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Spiritual issues of people living and dying with advanced heart failure in Kenya: a qualitative serial interview study

Kellen N Kimani,[1] Scott A Murray,[2] Liz Grant[3]

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[1]School of Public Health, University of Nairobi, Nairobi, Kenya
[2]Primary Palliative Care Research Group, The Usher Institute, University of Edinburgh, Edinburgh, UK
[3]Global Health Academy, University of Edinburgh, Edinburgh, UK

Correspondence to
Dr Kellen N Kimani;
K.N.Kimani@sms.ed.ac.uk

ABSTRACT

Background: Exploring patients' spiritual issues is vital for informing holistic care. The spiritual concerns of patients living and dying with advanced heart failure in sub-Saharan Africa remains unknown. Our aim was to describe spiritual issues in the context of the lived experiences of patients with heart failure in Kenya.

Methods: We purposively recruited 18 patients admitted with advanced heart failure at a rural district hospital in Kenya. We conducted serial in-depth interviews with patients at 0, 3 and 6 months after recruitment. We conducted bereavement interviews with their carers. Interviews were recorded, transcribed into English and analysed using a thematic approach, assisted by Nvivo software package.

Results: Patients expressed traditional and Christian spiritual beliefs in response to their illness. At diagnosis, some patients felt their illness had occurred because they had wronged God, while others felt betrayed by God. Some expressed comfort from God and optimism believing that God was in control and would heal their illness. During acute episodes patients questioned whether witchcraft or curses caused their illness. Younger patients experienced more spiritual distress. Although church fellowship generally offered spiritual and social support, some patients felt let down by the church which they perceived to favour those who offered more tithes.

Conclusions: This is the first study to explore the spiritual issues of people living with advanced heart failure in Kenya. Understanding patients' spiritual concerns is important for developing evidence-based patient-centred holistic care to promote multidimensional well-being.

Key questions

What is already known about this topic?

- Spirituality influences how people experience illness.
- Diagnosis of a life-threatening illness may trigger existential angst.
- Spiritual distress may trigger physical and emotional distress and lead to increased health service use.

What are the new findings?

- This is the first longitudinal study to explore spiritual concerns of patients with heart failure in sub-Saharan Africa.
- Patients' spirituality offered comfort but was also a source of distress.
- Younger patients experience considerable spiritual distress.

Recommendations for policy

- This study highlights the need for patient-centred holistic care to identify spiritual concerns contributing to distress.
- Spiritual distress may lead to poorer health outcomes for patients.
- Holistic care may improve patients' wellbeing, reduce healthcare usage and curtail the vicious cycle of poverty associated with chronic diseases in this setting.

INTRODUCTION

The notion that spirituality influences how people experience disease is not new. Throughout human history, spirituality has strongly been associated with health and illness. For example, in prehistoric times, diseases were understood to be caused by supernatural forces and were treated by applying natural and spiritual practices.[1] In modern times, the importance of spirituality in health is evident from its inclusion in numerous clinical measures[2] including those that assess quality of life[3] Furthermore, spirituality is also as an important component of holistic approaches to care[4] including palliative care.[5]

Receiving a diagnosis of a life-threatening illness can be a traumatic experience. Questions such as *why is this happening?* or *why me?* often reveal existential angst as people attempt to make meaning of their diagnosis and the reality of death.[6] Previous studies on the experience of living with heart

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failure (HF) conducted in the UK reveal that patients experience multidimensional distress throughout the illness trajectory. As physical symptoms deteriorate patients suffer a decline in psychosocial and spiritual well-being. Unpredictable acute episodes and the risk of sudden death mean that patients may be unprepared for worsening symptoms which may heighten their distress.[7 8] Poor communication from health professionals and a lack of understanding of their illness may add to their suffering.[9 10]

