Research Article

A Heideggerian Phenomenological Study of the Lived Experiences of Ghanaian Patients Living With End-Stage Renal Disease

Clinical Nursing Research 1–12
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DOI: 10.1177/10547738211035456
journals.sagepub.com/home/cnr

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Abstract

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There is a lack of knowledge regarding perceptions, feelings, and experiences of Ghanaian patients living with ESRD. This study aimed to discover the experience and meaning of living with ESRD. This qualitative study was conducted using Heideggerian hermeneutic phenomenology. A total of 13 participants were purposefully selected, and data was collected through individual semi-structured interviews. The recorded interviews were transcribed and analyzed using Diekelmann, Allen, and Tanner method. After the final analysis, five main themes emerged: Spiritual fluctuation, Living in uncertainty, Period of agony and frustration, Tough fortification, and Changed roles and status. This study provided deep insight and understanding regarding the lived experiences of patients living with end-stage renal disease in Ghana. The results of this study may benefit nursing care in terms of considering the patients' lived experiences to provide quality and person-centered care.

Keywords

kidney failure, qualitative research, hermeneutics, nursing care, Ghana

Background

Chronic kidney disease (CKD) is increasing in incidence and prevalence worldwide and is estimated to be between 10% and 13% globally (Murphy et al., 2016; Seck et al., 2013). CKD is a disease of public health significance in sub-Saharan Africa with a reported prevalence of 13.9% (Stanifer et al., 2014). Its prevalence in Ghana is 13.3% in a recent study (Adjei et al., 2018).

CKD eventually leads to ESRD and when this occurs, the only means of survival is renal replacement therapy either by dialysis or kidney transplant. A patient is said to reach endstage renal disease (ESRD) when there is irreversible damage to the kidney(s) and loss of renal function with glomerular filtration rate (GFR) less than 15 mL/minutes/1.73 m² (Long et al., 2017). A research study (Ashuntantang et al., 2017) shows that for the last few years, between 2.3 million and 3.2 million patients die every year due to lack of dialysis. Endstage renal disease management has major significant social, clinical, and economic implications for health care systems, patients, and caregivers (Luyckx et al., 2020). Estimates of the

incidence of ESRD based on hypertension and diabetes prevalence have it that only 1.5% of patients needing renal replacement therapy in sub-Saharan Africa get it (Ashuntantang et al., 2017). This situation of huge numbers not being able to access treatment largely because of lack of funding and availability of services demands that we know the plight of these patients, how they suffer, feel, experience, and struggle for their lives with ESRD so that we can manage and care for them well till they die since most of them cannot afford or have access to renal replacement therapies to maintain life. That is why this study is to explore the lived experiences of ESRD patients who have not yet started dialysis so we can know how to tailor care to suit them especially in Africa and hence Ghana where

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Nicholas Danzima Yakubu, Tamale Teaching Hospital, P. O. Box 16, Tamale, Northern Region, Ghana. Email: nichlasdayah@gmail.com the majority of those afflicted with ESRD cannot afford treatment. And sometimes if people can afford there is a lack of availability of renal replacement therapy services.

The research is done in the Ghanaian context on ESRD focus on other areas to the neglect of patients' lived experiences. For example, a recent study on moderate to advance chronic disease in 2019, used a quantitative method to measure and quantify various elements such as quality of life using a questionnaire (Tannor et al., 2019). These quantitative methods both in and outside Ghana usually are based on the empirical psychological framework. This leaves a gap in knowledge regarding ESRD patients' lived experiences which can be elicited using qualitative methods that will allow patients to explain and elaborate on their experiences as against quantitative methods which do not allow patients to elaborate on their experiences due to the nature of questions. Most of these questionnaires adopt a structured and closed-ended approach, which limits the responses of the participants, in other words, the respondents are not allowed to explain and elaborate their experiences of the illness. As a result, an in-depth, detailed account of the person's experience is not achieved. Also, apart from the fact that these studies are not about lived experiences in the case of Ghana, the Cartesian dualistic worldview of the person is entrenched within the various quantitative studies conducted both in Ghana and outside Ghana. In other words, the emphasis on the perspective of the self as "subject" and the world as "object" forms their basis. As a result of this Cartesian view of the self, quantitative studies attempt to explore the person's experience of illness in terms of psychological or cognitive-based concepts, theories, emotions, and attributes. This suggests that these studies predominantly understood and interpreted the self cognitively as a subject. In interpreting the self in this manner, it is suggested that these studies may have effectively concealed, or covered over other equally valuable interpretations of the person and his/her experience of ESRD. This is because the contextual background information about the person is usually not captured with the use of quantitative methods. Therefore, there is a need to provide a different approach to explore the person's experience, which would nullify the subject/object dichotomy retained in quantitative research and also to be able to obtain detailed background contextual information about the participants through elaborate narratives.

