

“From the Time You Start With them Until the Lord Calls You”:  
A Qualitative Study on the Experiences and Expectations  
of People Living with Advanced Cancer Interacting With  
Palliative Care Services in Uganda, Nigeria and Zimbabwe



Elizabeth Namukwaya, MBChB, PhD, Elizabeth Nabirye, BSN, Adlight Dandadzi, BSc, David Akeju, PhD, Samuel Adejoh, PhD, Eve Namisango, MSc, PhD, Kennedy Nkhoma, BSN, MSc, PhD, Bassey Ebenso, MBChB, MSc, PhD, and Matthew J Allsop, PhD

Department of Internal Medicine, Makerere University, Kampala, Uganda; Clinical Trials Research Centre, University of Zimbabwe, Harare, Zimbabwe; Department of Social Work, University of Lagos, Lagos, Nigeria; African Palliative Care Association, Kampala, Uganda; Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK; Nuffield Centre for International Health and Development, University of Leeds, UK; Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, UK

## Abstract

**Context.** A challenge facing the provision of palliative care in sub-Saharan Africa is a means of increasing coverage of services whilst maintaining quality. Developing an evidence base that reflects patients' experiences and expectations of palliative care services, the context within which services are provided, and the approaches adopted by services in caring for patients, could facilitate and inform the planning and development of patient-centered and responsive services.

**Objectives.** To explore the experiences and expectations of palliative care for people living with advanced cancer in Nigeria, Uganda, and Zimbabwe.

**Methods.** A secondary qualitative analysis of in-depth interviews with 62 people with advanced cancer in Nigeria, Uganda, and Zimbabwe. Framework approach to thematic analysis of transcripts was adopted, focusing on patients' experiences and expectations when interacting with palliative care services, aligning reporting with the COnsolidated criteria for REporting Qualitative research (COREQ).

**Results.** Four main themes were generated from the analysis: 1) Condition and community as drivers of a multidimensional burden when living with advanced cancer; 2) The expectations and endeavors of palliative care to ameliorate the impact of cancer on physical, psychological and basic needs; 3) Processes and preferences for interacting and communicating with palliative care services, and; 4) Restoration of hope in the context of limited resources.

**Conclusion.** Wide-ranging physical, psychological, social and financial impacts on participants were outlined. These concerns were largely met with compassionate and responsive care in the context of constrained resources. Study findings can inform evolving notions of patient-centred care for serious illnesses in the participating countries. *J Pain Symptom Manage* 2022;64:588–601. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

## Key Words

*Palliative care, sub-Saharan Africa, patient experience, qualitative research*

## Key message

This article reports the findings from a secondary qualitative analysis deriving experiences and expectations of palliative care for people living with advanced cancer in Nigeria, Uganda, and Zimbabwe. Aspects of care provision deemed important by participants can

guide evolving notions of patient-centred care for serious illnesses in the participating countries.

## Background

The largest proportional rise of serious health-related suffering over the coming decades is projected

Address correspondence to Matthew J Allsop, Worsley Building, Clarendon Way, University of Leeds, Leeds, LS2 9LU, United Kingdom. E-mail: [m.j.allsop@leeds.ac.uk](mailto:m.j.allsop@leeds.ac.uk)

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to occur in low- and middle-income countries (LMICs), driven by rises in cancer deaths and seen most rapidly among people aged 70 years or older.<sup>1</sup> Sub-Saharan Africa (sSA) which includes 46 countries (population 1.1 billion) will see one of the highest proportional increases (126% by 2060).<sup>1,2</sup> Similar to other low- and middle-income country (LMIC) settings, the majority of people with cancer in sSA present late for care with advanced disease.<sup>3,4</sup> Late presentation is associated with a high symptom burden and social, psychological and spiritual needs and concerns.<sup>5-9</sup> For cancer, sSA has one of the highest death-to-case ratios in the world.<sup>10</sup> The high symptom burden (for example, high levels of reported pain, sexual problems, weight loss, negative self-image, and lack of energy<sup>11</sup>) and multidimensional impact (including physical, psychological, social and spiritual needs, and concerns<sup>12</sup>), highlight the critical need in the sSA context for palliative care - the prevention and relief of physical, emotional, social, or spiritual suffering associated with any chronic or life-threatening illness, which is fundamental to health and human dignity and is a basic human right.<sup>2</sup> Palliative care is an essential service within universal health coverage<sup>13</sup> and its timely and effective implementation has been recommended alongside oncologic treatments.<sup>14</sup>