As patients struggle to find meaning they may rely on their spirituality to make sense of their experience. Westlake and Dracup[11] identified ways in which spirituality may help people with HF adjust to their illness. By searching for meaning in their experience, patients may regain hope and renewed optimism. Such positive spiritual responses have been associated with better health outcomes as patients experience fewer symptoms of depression,[12] enhanced quality of life[13] and better health practices[14] such as improved adherence to treatment.[15]

Sub-Sahara Africa (SSA) now faces a burgeoning epidemic from non-communicable diseases.[16] Although countries in North America and Europe may bear a greater disease burden, low-resource settings experience higher mortality rates. While the extent of the disease burden is yet to be quantified in SSA, hospital surveys estimate that HF accounts for 9–15% of admissions.[17] The unpredictable and long-term nature of these illnesses, together with its potential for significant psychosocial and spiritual distress, is likely to place a significant strain on the existing fragile health systems.[16 18]

In order to develop holistic services that can respond to patients' dynamic needs, it is vital to explore how their spirituality influences their illness experience. Unmet spiritual needs may lead more to physical, psychological and spiritual distress which results in more health service use.[19] Given the highly spiritual nature of communities in SSA and the considerable role of spirituality in well-being, it is crucial to explore how this influences the experience of living with HF in SSA. In this region, literature exists describing the role of spirituality for patients with chronic diseases such as cancer and HIV;[20–22] however, similar evidence from people living with HF remains scarce. This paper aims to fill this gap by reporting the spiritual issues of patients with HF in Kenya.

We acknowledge that spirituality is a complex phenomenon and definitions vary.[23] In this paper, we embrace a broad definition: "spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred".[24]

METHODS

Study design

We conducted a longitudinal qualitative study using serial in-depth interviews to explore patients' lived multidimensional experiences. This methodology is useful for capturing dynamic needs and preferences along the course of illness. Given the sensitive nature of patients' accounts, longitudinal techniques allowed time for trusting relationships to develop between the participants and researchers facilitating the exploration of these sensitive issues.[25 26] Similar methods have been used to explore the spiritual concerns of patients living with cancer and non-malignant illnesses.[7 19]

Interviews were conducted at three monthly intervals up to a maximum of 6 months. However, this was flexible and dependent on a patient's health status or the occurrence of an event, such as a hospital admission triggering an earlier or later interview. KNK, a female Kenyan public health doctor conversant in the local vernacular as well as Kiswahili and English conducted the interviews. Interviews took place in hospital wards or at the patient's home and lasted 25–125 min. Patients were contacted on phone monthly to maintain contact and schedule subsequent interviews. Changes in their condition were recorded. Written consent was obtained before starting the first interview and confirmed verbally prior to subsequent interviews.

A topic guide was used to steer interviews. It explored patients' subjective physical, social, psychological and spiritual experiences including their experiences and expectations of care (see online supplementary file). Interviews were conducted in local language Kiswahili or English. Interviews were audio recorded in local language and transcribed into English by KNK with the assistance of an experienced transcriptionist. Field notes were written after each interview to record the observations made while interviewing.

Methodological orientation

This research was underpinned by a critical realist theoretical orientation. Critical realism is a philosophy between relativist and objectivist theoretical perspectives. It claims to be a realist ontology and a constructivist epistemology. Reality is viewed as being external and independent but individually constructed. It underpins several analytic approaches including thematic analysis.[27–29]

Study participants

Patients were purposively recruited from a county hospital (previously a district hospital) serving a predominantly rural population in Kenya. Hospital doctors and nurses identified potential patient participants on the ward and informed them about the study. Patients were sampled to reflect the local epidemiology and sociodemographic characteristics of people with HF in this setting. This was guided by local statistics, hospital data and published literature.[30] We also asked patients to identify a carer for bereavement interviewing. In some cases we anticipated that patients would not wish to identify a carer. In such instances, we respected the patient's preference.

