"We never speak about death." Healthcare professionals' views on palliative care for inpatients in Tanzania: A qualitative study

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ABSTRACT

Objective: Little is known about the current views and practices of healthcare professionals (HCPs) in Sub-Saharan Africa (SSA) regarding delivery of hospital palliative care. The present qualitative study explored the views of nursing staff and medical professionals on providing palliative and end-of-life care (EoLC) to hospital inpatients in Tanzania.

Method: Focus group discussions were conducted with a purposive sample of HCPs working on the medical and pediatric wards of the Kilimanjaro Christian Medical Centre, a tertiary referral hospital in northern Tanzania. Transcriptions were coded using a thematic approach.

Results: In total, 32 healthcare workers were interviewed via 7 focus group discussions and 1 semistructured interview. Four major themes were identified. First, HCPs held strong views on what factors were important to enable individuals with a life-limiting diagnosis to live and die well. Arriving at a state of "acceptance" was the ultimate goal; however, they acknowledged that they often fell short of achieving this for inpatients. Thus, the second theme involved identifying the "barriers" to delivering palliative care in hospital. Another important factor identified was difficulty with complex communications, particularly "breaking bad news," the third theme. Fourth, participants were divided about their personal preferences for "place of EoLC," but all emphasized the benefits of the hospital setting so as to enable better symptom control.

Significance of results: Despite the fact that all the HCPs interviewed were regularly involved in providing palliative and EoLC, they had received limited formal training in its provision, although they identified such training as a universal requirement. This training gap is likely to be present across much of SSA. Palliative care training, particularly in terms of communication skills, should be comprehensively integrated within undergraduate and postgraduate education. Research is needed to develop culturally appropriate curricula to equip HCPs to manage the complex communication challenges that occur in caring for a diverse inpatient group with palliative care needs.

KEYWORDS: Palliative care, Inpatient, Sub-Saharan Africa, Qualitative, Healthcare professionals

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INTRODUCTION

Palliative care services in Tanzania, as in much of Sub-Saharan Africa (SSA), have been poorly integrated and are patchy, with heavy reliance on charitable and faith-based organizations (Harding & Higginson, 2005; Hartwig et al., 2014; Nanney et al., 2010). Tanzania is among the six SSA countries categorized as having "preliminary integration" of its palliative care services, while only one SSA country (Uganda) has reached "advanced integration" of its palliative care services (Lynch et al., 2013). In most regions of the world, the majority of the population would prefer a home death (Gomes et al., 2013); however, in SSA there is some evidence that a hospital death is to be preferred (Downing et al., 2014; Uwimana & Struthers, 2008). There is likely to be better access to morphine and symptom relief at inpatient institutions (Jang & Lazenby, 2013), and there is evidence that hospital-based palliative care teams can also help to enable a home death in SSA, where that is the preferred place for end-of-life care (EoLC) (Desrosiers et al., 2014). Community palliative care services in Tanzania are few in number and overstretched (Hartwig et al., 2014), and dispensing of morphine is limited to only a few hospitals with licenses (four in 2010). The views of healthcare professionals (HCPs) about providing palliative care has seldom been studied in SSA, yet HCPs at the hospitals in urban centers across SSA frequently care for patients who present with malignancies, HIV/AIDS, and end-stage organ failure (Jacinto et al., 2015). We aimed to explore the views about, and perceived challenges to, the delivery of palliative care at a busy tertiary referral hospital based on the perspective of the HCPs employed there.

METHODS

Research Team and Reflexivity

The first author (E.G.L.) is a white British female doctor with experience working in medical hospital settings in the United Kingdom. A Tanzanian female Ph.D. candidate (J.R.) facilitated the focus group discussions (FGDs) conducted in Swahili. She was selected both as a highly qualified and experienced qualitative researcher and as a woman of similar age and background to our nursing participants. In addition, as a trained nurse herself, she would be regarded as a peer who could be trusted to facilitate their engagement in the project. E.G.L. was the primary interviewer for FGDs conducted in English. There was no significant power imbalance that could have led to coercion to participate or skewing of the data.

Ethics

Ethical approval was granted by the Kilimanjaro Christian Medical College Research Ethics and Review Committee (certificate no. 897) and by the Tanzanian National Institute for Medical Research. Participants were given an information sheet in Swahili to read and digest before starting the interviews, and informed written consents were obtained.