To overcome this Cartesian dualistic perspective, this research study proposes an alternative to exploring the person's experience of ESRD. Hence it is suggested that the use of a hermeneutical interpretive phenomenological methodology, based on the philosophy of Martin Heidegger will provide this different perspective in this research.

Methods

Phenomenology is both a philosophy (Spiegelberg & Schuhmann, 1994) and a qualitative research method

(Munhall, 2012). For example, Benner's (1994) method of interpretive phenomenology among others is a method that stems from the Heideggerian school of thought (Heidegger, 2008). This method gives significant understanding and interpretation to human existence, this human is referred to as Dasein (Létourneau et al., 2020).

In this particular study, the study was conducted using Heideggerian interpretive hermeneutic phenomenology to interpret the lived experiences of patients living with endstage renal disease in Ghana. Phenomenology is the best approach to study the lived experiences of patients. Heideggerian hermeneutic phenomenology was used because the key tenets in it such as everyday ordinariness, Dasein, being in the world, being with, encounters with entities, temporality, spatiality, and the care structure, inherent in his philosophy can serve to uncover the meaning of everyday ordinary human existence and experience for the patient living with end-stage renal disease (Horrigan-Kelly et al., 2016).

The participants of this present study were purposefully selected from the medical ward of the hospital where the study was done. The hospital has a bed capacity of 800 and a staff strength of about 2800. It has various departments and specialty areas: Neuro-surgery, orthopedics, Urology, gynecology, plastic surgery, etc. The medical ward where the participants were selected has a bed capacity of 64 and a nursing staff strength of 48, four doctors which comprise of two nephrologists and two general practitioners. The selection of participants was based on their abilities, willingness to participate, and their experiences regarding the phenomena under study. Inclusion criteria for the study were being 18 years and older, having the ability to communicate and speak Dagbani or English, willingness to share personal experiences, being oriented to time, person, and place, and being diagnosed with end-stage renal disease for at least 6 months or more. The exclusion criteria were; if the patient was so ill to the point where it could interfere with informed consent or participation in interviews, those diagnosed with the end-stage renal disease but below 18 years, those diagnosed with stages one to four of chronic kidney disease either below or above 18 years because these patients have not yet advanced to stage five or end-stage renal disease which is the focus of this study and those above 18 years but diagnosed with ESRD less than 6 months because we were considering patients who have experienced ESRD for at least 6 months.

The data collection process took place between February to September 2019. This was done by the third author of this article. Heideggerian Phenomenology focuses on encounters with entities, temporal,y, and the care structure, and serves as a means to uncover the meaning of everyday ordinary human existence, hence the following questions structured around these tenets of Heidegger's philosophy will help uncover lived experiences of ESRD patients. The participants' experiences regarding ESRD were elicited using individual in-depth semi-structured interviews, structured around main questions,

and probing questions such as: What effect does ESRD have on you since you encountered it? How has your encounter with ESRD changed your life? What influence does the condition of ESRD and its treatment and associated challenges affect your day-to-day living? Can you tell me more about the condition? The recordings were carefully listened to several times immediately transcribed verbatim and analyzed. Each interview lasted for about 30 to 55 minutes. Data saturation was reached during the interview of the 13th interviewee when no new information was being obtained and hence interviews ended. The first interview was made with a 36-year-old illiterate woman whose husband had divorced her. After establishing rapport, and confirming she has been living with ESRD for 9 months, the first question she was asked was, what effect does ESRD have on you since you encountered it? Probing questions mentioned above were also asked. This interview lasted for 45 minutes and after that, the interviewer thanked her for sharing her experiences. The interviewer transcribed the recorded tape later and it was reviewed several times with frequent stops. In reviewing the tape, some questions were slightly changed and new questions were added to the interview guide (Appendix). The research team met to review the text transcript.

Data analysis was done using Diekelmann et al. (1989) methodology which was revised by Diekelmann (2012), as shown below:

- 1. The hermeneutic analysis began with each team member reading each interview text to gain an overall understanding of the participant's experience.
- Common themes were identified themes describe recurrent categories or ideas that reflect the shared experiences and practices embedded within the text.
- 3. The research team met and members read the themes they identified and their interpretation of these themes aloud. Each team member supported his or her interpretation of identified themes with excerpts from the interview text obtained from participants.
- 4. As we analyzed texts subsequently team members discussed the commonalities and differences emerging in the interpretations and clarified unclear, vague, or conflicting meanings that surfaced during the analysis by referring back to the interview text or by reinter-viewing the participants.
- 5. As we continued the analysis of interview text, team members investigated recurrent themes those themes that were identified across multiple texts more fully, challenging, and elaborating on the interpretations using the philosophical text of Heidegger, Gadamer, and merleau ponty to add richness and complexity to the interpretation by exploring nuances and qualitative distinctions present and a manuscript was then drafted
- The principal researcher received individual feedback about the manuscript drafted from research

- team members and persons outside of the research team including two nurse researchers familiar with the research approach and topic.
- The principal researcher incorporated the feedback from the interpretive team and from others who are familiar with the content and methods of the study into the final manuscript (Diekelmann, 2012)

It is worth noting that during the interpretation process, the continuity of movement from parts to whole and from whole to parts was observed. This was to ensure that the true essence of the experience was uncovered by "reading between the lines" and hence resulting in a shared understanding of the phenomenon of ESRD people's lived experiences. Several strategies were used to enhance the rigor of the findings. The rationale for ensuring rigor is that it guarantees quality and credible qualitative studies.