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Forty patients admitted with a diagnosis of advanced HF classified as New York Heart Association Grade III/IV were found suitable by their clinician and approached for recruitment. Of these, 18 agreed to take part and 22 declined. Eighteen carers were also identified by patients for possible bereavement interviewing. We excluded patients with cognitive impairment, with a primary diagnosis of another advanced life-limiting illness (such as cancer) requiring most care, and those living beyond 35 km from the recruiting facility. Our sample size was informed by previous research in the experiences of patients with advanced HF in the UK suggesting that serial interviews with 20–25 participants would generate ample data to approach saturation and answer our research questions,[31] guidelines from ethics committees and resources available to successfully complete the study.[32]

Analysis

Transcripts and field notes were analysed using the Braun and Clarke[33] approach to thematic analysis. The analysis included an initial data familiarisation phase followed by code generation to identify patterns. Codes were organised to form themes portraying participants' experiences with an ongoing review of themes to ensure data within themes were coherent and variations between themes were distinguishable. The analysis was iterative and occurred throughout the research process.[34] Regular multidisciplinary advisory group meetings (with LG, KNK, SAM) were held to review the emerging codes, themes and assess for data saturation. In addition, a research journal was kept to maintain reflexivity. Data management was assisted by qualitative package Nvivo. The COREQ checklist guided reporting.[35]

RESULTS

A total of 18 patients (10 women; 8 men) took part in this study. Five patients died and four were untraceable by the end of the study. Two interviews were held with bereaved carers. All patients ascribed their religious affiliation as Christian and reported a belief in God with 15 regularly attending a church service. Attempts were made to recruit participants from other religious groups, but the predominance of Christianity in this community prevented this. All participants were Kenyans, the majority being Kikuyu.

Table 1 summarises participants.

Throughout their illness, patients experienced considerable multidimensional distress. Their physical decline was interrupted by periods of acute exacerbations. Physical symptoms such as breathlessness, fatigue, ankle swelling, exercise intolerance and insomnia were common. Most were poorly informed as they did not understand their diagnosis, treatment regimen or how to plan for the future. The cost of care was a significant burden for patients which at times resulted in significant distress. Within this context spiritual issues were identified.

Spiritual issues expressed at the time of diagnosis

Although most patients knew they had a 'heart problem', they were not aware of the significance of their diagnosis. They felt vulnerable as they were confronted by an unfamiliar illness. This often caused anxiety as patients questioned the origin of their illness. At this time, some patients derived comfort from their belief in an omniscient God.

> Where is this illness from? We don't have this illness in our family….only God knows where it's from (Patient 6, woman, 60, 1st interview).

Other patients considered whether their illness was caused by a 'curse' from an estranged family member or a friend. These thoughts brought about feelings of victimisation particularly during periods of acute physical deterioration. However, once the symptoms had subsided with treatment these thoughts were ameliorated as patients felt confident that their improvement was proof that God had control over their illness.

> Before I wonder whether if this (illness) is a curse because it (the illness) wasn't like this before…. but I stopped thinking about those things. It's God who knows and if it was a curse I would have died a while ago. It's only a disease and it will come to an end (Patient 12, woman, 19, 1st interview)

Most patients believed that their illness like other life events, were orchestrated by God. In their suffering, some patients felt it was inappropriate to express distress as this would reveal their distrust in God.

> I don't worry about the concerns of this world… God does as he wills. I've decided never ask to ask God why he made me sick….he also takes those who are not ill. It's better to be ill as the Lord would wish. This body isn't mine. My body is his, my heart is his. God will do as he wills. The best you can do is be patient and wait on him (Patient 14, woman, 60, 1st interview)

For some patients diagnosis led to a questioning of belief in God.