Setting

The Kilimanjaro Christian Medical Centre (KCMC) is a busy tertiary referral hospital with beds for around 800 inpatients. The hospital serves a population of 11 million in the north of Tanzania. The majority of people in the Kilimanjaro region are rural-dwelling, and their main occupations are subsistence farming and running small businesses. The predominant ethnic group in the region are the Mchagga; however, the Mmaasai, Mpare, and Mmeru also live in the vicinity (among many others). The predominant religion is Christian, with the Lutheran and Catholic denominations being the most common. As a tertiary level hospital, one of the four in Tanzania, it receives patients from many other regions across the nation. For more details, Appendix 1 (see the Supplementary Materials) describes the results of a survey of the demographic characteristics of inpatients on the adult medical wards conducted by the authors. The KCMC is a Christian institution, with chaplaincy members representing both of the main denominations. Muslim patients are encouraged to make their own connections with their mosque for any spiritual support that they require, and Muslim faith leaders are welcomed to attend to patients on the wards. The hospital receives patients with many chronic and life-limiting illnesses, of which malignancies and HIV/AIDS are the most common conditions potentially requiring palliative care in this setting (Jacinto et al., 2015). According to hospital records, the average number of inpatient deaths per month in 2015 was 72 on the adult medicine wards. At the time of data collection, the palliative care team was inactive for both inpatient and outpatient care, largely due to resource limitations.

Participants

Participants were selected and interviewed in small groups according to profession and experience level. The two nursing heads of department were approached to assist in selecting appropriate participants and to excuse them from their usual ward duties in order to participate. FGDs were conducted until the point of data saturation was reached, when no new ideas were being expressed.

Participants were purposively selected in order to represent healthcare workers of varying levels of experience and of different professional backgrounds at the two KCMC departments (Table 1). Participants were eligible for inclusion if they were currently employed at the KCMC hospital and working in the adult medical or pediatrics department. The most important reason for exclusion from the study was working in a role that involved no regular patient contact. The adult medicine and pediatrics departments were selected because the burden of palliative care need was thought to be greatest in these departments, based on data gathered from a similar tertiary referral hospital in Kampala, Uganda (Jacinto et al., 2015). The other data included were from a semistructured interview (SSI) with one of the chaplaincy members, a male Lutheran chaplain with three years of experience in his role at the KCMC who had previously received theological training at the Evangelical Lutheran Church in Arusha, Tanzania. His interview took 37 minutes. This participant was appointed as a representative by the other members of the chaplaincy, and the reason cited for his not participating in an FGD was his heavy workload. The fact that he was chosen by the other chaplaincy members suggests the authority and level of respect they accorded him, which may give additional weight to these data.

Data Collection

Interviews

Three interview guides were developed for each of the professional groups interviewed. These were translated by a professional Tanzanian linguist, Lucy Mariki, and then reviewed and edited by J.R. to ensure that the language used would be familiar and well-understood (Appendix 2; see the Supplementary Materials). The interview guides for the FGDs with doctors and nurses included vignettes based on anonymized cases observed by E.G.L. over a period of five months spent observing practice and behaviors on the wards and attending the daily medical department handover meeting where deaths and seriously ill patients were discussed. The vignettes were read aloud, and repeated if necessary. An opportunity was given for participants to ask questions for clarification, and prompts were employed to stimulate discussion about the issues raised by the cases.

Data Analysis

The interviews were transcribed verbatim from Swahili to English. The transcripts were thematically analyzed in the following stages: familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and a final report (Braun & Clarke, 2006). The data were coded separately by two researchers (L.L.O. and E.G.L.). These codes and categories were reviewed and compared, which led to theme development. NVivo 11 Pro software (QSR International, London, UK) was utilized to input the developed codes, so that the data could be navigated by the authors when developing themes.

RESULTS

A total of 32 healthcare workers currently employed in the adult medicine or pediatrics wards of the KCMC were interviewed via 7 FGDs and 1 SSI. FGDs lasted between 37 and 85 minutes (average = 69 minutes), with a total recording time of 9 hours and 20 minutes. The four themes developed were "acceptance," "barriers" to delivering palliative care in hospital, "breaking bad news," and "place of EoLC." Sample quotations for each of the themes discussed herein are provided in Table 2.

Acceptance

Participants frequently referred to the need for acceptance of one's diagnosis and prognosis in order to both live well with a life-limiting illness and die well. Palliative care was conceptualized as a means of helping one through a process to achieve this state of acceptance:

Table 1. *Summary of the sample characteristics*

Participant role	Female sex	Years of work experience in current role, median (range)	Previous palliative care education or training
Doctors ($n = 11$)	6	1 (1–3)	None = 6 Some undergraduate level = 3 Some postgraduate level = 2
Nurses ($n = 20$)	20	15 (4–33)	None = 9 Some undergraduate level = 9 Some postgraduate level = 2

Table 2. *Focus group discussions, numbered with their details*

Focus group discussion	Interview length, min	Number of participants	Date of interview
1. Adult medicine doctor	85	4	15 December 2015
2. Adult medicine doctors	77	4	17 December 2015
3. Adult medicine nurses	78	5	15 February 2016
4. Adult medicine nurses	77	5	19 February 2016
5. Pediatric doctors	58	3	14 December 2015
6. Pediatric nurses	82	5	11 February 2016
7. Pediatric nurses	58	5	12 February 2016

When you talk about death, death happens in different situations. It can be that you die suddenly. Others pass through different stages of dying. For the ones who pass through these stages … our role is to help patients through those stages to acceptance, from denial, so that they can accept these stages and so that we help these patients to die well. — FGD6