In countries in sSA, including Nigeria, Uganda, and Zimbabwe, there is a growing number of palliative care services. In sSA, palliative care is offered mainly through hospital-based teams and home-based care hospices.<sup>15</sup> For Nigeria, Uganda, and Zimbabwe, the availability of different palliative care services and contextual data on each country is summarized in Table 1. A challenge facing the provision of palliative care in sSA is how coverage of services can be increased whilst maintaining quality.<sup>16</sup> Care should be patient-centered, effective and efficient and ensure health system responsiveness.<sup>17</sup> This is particularly important for people living with serious illnesses in which prominent aspects such as clinical uncertainty, the involvement of significant others, and the need for high-quality communication need to be considered.<sup>18</sup> However, there is no one

approach for palliative care service provision across settings in sSA, and provision must involve the development of culturally appropriate programmes that meet local needs and priorities.<sup>19</sup> The evidence base underpinning palliative care provision in sSA is very limited,<sup>20</sup> including a critical gap in the perspectives of the service users. Developing an evidence base that reflects the experiences and expectations of palliative care services by people with cancer, the context within which services are provided, and the approaches adopted by services in caring for people, could facilitate and inform the planning and development of patient-centered and responsive services.<sup>21,22</sup> The first of these, experiences and expectations of people living with advanced cancer is addressed in this study. Understanding their perspectives and needs relating to health service delivery aligns with the WHO global strategy on integrated people-centered health services 2016–2026.<sup>23</sup> The report highlights that integrated people-centered care systems have the potential to facilitate significant benefits to the health and health care of all people, including improved access to care, improved health and clinical outcomes, better health literacy and self-care, and increased satisfaction with care. Furthermore, in recent research to identify palliative care priorities in low-resource settings the need to elevate the patient voice to enhance its legitimacy was highlighted.<sup>24</sup> In the context of high-income countries, people report having three broad expectations: 1) a comfortable and safe atmosphere, 2) receiving honest communication, and 3) respectful and holistic care from competent, reliable and trustworthy health care professionals (HCPs).<sup>25-29</sup> Positive involvement of palliative care services in high-income settings include, for example, instances where care providers have supported improvements in symptom management for people, restored independence, a better sense of control and hope, opportunities for socializing with peers, receiving autonomy and respect, prompt care, and getting access to information.<sup>26,30-33</sup> Negative experiences can include poor coordination of services, poor

Table 1  
Types of Palliative Care Services Available in Nigeria, Uganda and Zimbabwe. Data Sourced from Rhee et al<sup>15</sup>

Country	Palliative Care Related Indicators			Country-level Markers of Development		
	Metric	Number of Home-based Care Services	Percentage of Hospitals With Palliative Care Services in the Country (%)	Number of Districts With Palliative Care Services	Population Size, Total (2021) <sup>a</sup>	GDP per Capita (U.S. Dollars) <sup>b</sup>
Nigeria	10	0.4	27	211,400,704	2085	55
Uganda	13	20	80	47,123,533	858	64
Zimbabwe	25	4	18	15,092,171	1737	62

<sup>a</sup>Reported using data from The World Bank: <https://data.worldbank.org/indicator/SP.POP.TOTL?view=chart>

<sup>b</sup>Reported using data from The World Bank: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?view=chart>

<sup>c</sup>Reported using data from The World Bank: <https://data.worldbank.org/indicator/SP.DYN.LE00.IN>

continuity of care, overly intense care from multidisciplinary teams, and a lack of consistent information sharing.<sup>26,31</sup>

In the context of SSA, to date, studies have explored the palliative care needs of people with cancer.<sup>6,11,34–36</sup> This includes literature highlighting that context-driven specific needs of people with cancer and their families exist in sSA which need to be met to ensure that the benefits of palliative care can be realized at the patient level.<sup>37</sup> Recent literature includes, for example, exploration of perspectives of people with cancer and their caregivers on the role of palliative care in improving wellbeing and assisting to reduce fear and discrimination for people living with advanced cancer in Malawi.<sup>38</sup> However, there remains a need for further research exploring the meaning and practice of person-centered care for serious illness,<sup>18</sup> including determining the experiences and expectations of patients with serious illnesses to guide the response and adaptation of care delivery. This secondary qualitative analysis aims to derive novel insights from service users to address this gap in research to guide how palliative care delivery can be refined and adapted to facilitate person-centered care for people living with advanced cancer in Nigeria, Uganda, and Zimbabwe.