> The other concerns I have are religious….we all don't know where we are going to go. I've been a religious person but not that committed. Maybe I should believe in salvation….in case anything happens, I have nothing to lose….But if I choose not to believe I won't be sure of my fate. But with salvation I will have nothing to worry about (Participant 7, man, 50, 1st interview)

Spiritual issues experienced during the time of treatment

For some, the second interviews revealed that once acute symptoms had subsided they felt confident in their hope for a full recovery. A reduction in

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Table 1 Participant characteristics

Patient number	Gender, Age	Aetiology of heart failure	NYHA class	Interviews T1	Interviews T2	Interviews T3	Duration in study (months)	Alive or dead at end of study	Bereavement interviews
1	Female, 57	Hypertensive heart disease	III	P	P	P	6	Alive	
2	Female, 35	Hypertensive heart disease	IV	P	P	P&C	6	Alive	
3	Male, 65	Dilated cardiomyopathy	IV	P	P	P	6	Alive	
4	Male, 75	Right-sided heart failure (from COPD)	III	P&C	P&C	P&C	6	Alive	
5	Male, 31	Right-sided heart failure (from pulmonary fibrosis)	IV	P	P	P	6	Alive	
6	Female, 60	Hypertensive heart disease	IV	P&C	†		2	Dead	✓
7	Male, 50	Dilated cardiomyopathy	III	P	P	P	6	Alive	
8	Female, 50	Hypertensive heart disease	III	P	P&C	P	6	Alive	
9	Male, 38	Hypertensive heart disease	III	P	Untraceable		1	Not known	
10	Male, 45	Right-sided heart failure (from COPD)	IV	P	P	†	5	Dead	X—carer lived beyond 35 km from recruiting hospital
11	Female, 50	Hypertensive heart disease	III	P	P	P	6	Alive	
12	Female, 19	Extra pulmonary tuberculosis	IV	P	P	P	6	Alive	
13	Male, 60	Hypertensive heart disease	III	P&C	P	P	6	Alive	
14	Female, 60	Hypertensive heart disease	IV	P&C	†		1	Dead	✓
15	Female, 31	Dilated cardiomyopathy	III	P	Untraceable		1	Not known	
16	Female, 33	Hypertensive heart disease	III	P	P	P	6	Alive	
17	Female, 50	Hypertensive heart disease	III	P	P	Untraceable	5	Not known	
18	Male, 36	Right-sided heart failure (from COPD)	IV	P	Untraceable		1	Not known	

†Death.
C, Carer; COPD, chronic obstructive pulmonary disease; NYHA, New York Heart Association; P, Patient; T1, 1st interview; T2, 2nd interview; T3, 3rd interview.

breathlessness and symptoms such as fatigue and ankle swelling were interpreted as signs of their illness abating due to God's intervention. However, while hoping to recover, many patients also resigned their fate to the will of God. This acceptance was based on the belief that God controlled life and death. A few patients illustrated this conviction by describing how death was not limited to those who are ill.

> I don't worry…God knows how long I will live….I leave it to him. You know, someone in good health can die before someone who is ill (Patient 11, 50, woman, 2nd interview)

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Patients whose symptoms persisted despite treatment expressed disappointment as they expected to recover. These feelings were compounded by those of guilt as they felt they had wronged God and that he had abandoned them in their time of need. In the absence of information, these feelings of guilt and disappointment exacerbated their distress

> What have I done against you God? Haven't I lived my life as you expect me to? I have 'pressure', 'sugar' (diabetes), kidney and heart problems. Why should I be the only one to have these problems? Even after asking this, there is no answer. These illnesses are more than I can handle (Patient 1, 57, woman, 1st interview)

These feelings of guilt and disappointment were heightened especially in patients whose condition deteriorated requiring repeat admissions. In particular, younger patients experienced greater distress as they felt their illness had limited their ability to work and provide for their families. Additional challenges from unaffordable treatment and declining social support deepened their despair. One orphaned young man, who had made several attempts to end his life, told of his desire for God to end his suffering.

> Instead of suffering and I'm not getting better, I'd pray to God to take me away. I don't have a job and I can't afford my drugs …I pray to God to take away this problem….to shorten it rather than I continue to suffer (Patient 5, 31, man, 2nd interview)

And yet the powerfulness of the sense of God's ownership of life and the spiritual value of life enabled him to hold a counter narrative to his despair.