Living in a state of acceptance allowed one to prepare for death by engaging with practical preparations (e.g., organizing one's inheritance), but it was also thought to improve one's quality of life. For example, achieving acceptance was thought to help patients living with HIV/AIDS to eat well, to take their medications as prescribed, to address stigma, and to help educate the community more widely:

In my opinion, HIV is a disease which needs palliative care because … when a patient receives palliative care, they will accept their problem, that it is this way, when they accept, [and] it will be easy for them to use the medicine … Also, when they get this care, they will be avoiding stigmatization in the family. Also, when the patient receives palliative care and accepts their situation, it will be easier for them to advise others, seeing themselves as different to others. So when they get this care well, they will also advise others that you are supposed to follow the treatment well, and because they are receiving good palliative care they can help those who are not ready to accept the situation. — FGD5

Importantly, a state of acceptance was required to prepare oneself spiritually for dying and was the goal of the process within which palliative care played an important role. Accepting one's situation meant not only an absence of "struggle" but also the presence of a "closeness" with God. Helping someone achieve acceptance was accomplished through psychological and spiritual counseling, emphasizing hope, and by remaining with the patient. These healthcare workers felt it was part of their professional role to accompany patients through the process:

Because when you are counseled spiritually, even the depression [of my brother] will go away, because you'll accept the situation. Then your sufferings will be relieved. That much I understand. — FGD2

Acceptance was also important for the family in order to prepare for the patient's death. Components of the acceptance theme of hope versus despair illustrate this, whereby involvement of the family early on was described as a way of avoiding despair through "closeness" and "counseling." The need to communicate better and earlier with relatives was highlighted:

We were supposed to counsel the daughter to tell her, "The condition is like this, so the condition could get worse." Then she could not cry loudly like that. Because she would be expecting something to happen. If the daughter was counseled before the death, she could accept that which will happens. — FGD1

Barriers

Having discussed the importance of "acceptance" in EoLC, healthcare professionals reflected that they often failed to enable this for their patients on the wards. All participants regularly cared for dying patients and bereaved families and were keen to highlight the many particular challenges, or "barriers," that they faced in their workplace. "Barriers" can be broadly categorized into either problems of knowledge or attitude and those caused by a lack of resources. Nurses spoke frankly in raising concerns that they did not have up-to-date knowledge or always show the correct attitude when caring for dying patients:

So we are weak on this, that we do not care much when a person is dying … Even about respecting the dead body, we do not care for it as we are

supposed to. Because sometimes you will find a patient's dead body lying down on the corridors, and all the relatives are passing, and we do not care. So this situation shows that we do not respect the body. So we do not have a private place for this. So we do not support the relatives and the patient so that they can die peacefully.

J.R.: Why do you think we do not respect the body? Maybe it is lack of education and wrong attitude? A person can have knowledge, but it does not change their attitude. — FGD6

One particular identified barrier was a lack of knowledge of who should receive palliative care and when. Some patients believed that patients should be classified as requiring palliative care based on their diagnosis (e.g., cancer or HIV/AIDS), while others felt that those with symptoms should be offered palliative care regardless of whether their diagnosis was life-limiting (e.g., painful arthritis). In those with HIV/AIDS, there was disagreement about when palliation should begin: at diagnosis or when symptoms occurred:

Absolutely, HIV and AIDS is a condition which needs palliative care. The reason is that the illness itself is a lifelong illness with a lot of demands, and the fact that these people have no future in terms of being completely healed, and the fact that they look at this illness as a statement of death, that in the first place suggests that they need people to travel with them in this difficult time they are in. — SSI

In my opinion, I think HIV needs more psychological support and care because a patient with HIV, if you speak to them and advise them to follow guidance, exercise, a diet with fruit, and to take their medicine, they are not a sick person, and will live a normal life. A patient with a disease which cannot be healed like cancer is a patient who needs palliative care. — FGD6

Beliefs about morphine were also noted as being a barrier, despite the fact that most participants acknowledged that it was an important medication that could be used to effectively relieve symptoms. Some admitted that their main worries were about causing addiction and misuse:

Actually, that is our main concern, though it has some side effects as well, like itching and constipation, but the main thing that we are worrying about is addiction if they are keeping on using it for some time. — FGD3

Medical staff also admitted that they were often too late in recognizing that the patient was dying, which could lead to futile attempts at resuscitation. This was expressed particularly in response to a vignette describing a patient with a severe stroke who was resuscitated (Appendix 2; see the Supplementary Materials):

I mean, this is misconduct actually, using hydrocortisone [for resuscitation] in such types of cases. So maybe teachings should stress this also. Are we lacking curriculum in terms of resuscitating patients? In our training, maybe yes? People come in and are taught to treat hypertension, but they are not taught to treat patients who are approaching death. — FGD3

Another important barrier was lack of sufficient resources to be able to deliver palliative care. Such resources include an appropriate space, the time for nursing, a specialist palliative care team, and reliable access to essential palliative medications:

Here you can find a patient dying of pain, and at the same time morphine is not available, so surely the patient will die in painful condition. Also, we do not have the habit of letting the relative stay close to the patient; instead, we chase them away. So we don't have the culture of letting the relative be close while the patient is dying. — FGD6

Particularly relevant to this setting, we found that language and cultural barriers could occur between the HCPs and the patients and their relatives (see Table 3, cultural and language barriers).

