a meaningful and hierarchical manner (Corbin & Strauss, 2015). In the third and final stage (selective coding), researchers integrated, unified, and refined the emerging theory, verified and validated our categories against data, and focused literature. Using this process, the researchers were able to clearly capture the core category and supporting categories and identify relationships between and among concepts. This process led to the emergence of a cohesive storyline (Corbin & Strauss, 2015) describing factors affecting the quality of life in patients with ESRD.

Trustworthiness

Trustworthiness was ensured in this study as the researcher utilized Lincoln & Guba, 1985's method of trustworthiness, which incorporates credibility, dependability, transferability, and confirmability. This method enhanced the reality and quality of study findings. Emerging findings were double-checked, and a second coder was used to confirm emerging codes and categories for credibility. In this study, dependability was ensured by triangulating data sources and validating transcribed interviews. In addition, all emerging codes and categories were double-checked by the research supervisor. Transferability was ensured by providing thick descriptions of the study context, settings, procedures, and findings. Confirmability was ensured through matching collected data against the participants' original understanding of the phenomenon of interest in this study.

RESULTS

The following categories emerged from the study: living in fear causing depression, dependency, and geographical remoteness.

Living in fear causes stress and depression

The majority of participants we interviewed revealed that they were living in fear of the disease or were scared of what would happen next in their lives as they were dependent on dialysis and could not survive without any form of renal replacement therapy. Findings also revealed that the majority of young participants we interviewed were stressed by the changes in body image as a result of hemodialysis or peritoneal dialysis side effects, which made them darker in complexion, caused them to lose weight, and become frail as a result of weak bones. Young females reported feeling embarrassed about change in their body image and being questioned about it. To validate this, some participants verbalized the following statements:

"I feel so scared as I'm the only person in our village with this disease..."

"I have fear of missing dialysis as I almost died after missing on session..."

"I feel so embarrassed at times when someone verbalizes that he or she cannot recognize me, then I start explaining myself."

"I used to be bright in complexion, now it's like I'm another person altogether and that makes me feel embarrassed..."

Dependency

Findings from the study revealed that dependency has four dimensions, which are: dialysis dependence, financial dependence, social dependence, and transportation dependence.

Dialysis Dependence.

Dialysis dependence was vital for patients with ESRD to survive or to prolong their lives. The study participants ($n = 18$) were all on dialysis, either on hemodialysis or peritoneal dialysis. Renal replacement therapy was too costly and out of participants' reach. Participants' lives largely depended on adherence to their treatment. The experiences by the participants made them realize that their lives depended on dialysis and the extracts below support this statement:

"...I nearly died, and I realized that truly my life depends on this dialysis."

"... I was very scared that for me to survive, I have to come for hemodialysis two times a week."

Financial dependence.

Financial dependence was brought about to patients on dialysis mainly as a result of unemployment. Patients who are employed are affected by dialysis schedules and can lose their jobs as a result of absenteeism. Findings from this study revealed that unemployment occurring as a result of dialysis schedules contributed to financial dependence among participants, which was expressed by the majority of patients we interviewed, who felt that they were dependent on their families for financial support. Some participants had to depend on relatives or friends for financial support to avoid missing dialysis schedule. Financial dependence is supported by the following extracts:

"Surviving by my grandmother's pension all the time..... when I'm at the age of being employed"

"...I travel a long distance and have to borrow money since I'm no longer employed."

Social dependence.

Social dependence was found to be a facet of social domain, which had a positive influence on the

survival of patients with ESRD. Few patients felt that they were a burden to their families as a result of the health challenges which they encounter. The extracts below support this statement:

“...It is so amazing that my family has been supportive through my journey.....”
“...but I’m fully dependent on my grandmother’s pension.”
“... I feel that as much as I get all the support that I need, I am also a burden....”

Transportation dependence.

Transport dependence to hospitals emerged as strongly associated with financial dependence. Patients with ESRD depend on dialysis for survival, however, transport dependence mainly affects patients on hemodialysis as they frequently travel to the hospital for dialysis. To validate this, some participants verbalized the following statements:

“.... have to ask my son to transport me to and from dialysis which is so stressful”

“... I spend most of my time in the bus going to and coming from dialysis”

Geographical Remoteness

Patients traveling long distances.

Geographical remoteness emerged as an important issue among the participants interviewed, who revealed that they traveled long distances to the hospitals for dialysis. Participants highlighted the unequal distribution of dialysis services, resulting in them having to travel long distances to health institutions that offer dialysis. The impact of geographical remoteness on QOL was especially evident in patients living in rural areas, with some participants verbalizing that they had to travel from Northern KwaZulu-Natal to midlands and the southern part of the province. Besides the physical ill-effects associated with traveling long distances, participants verbalized that traveling long distances was associated with poor social relations and financial constraints, which negatively affected their QOL. This is indicated in the following extracts:

“I can’t go home as the services of hemodialysis are not available in our local hospitals....”

“I travel a long distance and have to borrow money....”

Scarcity of renal experts.