## Methods

### *Design and Setting*

We conducted a secondary data analysis of interview data from a larger parent study—a multi-country cross-sectional qualitative study that was conducted in three countries in sSA (Nigeria, Uganda, and Zimbabwe) by our research group between February 2019 and September 2020.<sup>39</sup> The parent study conducted a total of 195 interviews with participants across the three countries (people living with advanced cancer ( $n=62$ ), informal caregivers of people with advanced cancer ( $n=48$ ), palliative care health care professionals ( $n=59$ ) and policy-makers ( $n=26$ )). Details of eligibility criteria and recruitment processes are reported in the study protocol<sup>40</sup>. Only data from interviews with people living with advanced cancer were used in this secondary data analysis. The interviews, conducted by the authors of this paper (both female (ENab, AD, Enami) and male (DA, SA)), covered different topics for each stakeholder group, focusing on the role of patient-level data and digital health approaches to inform the development and delivery of palliative care in sSA. Qualitative data are under-analysed<sup>41</sup> and secondary data analysis provides a valuable, cost-effective method of maximally using collected data.<sup>42,43</sup> One-off interviews with people living with advanced cancer for the larger study explored the impact of cancer on their lives, their current access to palliative care services, the acceptability

of digital technology approaches to support contact with health services and data collection, the clinical response anticipated from health services and alternative approaches to patient-level data collection without mobile phones.<sup>44</sup> Topic guides were developed by the research team and pilot tested and refined on 2–3 people living with advanced cancer in each country. The topic guide used in the parent study for interviews with people living with advanced cancer is included in Supplementary file 1. Interviews took place with only a person living with advanced cancer and the interviewer present, at participants' preference of location, either in their home or in clinic settings. Those undertaking interviews included palliative care clinical researchers (ENab), those with doctoral training in health research (DA, SA, Enami) and a social and behavioral scientist with a degree in sociology (AD); all with prior interest and a focus on palliative and cancer care in their research activities. No researchers were known to participants prior to the interviews.

All interviews were audio recorded, transcribed verbatim and translated into English (where necessary from Yoruba in Nigeria, Luganda in Uganda, and Shona in Zimbabwe) before being imported into NVivo version 12. Transcripts were not returned to study participants for comment. This paper uses data gathered during interviews with people living with advanced cancer. Following the primary analysis for the parent study, there were multiple important aspects of interviews with people living with advanced cancer that had not been sufficiently focused on which warranted further secondary analysis.<sup>43</sup> The dataset was assessed to establish the extent to which it was aligned to the research question (i.e., what are the experiences and expectations of palliative care for people living with advanced cancer in Nigeria, Uganda, and Zimbabwe?), was of the required quality, and that the time passed since the collection of data had not affected the relevance of the data.<sup>41,45</sup> We determined that secondary qualitative data analysis was suitable with a large corpus of data providing rich descriptions across transcripts for Nigeria, Uganda and Zimbabwe outlining experiences and expectations of palliative care services by people living with advanced cancer.

### *Sample*

In the parent study,<sup>39</sup> participants who were people living with cancer were at least 18 years of age with advanced cancer (defined as those with metastatic cancer determined, where possible, through histological, cytological, or radiological evidence) and receiving palliative care (although participants may have also been receiving anticancer therapy), and all participants were aware of their diagnosis. Clinical staff at recruiting facilities reviewed clinical records to identify potential participants, introduced the study and referred them to

research assistants if they were willing to participate. In each country, participants were purposively sampled to include variations in age, sex, cancer type, location at the time of interview (hospital or community) and duration of time receiving palliative care services. Potential participants were excluded if deemed ethically inappropriate by members of the clinical team, which included where it was unclear if participants were unaware of their diagnosis or if death was imminent.