Breaking Bad News

Breaking bad news, defined as the disclosure of "any information likely to alter drastically a patient's view of his or her future" (Buckman, 1984), was acknowledged to be important when receiving palliative care and could help to eventually achieve acceptance, the goal for living and dying well with a life-limiting illness. However, there was a lack of clarity about who should break the bad news, with all professional groups identifying others who they thought would best manage the task:

I think there's a problem in breaking bad news. So many would tell you they had no idea they are suffering from a terminal illness ... I am not competent to break bad news. I thought it should have been the work of the clinicians, which was quite often not done, so when you look at a person who is in terminal illness and the person has no idea whatsoever, it was really a hard time on my part, because how do I get in? — SSI

Table 3. *The four major themes illustrated with example quotations*

Major theme	Components of the major theme	Example quotation
Acceptance	Acceptance (needed for a good death)	Our role is to help patients through those stages to acceptance, from denial so that they can accept these stages and so that we help these patients to die well. — FGD6
	Isolation vs. closeness	J.R.: So what is your role, what are you supposed to do? To be close to them so that they don't feel isolated, so they feel amongst other people and do not feel bad. — FGD7
	Hope vs. despair	We have to look for these patients and look for counseling the patient with the relatives to accept the situation and to live under hope to make sure we have all the supportive care available in the environment, so that the patient can have the last of their life in a better situation or condition. — FGD2
	Counseling (psychological and spiritual)	Even if it is a disease from which you know you cannot recover, prepare the patient so that they can have peace, so that the patient does not die complaining that "If only they would help me, I would not suffer like this." Rather, when we help the patient psychologically and spiritually, it will help the patient to go in peace. So it's when the patient shifts from this world to another. — FGD5
	Priorities at the end of life	If I'm diagnosed with a serious illness now, with a time limit of living, one year to live. Sometimes I may have a lot of thinking in my head. "What is going to happen with my family, my parents?" All of those things may come into my mind. But, to me I'm a Christian, and there are some things I want to put well with my God, so that's what I can say. When you have a time limit you will make sure that your life is good, that you're in line with your God. — FGD2
Barriers	Attitudes and knowledge of healthcare professionals	So I would expect that at least nurses and doctors would get these basic concepts and understand that it is unfair for patients to be in pain while the medication is there. Sometimes they will prescribe medication, not at the level of the pain, so that is important, I think. It is about getting all healthcare providers to see the right perspective and to identify themselves in this noble work. — SSI
	Conflict with relatives (differing expectations)	They won't believe in the disease pathogenesis you are telling them, which will lead to the death of a particular case. For them it's easy to believe even traditional healers or go to spiritual groups, before they come to seek our service. Some even try that before, so when the condition keeps on deteriorating, that's when they come back to us, and you find it's too late even to intervene. — FGD3
		Most of them, if they come today, in 2 to 3 days they want to see the improvement. So if the child or patient is not improving, they start to panic and search for traditional healers and church. — FGD1
	Cultural and language barriers	They are nonbelievers where you find a mother who does not believe—for example, a Maasai mother. Only few believe, and sometimes it's difficult to speak with them. Those who come who speak Kimaasai only, we have a language barrier, so that you fail to understand each other. But as a nurse, I have my belief, so it reaches a point because the mother does not understand. So you pray for the child according to your religion. — FGD5
	Need for training and education	We also need more training, because most of us had our training a long time ago, and we need to refresh. This should be delivered by people with good knowledge and good experience of palliative care. — FGD5
		The training I got in Uganda … it was not sufficient that I can now say, "Oh, I am confident." I don't know much about palliative care because the time was not sufficient. So we need to do as [my colleague] said and put palliative care in the curriculum. It has to be taught on the postgraduate as well as undergraduate courses. Students should be aware of palliative care, what are the components of palliative care, which patients are supposed to receive palliative care … so we need it actually. — FGD3
	Who needs palliative care?	The patient didn't need palliative care because the patient was receiving treatment for stroke, also with the pneumonia. Pneumonia can be treated. Others they recover. — FGD7
		I think maybe there's a need to be taught where to draw the line and say, "Okay, this is palliation." I mean, right now there's always one to two to three patients on the ward like this case, and it's never palliation. You know, we treat HIV and AIDS as it is. I mean, we don't know that this is palliation. — FGD1