Another finding related to the theme of geographic remoteness was a scarcity of qualified renal experts. Findings from our analysis revealed patients seen in one of the four hospitals (Hospital B) are seen by the renal registrar or nephrologist once a month if they are

lucky based on whether the providers happen to be at the department at that particular time. The scarcity of renal experts was an outcry which revealed that patients rely on the expertise of the renal nurses. Some participants reported when they schedule dialysis early in the morning or late in the afternoon they would usually miss the doctor and could not accommodate their dialysis schedule to the meet the availability of the doctor. This was highlighted in the extracts below:

“It is so sad that we hardly see the doctor as he only comes once a month. When he comes, he also does not have enough time to spend with us ...”

“... even if the nurses attend to our problems but sometimes you feel that you must be seen by the doctor...”

“We understand that there are no doctors, but this ends up being a situation where one will be lucky to be seen by the doctor, and that is not fair...”

Prioritization of patients traveling long distances over local patients.

Most participants in Hospital C revealed that patients who come from outside the catchment area of the hemodialysis unit are prioritized over the local patients as ambulances wait for them to finish dialysis. Local patients have their slots move from the day and are dialyzed overnight. This results in local patients in Hospital C being deprived of spending quality time with their families. This is validated by the following extracts:

“It is so sad that we are always asked to allow the patients that come from far to be dialyzed first just because we are from the local area...”

“...we end up spending the whole day and even nights in hospital as we give people coming with ambulances the priority...”

DISCUSSION

Results of this study revealed that a majority of South African participants with ESRD on dialysis we interviewed lived in fear of dying, reported feeling scared about what will happen next in their lives due to their dependency on dialysis, and feared they could not survive without any form of renal replacement therapy. Studies show that dialysis is a life-saving treatment, but is often burdensome to ESRD patients, with potentially serious impacts on QOL (Wan, Chen, Choi, Wong, Chan, Chan et al., 2015).

The majority of younger South African participants interviewed verbalized being stressed by the changes in body image that occurred because of side effects associated with their hemodialysis or peritoneal

dialysis such as darkening in skin color, weight loss, and frailty from weak bones. Reports of poor self-esteem and embarrassment due to changes in body image were common in young females we interviewed, especially when participants were questioned about their bodies. Most patients expressed feeling embarrassed when others did not easily recognize them.

Dependence emerged as an issue that significantly affected the psychological well-being of South African patients with ESRD on dialysis. Results of the analysis identified four types of dependence impacting patients with ESRD: dialysis dependence, social dependence, financial dependence, and transportation dependence.

Dialysis dependence was influenced by financial dependence, as patients are required to perform hemodialysis three times a week, or peritoneal dialysis four times a day, and also keep up with hospital appointments. In 2013, Gerogianni & Babatsikou found that patients with ESRD are often highly concerned about their future as they are completely dependent on dialysis for the rest of their lives. Results of their study found that dependence on dialysis leads to patients' depression, stress, anxiety, and fear of what the future holds (Gerogianni, Kouzoupis, & Grapsa, 2018; Xhulia et al., 2016). Another study also identified a close relationship between depression and adherence to treatment and suggested that multidisciplinary interventions are required to minimize complications (Stanifer, Maro, Egger, Karia, Thielman, Turner et al., 2015). These findings concur with another study that reported dependency on treatment could have gruesome effects on participants' psychosocial domain (Clark, Farrington, & Chilcot, 2014). Researchers found that interventions to facilitate treatment would reduce or eliminate depression while ensuring adherence and better QOL (Cukor et al., 2014). In 2013, the World Health Organization (WHO) described adherence includes taking medication as prescribed, following strict renal diet, and adjusting to lifestyle change which encompasses physical, social, psychological, and economic dimensions (Alikari, Matziou, Tsironi, Theofilou, & Zyga, 2015; Clark et al., 2014; Griva, Lai, Lim, Yu, Foo, & Newman, 2014).

For patients with ESRD on dialysis, some degree of social dependence is unavoidable as patients need their loved ones for complete support, irrespective of the circumstances. Studies show that strong social support from family, friends, relatives, and other social networks available to an individual, can have a positive impact on QOL for patients with ESRD (Ibrahim, Teo, Din, Gafor, & Ismail, 2015). Conversely, poor social support can result in depression, which is the major cause of non-adherence to treatment and high mortality in patients with ESRD (Chen, Wang, & Lang, 2016). Changes in social support may result in poor compliance such as missed dialysis sessions, and poor social relations make them feel lonely and isolated which results in mental health disorders such as depression (Chen et al., 2016). One study showed that

social support is associated with better survival in patients with ESRD, and it has recently emerged that poor social relationships may be an important contributor to poor QOL (Ibrahim et al., 2015).

Furthermore, financial dependence is exacerbated by unemployment, and patients can become a financial burden on their families (Banaga et al., 2015). Financial dependence on others to comply with dialysis sessions and make appointments was expressed by a majority of the South African patients interviewed, who often reported feeling like they were a burden on their families. These results are similar to findings from a study conducted by Banaga et al. (2015) in Sudanese ESRD patients, who found that 73% of patients on hemodialysis surveyed were unemployed, representing a financial burden on their families. Financial dependence for treatment has psychosocial implications which also affects patients' QOL (Banaga et al., 2015; Clark et al., 2014; George, Mogueo, Okpechi, Echouffo-Tcheugui, & Kengne, 2017).