The credibility of the findings was established through continued contact with participants and engagement with the data. The rationale was to ensure that we immerse ourselves in the participants' world (Gallicano, 2005). This helped us to gain an insight into the context of the study, which minimized the distortions of information that might arise due to our presence in the field. Also, this helped us improve the trust of the respondents and provided a greater understanding of participants' culture and context (Onwuegbuzie & Leech, 2007). Furthermore, as "extended period was observed rapport increased, and informants volunteered different and more sensitive information than they did at the beginning of the research project" (Krefting, 1991). Interrater reliability to achieve credibility was done as follows. Interviews were conducted and transcribed verbatim by the third author (NY). The second author (AM) did the data analysis, in line with the approach or method adopted by Diekelmann et al. (1989) and reviewed by Diekelmann (2012). Although AM, had not conducted the interviews, she listened to the audio recordings several times before engaging in the analysis of transcripts. After AM, had analyzed three of the transcripts, she invited the third author NY, and first author NN, to independently analyze the same three transcripts to increase the trustworthiness of the analysis and reach a consensus about the themes. Each researcher carried out the first two steps of the analysis process using Diekelmann et al. (1989) method, which was revised by Diekelmann (2012). This method begins by reading the transcribed texts for an overall understanding and then writing interpretive summaries and developing codes for the emerging themes. Once we had completed our independent analysis of the three transcripts, we met to compare our results. This meeting was audio recorded. We began by discussing our general thoughts and impressions of the three interviews and taking notice of presuppositions that we felt may have affected our analytical approach. We considered it important to acknowledge the possibility that our own prior experience(s) and perceptions may have influenced our responses to any given participant. We were aware

Part. code.	Ages	Stage of disease	Period on dialysis	Etiology	Ethnicity	Level of education	Gender	Occupation	Religion	Marital status
I	36	Fifth	Not yet	Hypertension	Dagomba	Illiterate	Female	Petty trader	Muslim	Married
2	58	Fifth	Not yet	Hypertension	Dagati	Bachelors	Male	Priest	Christian	Single
3	56	Fifth	Not yet	Hypertension	Dagomba	Junior high	Male	Driver	Muslim	Married
4	40	Fifth	Not yet	Hypertension	Gonja	Diploma	Female	Teacher	Muslim	Married
5	29	Fifth	Not yet	Hypertension	Dagomba	Bachelors	Male	Lab. Tech.	Muslim	Married
6	65	Fifth	Not yet	Herbal drugs	Bimoba	Junior high	Male	Taylor	Christian	Married
7	58	Fifth	Not yet	Herbal drugs	Dagomba	Bachelors	Male	Accountant	Muslim	Married
8	50	Fifth	Not yet	Hypertension	Bulsa	Bachelors	Female	Secretary	Christian	Married
9	29	Fifth	Not yet	Hypertension	Frafra	Diploma	Female	Nurse	Christian	Married
10	53	Fifth	Not yet	Hypertension	Gonja	Diploma	Female	Nurse	Muslim	Married
H	34	Fifth	Not yet	Herbal drugs	Dagomba	Junior high	Male	Trader	Muslim	Married
12	23	Fifth	Not yet	Hypertension	Mamprusi	Illiterate	Male	Farmer	Muslim	Married
13	33	Fifth	Not yet	Hypertension	Frafra	Senior high	Female	Lab. Tech	Christian	Single
Average age	43.38		,			J				3

Table 1. Demographic Characteristics of Participants With ESRD, Yet to Start Dialysis.

of the need to approach our respective contributions with the "curious stance" suggested by LeVasseur (2003). This enabled us to probe each other's analysis in a non-threatening, open, and interested manner. Thus, employing Le Vasseur's curious attitude, we remained open to each other's perspectives and thereby further explored the similarities and differences in the way we were approaching and responding to the data which enabled us to achieve consensus. To verify dependability and conformability, detailed descriptions of the study including evidence and examples were used. Transferability of the findings were assured by providing sufficient contextual information, for instance by choosing participants from both sex, various age ranges, tribes, and from different regions of Ghana.

Ethical Consideration

This research was approved by the research ethics review committee of the studied university. Also, formal written ethics approval to conduct the study was granted by the research ethics committee of the hospital where the study was done. The nature and purpose of the study were explained to the participants. The participants were allowed to ask questions regarding anything they did not understand after which they were asked to sign an informed consent. The participants were assured that they have the right to accept or refuse participation in the study and also the right to leave the research at any desired time without any consequences. All participants were assured that their identities would remain confidential during the analysis and reporting of data.