Table 3. *Continued*

Major theme	Components of the major theme	Example quotation
	Resuscitation	So maybe teachings should stress this also. Are we lacking curriculum in terms of resuscitating patients? In our training maybe, yes? People come in and are taught to treat hypertension, but they are not taught to treat patients who are approaching death. Maybe that's the challenge, yes. — FGD3
	Views about morphine	Actually, that is our main concern, though it has some side effects as well, like itching and constipation, but the main thing that we are worrying about is addiction if they are keeping on using it for some time. Though oral morphine they are saying does not have … and sometimes the addiction is not that much, but it is our worry. — FGD3
	Workload	We cannot do it as we said, because we lack workers. We can't because we are few workers and the patients are many, so we can't do for them all things as we have said. — FGD7
	Resource constraints at the hospital	Because you can give ARVs [antiretrovirals]. but without proper food and nutrition, it's not going to work. This child is an orphan, and who is taking care of him? How will you manage to do the investigations and get the drugs? ARVs okay. They are given for free. What about co-trimoxazole, antibiotics? So I think that would be a challenge. — FGD1
	Lack of specialist social care	So the challenge is that the social welfare is one for everything: bill problems, escaping cases, food problems … the same place deals with all this. When you want to go, you think I cannot, and helping him personally I am not able, and how many is it possible to help? — FGD5
	Morphine supply unreliable	Because of the severe pain which they have, the doctor will prescribe the medicine which is available because sometime morphine is not available, but they will use any other way to write up a medicine which will reduce pain at that time. — FGD4
	Need for a specialist palliative care team	You need everyone to be informed, to have a basic knowledge. But, equally important, you also need a specialist team to deal with the difficult issues and so on. While it is important to make sure that everyone has a primary fundamental understanding, but it is still important to have a specialist team. Yes. — SSI
	Need for appropriate space for palliative care nursing	It is good if there would be a specific place for these patients because you would be able to be free to speak. When they are mixed with others, there is very little privacy. They should have a private place because they receive a different type of care from other patients. — FGD5 J.R.: Where do you take the body? We can put them at the end of the corridor and surround them with screens. Maybe in medical [ward] one there is a small corridor, so we close the door and put the screens up, and we do our last activities there. It is very close to patients, but because we use the screens the patients don't see. — FGD7
	Lack of community palliative care	But because we can help only with medication and cannot follow him up after the hospital, I see this as a big challenge. — FGD4

Breaking bad news	Admitting failure	Sometimes when we are looking after a patient like this, and we know there is nothing much we can do, I feel it is better not to be a doctor anymore . . . No, you tell a patient, "Here we cannot do anything." It's sad. And most of the time it's our task. It is really hard. — FGD2
		When I see a patient like this, I feel the limitation of medicine and human effort. — FGD2
	Reluctance to break bad news	But having said so, on the other side there is the difficulty of being seen as the bad news breaker. So it becomes difficult. Sometimes we do try to speak to the relatives, in terms of the prognosis of the disease, or the outcome we expect after some time, but most of the time it is not easy. The way the patient and the relatives receive the news, they are on different levels. Some cry—you break bad news to them, and they cry. They lose control. Some receive the news, and they just keep cool. Some, they never want to know what is going to happen. On the other hand, it's like bringing bad luck to your practice. As a practitioner, being the one to be breaking bad news of death to patients, it's like you are cursing yourself. — FGD3
	How to break bad news?	When you are told to go and counsel someone, what is the approach? What are the ABCs? What are you supposed to say to the patient? In which way? Those are the challenges. — FGD3
	Breaking bad news to family over patients	A close person to him should be told and not him. Because when he is told he will be very shocked, and could die before his time. — FGD7
		People perceive it differently, like if you are having a cancer, then your life is gone. So for me, actually, what I would do is just to talk to the relative, the one who is taking care of the patient. Explain what is going on with the patient and what could be the prognosis. The treatment of choice, instead of going straight away to the patient and telling him that "You have this. Actually, the time that you have left to live this way is just six months." . . . It won't be very good. — FGD3
	There are others who can do this	I think there's a problem in breaking bad news, so many would tell you they had no idea they are suffering from a terminal illness or that they are already on medication so I am going to be okay. So there is a serious problem here, because I am not competent to break bad news. I thought it should have been the work of the clinicians, which was quite often not done, so when you look at a person who is in terminal illness and the person has no idea whatsoever, it was really a hard time on my part because how do I get in? — SSI
		So you can consult the priest or the pastor or sheikh, we can tell them the truth of the problem [for example, they have cancer, they are stressed or have fear], and they will speak to them in their religious way and continue to educate them and things like that. — FGD4
	Seeking hope elsewhere	They go there [church], and they get all this talk about hope and future, and they come to the hospital, and all you talk about is how terminal this illness is. I mean, they will choose the better place. So I think we should encourage traditional healers to be involved. Maybe the medical field should involve traditional healers and spiritual leaders, so that when they go there. they try to tell them the importance of being treated in the hospital. That would be a very good idea, I think. — FGD1
	Wasting money on futile treatments	Otherwise, you will tell them they are going to die, and you discharge them. Then they will go to traditional healers. And at the end of the day, eventually they will die, but they have spent a lot of money on traditional healers. — FGD3