> I still have hope because being alive everyday while in hospital is a blessing. A lot of things that happen in the hospital are shocking…. but when I see a new day, I thank God (Patient 5, 31, man, 2nd interview)

Feelings of deep despair led to patients simultaneously resigning their fate to God, and gained comfort in the belief that while their problems were insurmountable God was in control of life events. For some being alive in spite of severe illness meant that life still had purpose. There was a hopefulness in the peace and purpose they experienced in the face of deteriorating health.

> God has a reason for everything. Even though it's a struggle to get to the hospital…I thank God for the help I receive (Patient 2, 35, woman, 2nd interview)

In these times of distress, the church was often viewed as a place of solace. The majority of patients described feeling a sense of tranquillity as they felt they were in the presence of God. Additionally, fellow church members offered support by sharing their experiences. However, a few patients described feeling abandoned by the church as it failed to understand the issues they were going through.

> Once church members found out I was sick they abandoned me. My senior pastor discouraged me to go to church. No one wants to be close to you when you have problems (Patient 16, woman, 33, 2nd interview)

Patients believed that illness created different dimensions of separation in some church communities. A few described discrimination and partisanship linked to wellness and prosperity.

> Nowadays the church is not helpful. If you don't offer tithe as expected no one will know you. You see, I don't tithe all the time because I don't have money. I noticed that when someone tithes more they plan to visit them. But I've been admitted here for almost a month and no one has prayed for me. There is a lot of discrimination (Patient 2, woman, 35, 2nd interview)

Spiritual issues as patients approached death

Most patients found it difficult to speak openly about death as they believed only God had authority over its timing.

> There are those who are not sick but die from other causes. Yet, I'm ill and I'm still alive…..I take my life as is and pray to God (Patient 13, man, 60, 2nd interview)

For some it was easier to talk indirectly about death by sharing their future plans. One elderly man shared how he had planned for his children to inherit his property, a sign that he was willing to 'let go' and had come to terms with dying.

> I have already made arrangements. Every child has a share of the land which they will get when I die (Patient 4, man, 75, 3rd interview)

Other patients responded by spending their last days in prayer asking God for forgiveness for past grievances. Their physical deterioration coupled with financial exhaustion from the cost of care and resultant tensions in social relationship appeared to aggravate patients' suffering. In this state of anxiety, patients felt let down by God and wondered if they had offended him.

> Interviewer: Did she speak about why this was happening?
>
> Carer: She would ask: 'Did I offend God?' She prayed a lot. She would pray day and night and ask God for forgiveness
>
> (Carer for patient 14, woman, 60; bereavement interview)

Despite deteriorating health, some patients in their third interviews remained hopeful that a cure was still possible. They were hopeful that this would prove that

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God had healed them. Patients were looking forward to sharing their experience with others to encourage and offer hope. For instance, 2 days prior to her death, a young female participant expressed her eagerness to share her illness journey as testimony of her belief in God's power to heal.

> This illness is like a testimony. I'll tell people about my experience with this illness and let them know that it's God who sustains me. I was once in the intensive care unit and on oxygen and I got better… I will share my testimony (Patient 2, woman, 35, 3rd interview)

DISCUSSION

Until recently, the multiple dimensions of the experiences of patients with HF in SSA were not described.[17 36 37] This paper illustrates ways in which spirituality influences the experiences of people with HF in Kenya. Spiritual distress was significant at diagnosis, during periods of acute deterioration and in the last days of life. This was often aggravated by the lack of information about their illness. Younger people were less able to cope with a loss of identity and independence. Patients rarely spoke about death as they felt that this was under God's authority although some had made plans for the future. Patients often relied on their belief in God to make meaning of their experience. Although this helped patients to cope, it at times contributed to their suffering as they struggled to reconcile their experience with a belief in a benevolent God. The church offered comfort for some but was also a source of distress.