Results

The demographic characteristics of participants' age, gender, marital status, educational level, occupation, ethnicity, etiology, and stage of kidney disease are shown in Table 1.

After the final analysis, five main themes emerged: (1) Spiritual fluctuation, (2) Living in uncertainty, (3) Period of agony and frustration, (4) Tough fortification, and (5) Changed roles and status, each including some sub-themes. The meaning units, sub-themes, and themes are shown in Table 2.

Spiritual Fluctuation

Participants in this study exhibited what can be termed spiritual fluctuation. They expressed their belief in God in some instances and also in other instances showed some lack of belief as their faith was tested with the emergence of the disease. For example, participants expressed their belief in God through activities like resorting to prayer, reading the bible, meditating, and reflecting on God, but at the same time showed disbelief when they question the existence of God and whether God was available to help or rescue them in times of difficulty. Two subthemes emerged from the main theme of spiritual fluctuation. (1) "Believe in God"; (2) "Slip of faith."

Belief in God

This phenomenological study found a construct exhibited by participants which Heidegger refers to as "being toward the future" The participant's sense of "being toward the future" in the context of this study is revealed in participant's 9 statement: she revealed her sense of future directionality in hoping, desiring and having the goal of forgetting about kidney problem by being healed through believing in God.

Participant 9 said "I went for prayers and the pastor said there is nothing God cannot do because he created human beings and the organs in us so if any of them get spoilt he God has a spare one and he can replace it for

Table 2. Summary of Meaning Units, Subthemes, and Themes.

Meaning units	Sub-themes	Themes	
Praying to God, meditating on God, and reading the bible	(a) Belief in God	Spiritual fluctuation	
This sickness made me not believe in God sometimes, it weakens my faith in God	(b) Slip of faith		
Living but not knowing what can happen the next moment.	(a) Unstable life	Living in	
I was thinking that eeeeh, so am I going to die like that?	(b) Fears	uncertainty	
I feel very weak, tired, and a whole lot of things. Always feeling sick, limited in everything I use to do	(a) Ailing and bounded	Period of agony and frustration	
I feel so sad, I am distressed and cannot pull myself together in this situation, I feel doomed, I feel depressed, frightened, and even angry sometimes asking why me?	(b) Hopelessness and emotional distress		
I have to give myself morale to fight it, to accept it and fight it that is all	(a) Fortified through embracing and adaptation	Tough fortification	
Hymn, I gain my strength from my wife, and parents. God leave them for me. They are exceptionally good and supportive.	(b) Fortified through Support and empathy		
You are sick and you cannot drive, two weeks ago I got up and I could not drive. So I had to let a friend bring me.	(a) Being dependent on others	Changed roles and status	
I have spent all my money, treatment is very expensive and it's now family members that are contributing	(b) Financial burden		
Half of my friends have separated themselves from me and are passing comments that I hear. Hmmm (crying and sharing tears at this point), they won't eat with me or share a cup with me.	(c) Stigmatization		

you only if you trust in Him, only trusting and I said if that is the case I would throw this thinking away and just trust in God and believe in Him because He can do anything at His own time and since then, I am not thinking about it again like before I thought this sickness is a punishment or test from God and so I accept my situation and give everything to God. I read the Bible all the time and pray. I am a Christian; I have my faith in Christ. I am hoping that one day I will forget of kidney problem that is my goal and desire and what am thinking."

Slip of Faith

The focus of Heidegger's existential analytic of Desain is on human beings' existence as an individual in his or her world as well as in their social context. From a Heideggerian stand, therefore, being in the world depicts a union of the world's objectivity and the subjectivity of Desain or human beings and hence are inseparable from each other (Horrigan-Kelly et al., 2016). Desain jointly exists with others in shared humanness and interacts with them in the world (Horrigan-Kelly et al., 2016). For this study, the world was defined as the participants' view of being in the world as people living with chronic kidney diseases embedded in a world of inseparability and interacting with other entities they encounter. The participants in this study's recount of existing in the world uncovered their sense of "throwness" that is they are being subjected to the impact and influence of the larger societal norms, values, beliefs, and even decisions and suggestions from family members and friends into which they

were born. This exposes their sense of changed existence from people who once believed strongly in God so much to people who now doubt God or have disbelief in God due to these societal values, customs, and influence of other entities they encounter in their world (Horrigan-Kelly et al., 2016). Participants slip in faith in God and changed existence can be seen from the following statement;

Participant 13 said: "In my most difficult times, I wondered whether God was in existence and could save me from my troubles. My thought was is this a test or a lesson from God for me? My faith in God was weakened. It was reduced at times especially when friends and family members advised me to seek help from smaller gods and "juju men" and stop believing in God.

Living in Uncertainty

This main theme included two subthemes: Unstable life and Fears. Participants of this study experienced a lot of uncertainty in their lives following the diagnosis of this condition. They had varied experiences ranging from not knowing what could happen to them the next moment, being afraid of dying anytime soon since there is no cure for the condition.