Table 3. *Continued*

Major theme	Components of the major theme	Example quotation
Place of EoLC	Duty of the family	In the area where I come from, they had a mission of building a "hospice center" for old people and those suffering with a terminal illness to come and finish their lives there. But … you will have a very good center there, but most likely you will find most people will not want to be going there, even going as far as saying, "You want our people to be cursed by their parents." The understanding being that "You are fed up with me so you want to take me to this facility with healthcare workers and nurses and medical people can take care of me," while it is your responsibility, as a family member. — SSI
		I am certain she will never be left to fend for her own, like to feed herself or anything. In our society, we were raised to take care of our parents, or people who are ill. So I am pretty sure that the people around her, in her community will take care of her. But there is no organized system to take care of these patients, but they are being taken care of in the sense of family care and psychological or social [care]. — FGD1
	Financial factors at the end of life	It is more expensive transferring a dead body, compared to transferring a patient. … We are looking at the economic status of the patient, the relative, or carer. You may see, maybe this patient has a very low economic status, so it is easier for them to take the patient even in their community transport. But when you have a dead body you cannot use that, you must have your own private transport to transport the body. — FGD2
	Home more culturally appropriate	GL: In Kilimanjaro region, in your experience where do people prefer to be cared for at the end of their lives? [for example, hospital or home] Can you explain why?
		Okay. I'm born here and raised here, and I see that mainly it is at their homes. Sometimes they will be brought to a health facility when they are in a critical condition. But especially for these nonresponsive illnesses, they would wish to be taken care of at home. — SSI
	Hospital best for managing symptoms	I think hospital is the best place for caring for the people who are very sick, because at home you can't give a drip, and at the hospital they can be reviewed regularly to see how they are doing. And the relative will feel good that their relative is receiving care at the hospital. — FGD6
		J.R.: What is your preference for place of care at the end of life for example hospital or home?
		I would like to be at the hospital, so that if there were any problems like being unable to breathe, they could give me oxygen, or if I get severe pain they can give me painkillers. — FGD7
	Limited resources at home/community	You should counsel them that if they take the patient home they will not be able to care for her as well as she would be cared for while at the hospital. The care which she is getting at the hospital, it will not be available in the home. — FGD7
	Ambivalence about place of care at the end of life	To be culturally sensitive, it would make sense if it, (care at the end of life) were to be done at home, but then if you would do it at home, there would be some basic things that you would miss which would be available in the healthcare facility. I am thinking about issues like pain. If someone has a terminal illness like cancer, they would not be in a position to mention the level of pain … so I think that is the shortcoming I see when you are cared for at home. — SSI

EoLC = end-of-life care; FGD = focus group discussion; SSI = semistructured interview.

Another reason given for avoiding breaking bad news was the concern that harm could come to the patient from the shock of the news, particularly if they were elderly or frail:

> A close person to him should be told and not him. Because when he is told he will be very shocked and could die before his time. — FGD7

Doctors feared that harm could be caused to the patient and their family by them seeking second opinions from traditional and faith healers, and this was often cited as a reason for not disclosing a diagnosis or prognosis. Alternative healthcare practitioners are blamed for causing a delay in presentation to the hospital, for patients' deteriorating health and sometimes their death, and for wasting patients' and families' financial resources:

> So you treat. First, if you say, "This is the end, we don't expect much," they may abscond from the treatment and then come back worse. They may use local herbs, which are very toxic to the kidneys, so you may end up losing your patient who you would expect to live one or two years. That's why I think we don't [break bad news]. — FGD1

Doctors reported their discomfort with provoking emotional responses and expressed a lack of confidence in knowing how to break bad news empathically. Breaking bad news was even framed as an admission of failure. In this setting, doctors conceptualized it both as a personal failure and an admission of the failure of allopathic (also termed "modern" or "Western") medicine:

> Sometimes when we are looking after a patient like this, and we know there is nothing much we can do, I feel it is better not to be a doctor anymore ... No. You tell a patient, "Here we cannot do anything." It's sad. And most of the time it's our task ... it's really hard. — FGD2
>
> Because of our culture and the traditions we have, as I've said, we never speak about death. When you declare that the patient is going to die, it means you have declared that you have failed to use the modern medicine to help the patient. And because of our culture, most of the time, if you declare to have failed using the modern medicine, patients might think of being bewitched, most of the time. — FGD3

Place of Care

The preferred place of care was stated to be the traditional choice of the home, but these healthcare workers described the unacceptable choice between having symptomatic relief in the hospital and "struggling" at home with symptoms like pain and breathlessness:

> So my preference would be ... It's a tricky one. To be culturally sensitive it makes sense if it [EoLC] were to be done at home, but then if you would do it [EoLC] at home, there would be some basic things that you would miss which would be available in the healthcare facility. I am thinking about issues like pain ... so I think that is the shortcoming I see when you are cared for at home. — SSI