Financial implications are further exacerbated by frequent hospitalizations of patients with ESRD since they may encounter multiple complications related to ESRD such as bacterial infections, mechanical dysfunction of the catheter, and failing dialyses access requiring surgical intervention (Luyckx, Tonelli, & Stanifer, 2018; Niang, Cisse, Mahmoud, Lemrabott, El Hadji, & Diouf, 2014). Moreover, the study conducted by Niang, Cisse, Mahmoud, Lemrabott, and Diouf (2014) in Senegal revealed that peritonitis resulting from dialysis is associated with poor socio-economic status, especially when patients do not have access to clean water and electricity. Therefore, patients' hospitalizations and complications result in financial implications not only to the institutions, but also the family that mostly travel long distances to visit their beloved ones to provide love and support.

This study revealed that one of the four hospitals (Hospital C) had a wider catchment area and surprisingly, a fewer number of hemodialysis machines, compared to other dialysis centers. Participants from Vryheid to Hospital C travel 274 km, while those from Ladysmith to Hospital C travel 170 km and 96 km from Estcourt. Patients have to leave their homes early in the morning or the previous night to avoid missing ambulances, which take them to their dialysis center. The significant shortage of skilled health professionals and nephrologists in underdeveloped countries has a high impact on the physical, social, economic and psychologic dimensions of life (Kilonzo, Jones, Okpechi, Wearne, Barday, Swanepoel et al., 2017; Mburu & George, 2017). Although still a challenge due to rapid population increases, South Africa has made enormous improvements in health resources allocation during the twenty years following the end of Apartheid, despite significant challenges in resource availability (Kilonzo et al., 2017). Traveling to a hospital for dialysis three times a week is a heavy burden on patients from rural areas (Chao, Lai, Huang, Chiang, & Huang, 2015). In

particular, patients with ESRD in the sub-Saharan region have poor access to renal replacement therapy since most resources are primarily located in urban areas.

The scarcity of nephrologists in South Africa has been shown to negatively impact QOL for patients with ESRD and satisfaction with health services remains poor in most countries, where millions of citizens are without access to health services (Kilonzo et al., 2017). However, improvement in service delivery is essential to be able to achieve universal health coverage and improve QOL for patients with ESRD on dialysis (Luyckx et al., 2018; Stanifer, Muiru, Jafar, & Patel, 2016; Toro, 2015). As a matter of fact, the Global Strategy outlined by the WHO focuses on integrated, people-centered, health services which call for a paradigm shift in the way health services are funded, managed, and conveyed to meet the challenges faced by those in need of care worldwide (Toro, 2015).

Lack of data on health resource access and utilization in Africa has resulted in poor distribution of resources and a drastic rise in mortality rate due to comorbidities (Kilonzo et al., 2017; Naicker, 2013). The scarcity of renal experts not only delays appropriate referral for patients with ESRD, but it also affects their psychological well-being. Patients travelling long distances to dialysis units and patients from local areas are affected by insufficient resources to manage ESRD (Makkar et al., 2015; Park & Kear, 2017). Studies of transportation issues for patients in the United States with ESRD also highlights that barriers to transportation can negatively impact QOL. In addition, missing dialysis sessions due to poor transportation has been associated with excessive usage of the critical care and emergency units (Park & Kear, 2017).

LIMITATIONS

The current study was only conducted in public institutions, and as a result, findings cannot be generalized to all patients with ESRD on dialysis. Further research needs to be done on patients with ESRD who are not suitable candidates for dialysis and to include patients undergoing dialysis in private hospitals.

CONCLUSION

The lack of QOL in patients with ESRD is a serious health problem, especially in rural areas where there is a challenge of unemployment, socio-economic dependence, and geographical remoteness. Financial constraints as a result of unemployment have been found to be the most important challenge which impacts to psychological, physical, and social domains of QOL. However, this study reveals that a strong social support plays a major role in enabling patients with ESRD to cope with lifestyle adjustment as they undergo enormous challenges while on RRT. Furthermore, the findings and discussion in this study offer an opportunity for healthcare providers to be equipped

with necessary knowledge of what ESRD participants face and how to improve the QOL of patients with ESRD. Therefore, healthcare providers can have a better understanding of how patients can cope with physical, social, and psychological challenges that they encounter and live a better life.

RECOMMENDATIONS

The multidisciplinary team made up of nephrologists, nephrology nurses, social workers, psychologists, and dieticians is needed to ensure that patients with ESRD and their families, if possible, are continuously informed about renal failure and its challenges when on dialysis so interventions can be given at an early stage. Availability of sufficient training institutions for nephrology nurses, as well as the nephrologists, will enable the health care institutions to have the knowledgeable and highly trained personnel who will render efficient care to patients in need, without delay. Results from this study suggest that strengthened collaboration between all stakeholders (government, health care workers, patients and their families) is necessary to bridge the supply-demand gap, facilitate treatment, and improve the quality of life for patients with ESRD.

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DECLARATION OF INTEREST

The authors have no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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