Unstable Life

Employing Heideggerian terminology, participants in this study were found to be experiencing or having circumspective concern and angst about their situation and impending death since the cure was not possible. This circumspective concern and angst reveal what the human being cares about or is cautious about and what is of most concern to him/her. The participants were so angst and anxious about life and what could happen to them next. They knew what could happen next was death since the cure was impossible in Ghana. Participants showed instability in their life. This varied from living in suspense, unsecured future, facing life or death, and unknown future. They experienced a turbulent life and not knowing what could happen the next moment.

Participant 1 stated: "I feel I am suffering for nothing if I continue to do those things because anything can happen at any time. I am facing life and death [Hmm!] I am worried and thinking whether I will get well or I will die"

Fears

Participants were found to entertain fears as they struggle with the condition. Most of them were not afraid of only death but the fact that they were going to die and leave their children behind. Their children were of so much concern and matter so much to them. This was of more concern to them than even the death threat. This is what Heidegger refers to as care structure- which reveals what is of concern or most consequence or important to the human being or Desain. He analyses and interprets into detail the care structure as; "the structural totality of being in the world" or "Dasein's fundamental totality of Being" (Horrigan-Kelly et al., 2016). This uncovers the human being's watchfulness and carefulness to consider circumstances and their consequences and being worried about them. It is human being's circumspective concern and angst, to put it in Heideggerian terminology. This is illustrated in the following statement;

Participant 11 remarked: "Actually, my fears are in two parts one aspect is children, I am thinking in case I die how they will survive, who is going to take good care of them? And another aspect is when they misdiagnosed me as having H.I.V but I don't fear death because whether I like it or not when the day comes for me to die, I will go. But it is my children that I fear for and everything of me has gone backward.

Period of Agony and Frustration

This theme included two subthemes: (1) Ailing and bounded and (2) Hopelessness and emotional distress

Ailing and Bounded

Participants experienced a lack of normalcy, limitation to movement, difficulty carrying out physical activities. Participants demonstrated how they were physically restricted to one place because of ill health and could not do most of the things they used to do. Participants said they have tried their best to adjust and adapt to their situations and move ahead because they have no control over the situation. Like most of the participants, participant 12 said, I have adjusted and moved on with life but still when I remember the past and sometimes watch my pictures and compare, I break down. Participant 13 also said I have accepted my situation like that and moved on but if I look at my pictures hmmm (crying at this moment) if you want, I can give my pictures for you to look at how I was. This is what Heidegger would say that our past is always in front of us (Poorman & Mastorovich, 2019).

Also, with regards to Heidegger's philosophy, the tenet of "being with," this phenomenological study found that the study participants co-existed with structures, practices, and processes and other people all of which shaped and impacted the meaning of their lived experience as people living with ESRD seeking care in the health facility (Horrigan-Kelly et al., 2016). Heidegger postulated that the "They" or "Das Man" exist in the world of Dasein and thus have the influence to shape the opportunity of Dasein (Horrigan-Kelly et al., 2016).

According to Heidegger, the "They" or "Das Man" is something that goes beyond interactions with other human beings or Dasein and thus acknowledging interactions with structures, practices, and processes that can shape and influence human beings' existence (Horrigan-Kelly et al., 2016). Therefore from Heidegger's stands being with and interacting with other human beings or Dasein goes along with encountering with other entities that influence and shape Dasein's existence (Horrigan-Kelly et al., 2016).

Participants of this study revealed through this phenomenological study that, their encounter with the health facility and procedures and practices impacted and influenced their lived experiences so much. This is revealed in the following quotes from participants:

Participant 7 says "One thing I don't like coming to this hospital is the long bureaucracy and protocols and policies you are subjected to when you come here especially at the OPD"

Participant 10 says "I always become further when I am in this hospital because of the existence of poor infrastructure and social amenities, for example, you can't have a place of convenience as and when you wish because of lack of water flow from taps, and also as you know with this condition, we are weak and frail and they expect you to walk up and down the stairs to the second floor where the ward is for procedures with the excuse that the lift is not working."

Hopelessness and Emotional Distress

Participants in this study experienced various emotions as a result of the condition: anger, sadness, unhappiness, anxiety,

and depression. Whilst others tried accepting the situation and moving on with the time others fail to do that and so manifested such behaviors as depression, suicidal tendencies, and anxiety. Some of them said it seems at this point life is not worth living because the disease has no cure, meanwhile, all other diseases have a cure and hence were very worried about it. This is human being's circumspective concern and angst according to Heidegger. Participant 2 said: "I feel so sad, worry and always thinking about this condition. I am distressed and cannot pull myself together in this situation, loss of hope and doomed, I feel depressed, frightened, and even angry sometimes. . . asking why me?