Although home was usually reported to be the preferred place for EoLC, the hospital was preferred when there was a lack of resources at home or a high expected symptom burden, for example, in HIV/AIDS:

> Especially patients with HIV are told to receive palliative care at home, so they feel "some people will isolate me," and others might do whatever. But when the patient is at the hospital, they know that they are close to a healthcare worker, so when they need something they will be given it. — FGD5

The decision about the place of EoLC was often primarily a financial one, made by the family and HCPs. Examples were given where HCPs decided to discharge patients when they were expected to die within days in order to reduce the costs involved in transporting the body:

> It is more expensive transferring a dead body, compared to transferring a patient. ... We are looking at the economic status of the patient, the relative, or carer. You may see, maybe this patient has a very low economic status, so it is easier for them to take the patient even in their community transport. But when you have a dead body, you cannot use that. You must have your own private transport to transport the body. — FGD2

Bringing a patient to the hospital was often a demonstration of care on the part of the family, showing that they had not abandoned the patient. Therefore, the hospital was often not seen as the right place for EoLC but instead as a last gesture of seeking treatment, alongside or after attending to traditional or faith healers:

> We had to discharge a Maasai lady who was severely in pain. But we had to tell the son that "You have to go home. We can't do anything." She had stage four cervical cancer, and the son said,

"It's okay because you have told me, and now I know I have done my best for my mother. Let her die." It's very painful. — FGD2

DISCUSSION

Ubuntu, the African philosophy that can be understood as an ethos of solidarity and interdependence with others (Kamwangamalu, 1999), was found in our data within the themes. This philosophy accords others an inherent humanity and dignity through our interconnectedness and is often illustrated by the South African proverb "*umuntu ngumuntu ngabantu*," meaning that a person is a person through their relationships with other people (Gade, 2011). This philosophy could be found throughout our data. For example, it was expressed by one nurse in explaining how she attempted to overcome a cultural barrier:

Humanity is a valuable thing and a primary thing. This means that you cannot just treat them in a rough way or ignore them because they do not have religion. No. They have already been born. They are a human being in God's image, so there is humanity, and there is something of value there. — FGD3

The preferred place of care was the place where people could be close to the patient, whether this meant HCPs or family. The number one priority was to avoid isolation, stigmatization, and neglect, reflecting the solidarity associated with the philosophy of *ubuntu*. Talking through one's problems with family and religious leaders was also key to achieving a better quality of life and death through acceptance. In fact, according to our data, it would not be possible to achieve acceptance without the help of others, and this was the result of an active process. Acceptance was also a theme found among Kenyan patients with advanced cancer (Murray et al., 2003), but it was framed as a more passive fatalism, which was contrasted with Scottish patients' anger at their cancer diagnosis. In the theme "breaking bad news," the philosophy of *ubuntu* may also be present in the fact that some HCPs felt it was more appropriate to disclose and discuss life-limiting diagnoses with close family members first rather than with the patient. A Rwandan palliative care physician wrote about his experiences and explained succinctly that "When you are well, you belong to yourself, but when you are sick, you belong to your family/community," even where the patient had capacity (Ntizimira et al., 2016). Indeed, a street survey of views on EoLC in Nairobi found that concern for relatives and family and keeping a positive attitude were prioritized over pain control, while the converse was true in European countries (Downing et al., 2014; Higginson et al., 2014), suggesting that increased family and carer involvement is needed to improve communication in palliative care (Selman et al., 2009). Our findings highlight the need for more research into patient and family preferences, and to explore culturally appropriate communication at the end of life.

Interestingly, some of the "barriers" identified by our study participants echo recent discourse in the palliative care literature, particularly about the lack of clarity as to who should receive palliative care, and when. Our HCPs disagreed about whether patents with HIV, for example, required palliative care throughout the course of their disease, or only when they became symptomatic. It has been shown that patients' psychosocial concerns are better addressed by integrating palliative care into HIV/AIDS care (Lowther et al., 2015), lending weight to the calls to end the "false dichotomy" between disease-modifying and symptomatic treatment for HIV/AIDS (Selwyn & Forstein, 2003). Our study highlights that this topic remains a live issue, and a lack of palliative care training and lack of integration of services may be leading to reduced access to palliative care for HIV/AIDS patients in this setting.

Our data corroborate the findings of Hindley et al. (2016), where faith and traditional healers identified four causes of disease in Tanzania: biomedical diseases (which are treatable), bewitching, ancestral curses, and possession by devils. There is evidence to suggest that similar frameworks of belief are widely held in Tanzanian communities. In rural Mwanza, beliefs about the causes of HIV/AIDS included both sexual intercourse and witchcraft (Mshana et al., 2006). If we accept that this paradigm is widely held within communities in Tanzania, then we understand that by communicating a poor prognosis HCPs can lead patients and their families to conclude that one of the three other causes are to blame for this incurable illness. Thus, it is understandable that HCPs feel discomfort about breaking bad news, because, in addition to admitting to and feeling a sense of personal failure, this challenges their broader beliefs about health and disease. The ratio of traditional medical practitioners to the size of population is cited as 1 for every 350–450 in Tanzania, compared to 1 doctor for every 33,000 (Stangeland et al., 2008). Therefore, it was particularly uncomfortable for these HCPs to know that "false hope" could be gleaned elsewhere, and with more ease than that gained from allopathic medicine. In this region of Tanzania, many faith and traditional healers claim that they are able to cure HIV/AIDS and cancer, the two most common palliative diagnoses (Hindley et al., 2016).