Our results are comparable with similar longitudinal studies that show that patients experience multiple dimensions of distress.[7 8] In the UK, Murray *et al*[8] found that in people with HF spiritual well-being declines as physical symptoms deteriorate particularly during periods of acute exacerbations. Patients struggle to find meaning with thoughts of dying triggering existential angst as patients question divine indifference at the end of life.[38] People with HF may experience more prolonged distress and uncertainty compared with those with cancer as their persistent and fluctuating physical symptoms creates uncertainty.[39]

Although these results are similar to those of our study, some findings are unique. We found that younger people experienced greater spiritual distress. Their expectation of remaining physically able to work as well as the societal pressures to provide for their families increased their anxiety. These patients have more difficulties in facing changes in their identity and increasing dependence.[40] Our findings reveal that people with HF in Kenya, draw on their spiritual beliefs to cope with their illness. These beliefs possibly stem from traditional religion in which God is regarded as orchestrator of life and death.[41] These beliefs are further reinforced by a Christian world view. Although these beliefs have been viewed as fatalistic,[19] they are a source of comfort[42] but may also reflect a lack of information or a reflection of their deep hope for a cure.[43] Most of our sample expressed a Christian faith and turned to the church for solace. However, some patients felt rejected by the church's lack of support, especially those churches that appeared to assist more those who contributed most financially, exacerbated a sense of isolation among some.

Implications for practice

Spiritual issues are often a source of unmet spiritual needs which has been found in the UK to increase physical and emotional distress and lead to greater health service use.[19] We found that patients relied on their personal resources such as upholding their spiritual beliefs and practices, praying and attending religious services.[19] While these resources offered comfort they were sometimes a source of distress.

As countries in SSA develop services for patients with chronic diseases, it is vital to acknowledge the significant role of spiritual issues in patients' illnesses. These issues have the potential to trigger deterioration in patients' symptoms, increase need for health services, escalate financial costs for families and contribute to a vicious cycle of poverty.[44] This presents further significant consequences for socioeconomic development as HF occurs predominantly in those who are economically active in this region.[17] In addition, spiritual support for those who are ill may be declining in the face of an emerging 'health and wealth' theology.[45]

Previous studies have suggested that a patient-centred approach aimed at meeting holistic needs may be beneficial to people with HF. This approach would aim to care for patients physical symptoms as well their psychosocial and spiritual needs. In addition to receiving medical care, this approach would allow patients to express their concerns, worries and existential anxieties and receive help in coping with and finding meaning in their experiences.[19] This may prevent their spiritual distress from contributing to greater service use and reduce the economic burden of care on families.

Strength and limitations of the study

This is the first study to report the spiritual issues of patients living and dying of HF in Kenya. With a few exceptions past studies exploring the role of spirituality in health and illness have mostly relied on objective measurements.[46] In contrast, our longitudinal qualitative approach allows for dynamic and in-depth personal accounts of ways in which spirituality shapes patients' experiences. Patients were allowed to use their own words to explain how their beliefs not only helped them cope but at times added to their distress. The longitudinal nature of this study allowed us to build trusting relationships where patients felt at ease to disclose sensitive information.[25 26] The result, our approach was a rich and complex narrative in which patients described the role of spirituality in their illness experience. While

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attempts were made to recruit participants from various sociodemographic, ethnic and religious groups living in Central Kenya, it is unknown to what extent these findings may be applicable in other settings.

CONCLUSION

Spirituality for those living with HF in Kenya may be a source of comfort but also lead to distress. Patients' beliefs may mask underlying anxiety which may trigger multidimensional distress and lead to poorer health outcomes. This may increase health service use and plunge households into worsening poverty. A patient-centred holistic approach to care may be beneficial in identifying patients' spiritual concerns and offering support to improve their quality of care and quality of life.

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Competing interests None declared.

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