Tough Fortification

The participants had to find ways to toughen themselves to face their situation. Participants stayed positive, drew inner strength from themselves, self-inspired themselves as well as encouraged themselves to get going. This main theme consisted of two subthemes: (1) Fortified through embracing and adaptation; (2) Fortified through support and empathy.

Fortified Through Embracing and Adaptation

It was realized that participants of the study embraced, adapted, and endured their condition to live with it. The embracing, adapting, and enduring ranges from the pain they suffered from the condition, the discomfort of all kinds, to difficulty in living. They embraced by accepting their condition and adapted by learning to live with it and drawing inner strength from within themselves to fight the sickness. They found strength and being fortified through faith in their God because they grew to believe in God because of the religious background of their families. Participant 13 said" my family is a very strong Christian family and we are all very religious" According to Heidegger, the world is experienced as a home by human beings in which they distinctively make their homes as a way of being (Moloney, 1995).

Fortified Through Support and Empathy

Families played a crucial role in helping participants to get through their predicament and were a constant source of support that helped them to adapt and endure their illness. On many occasions, the participants referred to their families, friends, and nursing staff as a source of support and empathy. Following Heidegger's philosophy, his existential analysis of Dasein emphasizes human embeddedness in their world in a social context. Heidegger's stance of human beings being inseparable from their world means that there is a union of the objectivity of the world and the

subjectivity of the individual living in the world (Horrigan-Kelly et al., 2016). This includes the human being or Dasein living in a world with others where there is an interaction between the human being and the world in which they live (Horrigan-Kelly et al., 2016). For this study, the world was defined as the participants' view of being in the world as people living with ESRD and interacting with other entities they encounter. The participants in this study's recount of existing in the world uncovered their sense of "throwness" which is a situation where they have been born into the world and impacted, influenced, and shaped by the society at large. Also, the impact of ESRD, in turn, exposed their sense of being changed from normal adult human beings in control of their lives to vulnerable ailing and bounded adults who were no more being in control of themselves. They recounted how they shared their existence in the world as ESRD patients with others and their encounters with societal norms; values, beliefs, traditions, cultural practices, and procedures, and how it influenced and impacted their lives and existence in the world. The change in existence of these patients was exposed in their accounts of being changed in size and appearance of their bodies and how they have grown weary due to the sickness. They recounted being treated differently by some people they encountered due to their outward-looking and appearance. The health professionals (Dasein) who were rendering services and the health facility constituted the entities they encountered most and also including their caretakers. The participant's encounter with these entities during health delivery resulted in two experiences. One experience was that of exposure to a ready-to-hand (useful service entity) that helped them, supported them, and was so useful to them toward their well-being. For example;

Participant 11 expressed "Hymn as for my wife, and parents God leave them for me. They are exceptionally good and supportive." They are always there for me and doing everything for me. Sometimes when it is so hurting, I will let my wife dance for me. Sometimes I will let my children dance and we play among ourselves, also some friends and health workers are very supportive and empathic."

Participant 13 "And I also want to thank you people (referring to health staff) for your support and empathy and for giving me my life back. You do it well, very, very well. I would say hundred percent serious my dear and not forgetting the support of some friends and family members who are always present when needed."

On the contrary, they also gave accounts of encountering service entities that show useless service entities which Heidegger terms as entities unready or present at hand which did not help or support them in the process of receiving health delivery; Participant 11 said "I went to a private hospital and they treated me and the Doctor there told me I have HIV. He asked me whether I was aware of it and I said no I am not. And I said ahh where from this HIV? Then he told me I should go to another hospital with a referred letter. And I came and they directed me to one room and there was one old lady who collected the note and in fact, she wasn't of any help to me, my encounter with her was so horrible and scary, frankly speaking, the woman should be retired by now, she is in her menopause stage and behaves as if she is not a professional. When she collected the note instead of finding a way to calm me down so that I will not be scared she just told me straight away that I have HIV. I almost collapsed in front of her."

Changed Roles and Status

Participants of this study experienced a lot of changes in their roles and status. It ranged from not being able to do activities of daily living, inability to perform their roles, not having money to help them move on in life, and life not worth living again because of the stigma they experienced. Three sub-themes emerged from this main theme: (1) Being dependent on others; (2) Financial burden; (3) Stigmatization.

Being Dependent on Others

Participants of this study experienced dependency on people for their activities of daily living. They faced difficulties doing what they used to do because of the illness and hence had to depend on people for support.

Participant 13 said "Oh, the challenge? Walking is the most important thing in my life because if you cannot walk, it means they are doing everything for you and it's painful that you are alive and you can't do anything." This participant's quote reflects a construct by Heidegger known as "being toward" This construct reveals what a participant care so much about or what is of concern to them depicting the participant's "structural totality of being in the world" (Horrigan-Kelly et al., 2016). In this study, the meaning participant 13 ascribed to what mattered to her and is so important to her is walking as seen in her quote above.