The picture from our study is largely one of suspicion and distrust of traditional and faith healers, with many giving examples of having witnessed harm to patients from delays in presenting to the hospital, the toxicities from herbal medicines, and/or financial exploitation. However, previous literature has suggested that the local expertise of traditional healers can be harnessed cooperatively by palliative care services to improve palliative care coverage for rural communities (Campbell & Amin, 2014; Graham et al., 2013) and to facilitate a "bridging of worldviews." There are likely to be many shared values between allopathic and traditional medicine practitioners, as illustrated by South African traditional healers who expressed the importance of addressing psychological and spiritual problems at the end of life (Graham et al., 2013), a view also held by the HCPs in our present study. Indeed, the World Health Organization has called for the integration of traditional and complementary therapies within healthcare systems in order to help meet the goal of universal health coverage (World Health Organization, 2013). Our data highlight the significant challenge of achieving collaboration between allopathic and traditional healthcare in Tanzania. Future research should seek to establish the attitudes of traditional and faith healers and their willingness to collaborate with end-of-life and palliative care services in the region.

STRENGTHS AND WEAKNESSES OF OUR STUDY

All of our participants expressed a wish for more palliative care education, which in part may be due to a social desirability bias. This is unlikely to account for all of our findings, given that this arose in all FGDs and within the themes of "barriers" and "breaking bad news." Additionally, staff felt able to frankly acknowledge their own failures to meet the ideals for palliative care and EoLC delivery, which would not have been the case if they had been seeking to impress the research team. Another weakness is that traditional and faith healers were not interviewed in order to triangulate these healthcare workers' opinions, but this was beyond the scope of our study. The perspectives of traditional and faith healers toward palliative care and exploration of opportunities for greater collaboration between allopathic and traditional health practitioners in this setting would be an important focus for future research. The importance placed on spiritual and psychological counseling by our respondents may reflect the sampling from a tertiary referral hospital that is also a Christian organization. It may be that our results are not applicable in other settings with different religious

affiliations, or in poorer settings where practical concerns such as the need for food, shelter, and physical symptom relief might be prioritized (Kikule, 2003).

CONCLUSIONS AND IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

The data presented herein paint a rich picture of the challenges facing the healthcare workers at the Kilimanjaro Christian Medical Centre in delivering high-quality palliative care to inpatients with life-limiting illnesses. This group of HCPs identified themselves with palliative care despite having received very little formal training in that area. They displayed a deep understanding of the multidimensional nature of palliative care, emphasizing their belief that spiritual and psychological counseling were just as much a part of their professional role as management of physical symptoms. This is concordant with previous research into the experiences and priorities of palliative care patients in Tanzania (Sepulveda et al., 2003) and across multiple sites in Uganda and South Africa (Selman et al., 2011; 2013). Indeed, rural palliative care delivered by specialist nurses in Tanzania has been shown to improve symptom scores, even when morphine was not available (Hartwig et al., 2014).

Our findings suggest that, although the development of palliative care services in Tanzania has been categorized as being at the stage of "preliminary integration" (Lynch et al., 2013), the experience of HCPs may not reflect this. Palliative care education and training is not yet integrated within the medical and nursing schools in Tanzania, as is the case for much of SSA (Rawlinson et al., 2014; Harding et al., 2013). The lack of inclusion of palliative care in undergraduate and postgraduate curricula is in need of urgent remediation in order to meet the goals of universal health coverage (Worldwide Hospice Palliative Care Alliance, 2014). Communication training should be developed to reflect the special challenges faced by HCPs in this setting. In a snapshot view of the sociodemographic characteristics of inpatients on the adult medical wards at the KCMC, 20 different ethnic groups were represented (Appendix 1; see the Supplementary Materials). Therefore, communication training should particularly aim to equip doctors and nurses to deal with variations in culture, education, literacy, language, religious affiliation, and the health beliefs of patients, families, and the communities they serve across SSA. Cultural and linguistic diversity have also been reported as barriers to communication in studies addressing advanced care planning and communicating poor prognoses in South Africa (Stanford et al., 2013; Ganca et al.,

2016). The philosophy of *ubuntu* could be employed to enhance palliative care communication training and practice in SSA, given that it is rooted in concepts of humanism and caring (Kamwangamalu, 1999), which are integral to palliative care.

DISCLOSURES

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SUPPLEMENTARY MATERIALS

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