### Data Analysis

For the qualitative secondary analysis, we adopted a framework approach<sup>46</sup> to thematic analysis of data from transcripts with people living with advanced cancer, focusing on their experiences and expectations of palliative care services. Two authors read and re-read the transcripts (ENamu, MJA) to be thoroughly immersed in the data. Six transcripts were randomly selected (two taken from each of the three countries, ensuring representation of male and female participants across a range of cancer types) and coded inductively by ENamu and MJA. An initial coding frame was developed by ENamu and MJA in NVivo version 12 and was discussed with other authors (ENab, AD, Enami, DA, SA) who had conducted interviews and maintained field notes from interviews across all stakeholder groups in the three participating countries and who benefited from an in-depth knowledge of the parent study methodologies and data. Following refinements based on feedback from the wider team, ENamu and MJA finalised the coding frame. ENamu coded the remaining transcripts, meeting regularly with MJA to ensure reliability and consistency of coding, discussing, and agreeing on adaptation to the coding framework to accommodate the data in the transcripts. The findings were reported by describing the responses of the participants using the themes and subthemes identified. Our reporting is aligned with the Consolidated criteria for reporting qualitative research (COREQ).<sup>47</sup>

### Findings

Sixty-two semi-structured interview transcripts with people living with advanced cancer were analyzed, with interviews lasting an average of 45 minutes, ranging from 20 to 90 minutes. The sample consisted of more females ( $n=35$ ; 56.84%) with an overall mean age of 51.61 years. Over half ( $n=34$ ; 54.84%) of participants were married and half ( $n=31$ ; 50%) had a secondary level of education. The most common cancer diagnosis ( $n=18$ ; 29.51%) was breast cancer (Table 2). Where reported (14/62; 22.6%), the duration of time participants had been in receipt of palliative care ranged from one week to 15 years. Of all eligible people that were approached to participate, seven participants declined to participate due to being too tired ( $n=3$ ),

Table 2  
Characteristics of Participants in the Study

Characteristic	Total (%)
Sex (female)	35 (56.84%)
Mean age (SD)	51.61 (16.20)
Marital status	
Single	13 (20.97%)
Married	34 (54.84%)
Divorced/Separated	9 (14.52%)
Widow/widower	6 (9.68%)
Education	
No education	2 (3.23%)
Primary	9 (14.52%)
Secondary	31 (50.00%)
Tertiary	20 (32.26%)
Cancer type	
Breast	17 (27.42%)
Prostate	8 (12.90%)
Colorectal	6 (9.68%)
Liver	4 (6.45%)
Lymphoma	4 (6.45%)
Cervix	3 (4.84%)
Lung	3 (4.84%)
Uterine	3 (4.84%)
Bladder	2 (3.23%)
Leukaemia	2 (3.23%)
Multiple myeloma	2 (3.23%)
Ocular squamous cell	2 (3.23%)
Brain	1 (1.61%)
Kaposi's sarcoma	1 (1.61%)
Oesophageal	1 (1.61%)
Pancreas	1 (1.61%)
Penile	1 (1.61%)
Spinal	1 (1.61%)
Country	
Nigeria	21 (33.87%)
Uganda	20 (32.26%)
Zimbabwe	21 (33.87%)

not wanting to be interviewed ( $n=2$ ), too busy to participate ( $n=1$ ), or being unavailable for an interview ( $n=1$ ). Of those recruited who did not take part in an interview, four were attrition due to illness (e.g., difficulty breathing, unable to verbalize due to tumor in the throat) and four were attrition at random.

### Main Themes

Four main themes were generated from the analysis: 1) Condition and community as drivers of a multidimensional burden when living with advanced cancer; 2) The expectations and endeavors of palliative care to ameliorate the impact of cancer on physical, psychological and basic needs; 3) Processes and preferences for interacting and communicating with palliative care services, and; 4) Restoration of hope in the context of limited resources Table 3.

#### 1) Condition and community as drivers of a multidimensional burden when living with advanced cancer

Participants across the three countries had advanced cancer and were living with the illness, which affected them in physical, psychological, social