Financial Burden

Participants of this study experienced some problems of financial burdens in their lives which brought life to a tough situation following the diagnosis of end-stage renal disease. These included the inability to pay fees for their wards, pay the family bills, to inability to raise funds for treatment as well as fend for their families. A construct by Heidegger known as "being toward" reveals what participants care so

much about or what is of concern to them depicting the participant's "structural totality of being in the world" (Horrigan-Kelly et al., 2016). In this study's findings what mattered so much and was of concern to participant 7, was about how to finance dialysis expenses when he starts dialysis, and other expenses for treatment, and also how to pay his children's school fees. He also expressed what Heidegger refers to as circumspective concern and angst in his circumstances.

Participant 7 stated: "On my health and finances. The finances are the worst of it all and my children because I have to pay their fees and, in this situation, it is so difficult. I have a challenge with the dialysis, the amount they mentioned is too much and I don't have support, if my office can even support me with 50% of the amount, I would be happy so because of this it has a toll on me because I am always thinking where I am going to get the money to be doing the dialysis. And if I don't do the dialysis, I may die early than I should so this is my predicament."

Stigmatization

Participants also experienced stigma which varied from name-calling to refusal to eat with participants as well as passing comments about participant's situation among others. Some health workers' attitudes and behaviors were also considered not supportive and helpful. The participants felt stigmatized from the way people stared at them, ignored them, refusal to eat or drink from the same cup with them among other behaviors. These are encounters with entities in their social world that did not support them toward recovery and achieving their future directionality of desiring and aiming to get well as such Heidegger refers to such as encounters with un-useful service entities or entities present at hand.

Participant 11 said: "Half of my friends have separated themselves from me and are passing comments that I hear. Hmmm (crying and sharing tears at this point), they won't eat with me or share a cup with me, they ignore me and look down upon me as if I am not a human being, the way everybody was running away from me I believed I didn't have anybody apart from my wife and children or parents."

Discussion

This study showed that Ghanaian patients with ESRD experienced a range of emotions and faced a lot of challenges based on their lived experiences and perceptions. According to the emerged themes living with ESRD for a Ghanaian patient means experiencing spiritual fluctuation, living in uncertainty, living a period of agony and frustration, experiencing tough fortification, and having changed roles and status.

According to researches, how 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 (Al-Ghabeesh et al., 2018). Participants of this study experienced spiritual fluctuation with ESRD and considered spirituality as a way of accepting, understanding, and coping with ESRD. These results were similar to the findings of other studies like Al-Ghabeesh et al. Also, the findings of the current study were consistent with some other studies regarding the significance of spirituality (Al-Ghabeesh et al., 2018; Molzahn et al., 2012; Scaife, 2006).

Kaba et al. (2007), Sahaf et al. (2017), and Weitz (2012) have found that uncertainty is inevitable and is created in a patient's mind in the course of the disease, and people are forced to live with uncertainty and confusion when many things can go wrong or further disability is likely with the progress of the disease. The results of the current study regarding living in uncertainty were in line with the mentioned study above in this paragraph. Sahaf et al. (2017) reported that when the level of uncertainty was higher, it was more likely to be assessed as a risk or menace. This uncertainty led to fears and instability in the lives of patients. This means that nurses and other health care providers should take into account the feeling of uncertainty experienced by patients serious when they are rendering care for them. The findings of the current study were consistent with the following study regarding uncertainty in patients with end-stage renal disease (Duguay et al., 2014).

Based on the lived experiences of the participants of this study living with ESRD means agony and frustration which was similar to the findings by Dekker et al. (2005), Faber et al. (2003), and Polaschek (2003), which found similar situations of the physical and emotional turmoil of the study participants. One of the sub-themes that emerged in the present study was "ailing and bounded" which was consistent with Polaschek's (2003) study, where symptoms of insomnia, hypotension, tiredness, and malaise following treatments were considered significant issues in the lives of patients with ESRD on dialysis. Moreover, Cukor et al. (2007), Lopes et al. (2007), and Morsch et al. (2006) identified that all hemodialysis patients had to face increased limitations to their functional independence especially on the day of dialysis and this restricted their social participation which was in line with this current study's finding of physical limitation in patients with ESRD.

The theme of tough fortification consisted of two subthemes: Fortified through embrace and adaptation and fortified through support and empathy. The participants' statements in the present research suggested a significant role of the empathy of the health workers and family members in the care and support for them. In this regard, Nagpal et al. (2017) have found that family members, especially one's spouse, have the most important role in providing mental health services to a patient with chronic illness. Embrace

and adaptation were not found in previous publications. (Ghaedi et al., 2020) highlighted the significance of family unification and empathy and also responsible accountability of nurses which are congruent with the results of this research. Compassion and the support of family and health care providers can reduce the psychological tensions of these patients and help them to cope with their illnesses.

The main theme of changed roles and status included three sub-themes: being dependent on others, financial burden, and stigmatization. Being dependent on others, was consistent with the findings of the following studies (Peikani et al., 2018; Shahgholian & Yousefi, 2018). Haririan et al. (2011) showed that supportive care leads to increased compliance with therapeutic regimen, and improved quality of life. In a related study that investigated the barriers of adherence to the therapeutic regimen in patients with type 2 diabetes, the participants have stated that one of the factors impeding compliance with the therapeutic regimen has been inadequate family support (Shafiei et al., 2012). From the participants' statements regarding their dependants on others and the mentioned studies, it can be concluded that managing patients' dependency on others and trying to promote self-care is a very important factor that should be considered in designing a care plan for these patients.

Regarding stigmatization, the results of the current study were consistent with some similar studies where the adverse effects of stigmatizations on the self-image of patients have been highlighted (Orr et al., 2007; Tong et al., 2013). These two studies found that patients with ESRD experienced different and undesirable treatment of family members and friends because of their conditions which led to the frustration of patients.

Strengths and Weaknesses of the Study

The strength of the study is that findings are based on the lived experiences of patients and hence represent truly the feelings, perceptions, and opinions of the patients themselves who are experiencing ESRD, and also the study was done using a rigorous and trustworthy methodology which is the determining factor for quality qualitative study. The weakness, however, is that the findings of the study cannot be generalized since the data collected was limited to a small sample size.

Application in Nursing Practice/ Education/Administration

In nursing practice, clinicians can use the findings of this study to help them plan for the care of this category of patients since the findings reflect the needs and experiences of these patients. The themes of this study for example show this category of patients need adjustment and coping strategies to cope with their difficult situations because of the

physical, spiritual, emotional, and psychological stresses they experience. Hence clinicians can use valid coping strategies to educate their patients on how to cope with their condition. The results of this research may also be incorporated into the curriculum of health workers especially nephrology nursing programs so they are trained and educated about the emotional, psychological, physical, and spiritual stresses these patients experience with this condition and hence help them know the kind of coping strategies and care they need. Administratively, the findings can be used to advocate for and convince hospital stakeholders and managers to institute certain kinds of care for this category of patients. For example, spiritual leaders can be employed for patients' spiritual care, psychologists can be employed to provide psychological care based on the evidence of this research that these patients need psychological care.

Conclusions

This study provides insight into the lived experiences of patients living with end-stage renal disease in Ghana. From the findings of this study, living with ESRD for a Ghanaian patient means experiencing spiritual fluctuation, living in uncertainty, living a period of agony and frustration, experiencing tough fortification, and having changed roles and status. The results of this study may benefit nursing care in terms of considering the patients' lived experiences to provide holistic and person-centered care.

Recommendation for Further Study

This study was a qualitative study on the lived experiences of 13 ESRD patients, and therefore uncovered a snapshot of their experiences at this particular time and in their environment and cultural orientation. A study that can follow the whole process of the illness trajectory from diagnosis, through treatment processes till the end of life or recovery in case of a kidney transplant may reveal a lot of knowledge that can help health workers and patients altogether.

Appendix

Interview Guide

- 1. Please tell me about yourself with regards to the following:
 - Age
 - Employment status
 - Educational background
 - Family socioeconomic status
 - Religion
 - Ethnic group
 - Region you come from

- 2. Please can you give me a brief history of your sickness?
- 3. How do you feel about it?
- 4. How does it feel to live with this sickness every day?
- 5. What does it mean to live with this condition?

Probing questions; what meaning do you ascribe to it?

"What is the lived experience of being a patient with ESRD?

What effect does ESRD have on you as you have encountered it?

- 6. How does the sickness affect you psychologically, emotionally, and physically?
- 7. How has it affected your day-to-day living?

Probing questions: How do you cope with the condition of ESRD and its associated problems and treatment?

Can you tell me more about the condition and explain further your experiences with this sickness?

- 8. How did you receive the news of your diagnosis?
- 9. Did that cause some fears in you?
- 10. On a day-to-day basis what strategies do you use to help deal with the condition?
- 11. Has the sickness affected your social life?
- 12. Has it affected your relationship with your partner? Explain how.
- 13. How has the sickness affected your roles and responsibilities in the family?
- 14. How do people relate to you now compared to before the diagnosis?
- 15. So considering all the challenges you go through how does it make you feel?
- 16. What does the sickness chronic kidney disease mean to you?
- 17. How will you define it in simple terms for somebody to understand what you go through?
- 18. Is your life threatened by this sickness? How?
- 19. Has having this sickness made a difference in how you see yourself?

Probing questions; if so how do you see yourself now than before? How do others see you now? How has it changed your life?

Acknowledgments

The authors of this manuscript are grateful to the participants of this study for agreeing to participate and cooperate throughout the study. We also want to thank both the ethical review committees of Tehran University of Medical Sciences and Tamale Teaching Hospital for granting us permission and approval for this study. We also thank the staff of the medical ward and nephrology clinic for their cooperation during the study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for this article's research, authorship, and/or publication.

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Supplemental Material

Supplemental material for this article is available online at the journal's website.

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