**Table 3**  
**Exemplar Quotes Drawn from Participant Transcripts for Themes Derived from the Analysis**

Theme	Quote number	Participant transcript excerpt
Condition and community as drivers of a multidimensional burden when living with advanced cancer	Quote 1	"How do I feel? uhm sometimes I, I cannot walk too much. . . I feel tired easily like I can just sleep or sometimes I have pains or I would be having serious headache, especially these ones [referring to pains], I used to have pains there so and I feel tired easily." (Participant 27, Nigeria)
	Quote 2	"It has affected me, I used to wake up early and dig, and do other household chores but now I cannot do any of that. I used to be able to support myself in all aspects but now I am unable to do anything. Hmm, I am helpless now. I am very weak, I cannot do anything for myself. I now need someone to care for me, wash clothes for me, cook, do everything. Even when it is time to go to the hospital for my appointment, I have to get someone to be with me, to take me to the hospital." (Participant 53, Uganda)
	Quote 3	"Aah, it [Cancer] affects me very much because from the moment I learned that I had cancer, my wife and I have had no sexual intercourse up to this day. I have had no sex." (Participant 58, Zimbabwe)
	Quote 4	"Yeah, physically it has affected me because I can't travel very far, to reach other people of mine (family) who are very far, neither do I like climbing on the lorry to go to the market. Who is going to do my work now? I am a business person selling food, going to the market, and doing things like that. I am like a lame person now! I do things on my own, small, small, businesses, I am self-employed but now I no longer have money, [for that reason,] some of my two children are no longer going to school. Financially, I'm now not ok, I'm depending on other people." (Participant 61, Uganda)
	Quote 5	"I was not even leading Mass prayers anymore. Being a Catholic priest and not going to lead Mass, has affected me badly. So, but my life has been affected in that I'm not as active as I used to be as a priest." (Participant 59, Uganda)
	Quote 6	"Everything around me just changed, even people that were my friends before, everybody just. . . I can't see people around anymore; people just stop coming to my place. You know, people just abandon me with my daughter," (Participant 5, Nigeria)
	Quote 7	"Outside the house, there we get so many challenges, either you find a group of people are discussing you, or they are laughing at you. . . saying ah, that one has HIV. Yet it is not, things like that! Sometimes I feel. . . as a patient. . . I feel bad to be talked about. Hmm, yes, like in this condition I'm in, of cancer, how am I going to live? I think that they can advise me, make my people know this [cancer] isn't contagious, and they shouldn't neglect me. (Participant 61, Uganda)
	Quote 8	"And then I, I also saw, I had lost confidence in myself, moving with one breast (after mastectomy)." (Participant 37, Uganda)
The expectations and endeavours of palliative care to ameliorate the impact of cancer on physical, psychological and basic needs	Quote 9	"First, the costs of the drugs are quite expensive, they are very very expensive. If these drugs should be available in the hospital, I am sure it will be good for better response. Second, if care is at a subsidized rate, or if it means giving us [treatment] free of charge, fine, we give God the glory but with the situation of the country, I don't think err they can do that. But I would love it if they can give people [drugs] because cancer is not a short-term thing, it's a long-term case. . . That they will have done for me, if they can reduce the cost [of treatment], that is only what I ask for, if they can reduce it I am sure it will be very, very very good for everybody." (Participant 10, Nigeria)
	Quote 10	". . . if I have a problem with a hospice caregiver and I have shared it with this person, I think it would not be in order for this person to go and expose me to hospice. I may have personal problems, but they are professionals. If for example, I have problems with my wife and I share with you, not for a solution but just sharing [to be understood], it wouldn't be for you to go and share it out there that [with others]. This personal, personal interaction is supposed to also invoke some bit of confidentiality and trust." (Participant 46, Uganda)
	Quote 11	"Personally, what I want is help with what I want them to understand fully on me, is the issue that I am that person if I am really hurt right, I can't express it in words, I cry a lot such that I won't be able to talk. Such that the nurse will ask, "what is the problem?". You can keep on crying and they say ah, feel free to talk when you want to. Some people find that difficult. (Participant 32, Zimbabwe)
	Quote 12	"Yes, you would want feedback immediately so that they tell you, Mum, your diagnosis is like this and that, you are suffering from this and that. However, I see that it is proper to follow procedures and stages so that they say, Mum, we are now at such and such a stage. We want to focus on this, and that. That's what we are focusing on these days." (Participant 3, Zimbabwe)
	Quote 13	"Yes, like sometimes they give you medicine but when they. . . like. . . they have not told you that this medicine when you take, you don't have to eat this or this. I don't know whether they are also not aware of it, but when you reach home, you take that medicine, I don't know whether it's the cause or it's just something else, but when you eat the food, your body reacts to it. I don't know whether it's caused, it's caused by the medicine or it's just something else, so I'd like them to talk about that so that I leave when I'm contented with all the information (Participant 50, Uganda)
	Quote 14	"Currently what I would say, aah, I need; if the hospice could be able to provide food. That's what I'm short of. I would need some food. That's what is troubling me." (Participant 11, Zimbabwe)
	Quote 15	"Like if I go to radiotherapy, it will be for at least 28 working days, so you'll have to find your own accommodation. I went there (to hospice) thinking that maybe they can assist me with that. They told me, ah no, they just told me that they are also facing hardships. (Participant 52, Zimbabwe)
	Quote 16	"In my case, counselling is very important for me because it reduces worry. When I am just enclosed here in this room, I see myself as someone who is lost as if I am about to die and so forth. However, if you are ill but with hope and you go after 2 days; 3 days, it is better when you have someone to give you counselling; someone who can give you love. (Participant 3, Zimbabwe)
	Quote 17	"I was also looking forward to much of a group counselling, er talking to fellow patients, telling us their experience, how they've coped and how they have come out but unfortunately I have not yet got that experience. I think basically if you could make those group counselling more frequent that would be good. (Participant 37, Uganda)
	Quote 18	"I expect to go back to school to read books." (Participant 54, Zimbabwe)
The expectations and endeavours of palliative care to ameliorate the impact of cancer on physical, psychological and basic needs	Quote 19	"Aah, the palliative care doctors when it had actually [been diagnosed] when I had just found out that I had cancer, it [home visit] was almost on weekly basis. But when I had started improving a bit and of course, I started jumping. I was visited every two weeks or three sometime..." (Participant 42, Uganda)
	Quote 20	"They give me dates when to come [to the clinic] for the next visit. . . so, and they give me appointment dates like last week, when I was here I took gemisile (chemotherapy) and I have forgotten the other one, and they split it into two to reduce the reaction rate, so they say this week I should come [to the clinic] for the remaining part of it [treatment] which is why I am here." (Participant 10, Nigeria)
	Quote 21	"I call them on phone. I call the Hospital (or hospice) line, I call on it [mobile phone]. I can send them a voice message and I explain to them, sometimes I just text a message because it's not like calling, it is cheaper. Sometimes we use messages and sending of photographs" (Participant 34, Uganda)
	Quote 22	"Sometimes it would be to remind you of your appointment date, sometimes if there is sort of a party organised for patients. The Christmas day and the party day, they call you and inform you, sometimes when there are trainings for patients, they would still call you. Yes. When they want to find how I am doing, how my illness is progressing." (Participant 39, Uganda)

(Continued)

Table 3  
Continued

Theme	Quote number	Participant transcript excerpt
Restoration of hope in the context of limited resources	Quote 23	"... in my case, among those who care for us and those who give us palliative care, I have not noticed anything bad because the love given to us by the people who receive us at the Cancer Department is so profound because it makes you to-; it makes you live" (Participant 3, Zimbabwe)
	Quote 24	"... they have always been free and receptive. At any time, they are the kind of people who are receptive to what is being said and they also collaborate it with what they know and put the knowledge together, even new knowledge, and for them, they would be learning from it, and also imparting [the knowledge]. While they learn, I also learn" (Participant 7, Zimbabwe)
	Quote 25	"That's when I started also to take morphine and then started feeling that, ah I was now beginning to find what? Some sleep. I stayed on with the Hospice until, as it were, God intervened. All of a sudden that wound-; it used to be red; It started turning [to change]... every day, when I took morphine I, I would feel some pain which was slight enough for me to be able to sleep. But on a certain day, I realised that, ah, I had slept. My initial thought was, "Am I dreaming?" What has happened? Ah, I took a mirror, examined and noticed that the wound had changed colour slightly. . . From there, it actually started getting healed. It got healed more and more until it had what? The wound had become healed." (Participant 26, Zimbabwe)
	Quote 26	"There is a change in my attitude towards this cancer thing. And the other aspect, if you look at cancer as if it's a death sentence. With palliative care, you can get to some ripe ages. (Participant 59, Zimbabwe)
	Quote 27	"Because long ago I was very scared. I was scared. The one thing I was scared of is cancer. Whenever I thought of its English name 'cancer' I, I did not even want to hear about it. So, when I discuss now with those-; these people who help me-; I find what they say helpful, as they teach me properly. (Participant 11, Uganda)
	Quote 28	"Oh yes, like today I thought I would see the doctor, but he was not there! (He laughs) such cases, it becomes complex. You know you come all the way from home, hoping that you will see this doctor, explain to them ABCD, because there is a follow-up. He will know I saw this patient on such a day, I gave such a dose, and then when you get there you don't see him. And then you feel that explaining the same to another person, I feel that... I don't know whether you follow the trend! (Participant 58, Uganda)
	Quote 29	"At times you feel powerless to contact them [health professionals], that even if you contact them mhm expecting them to help you, they just counsel you, they just help you by counselling you. And when you actually; you need more than that. But the fact is they will just tell you that I even asked for stop pain, they said we don't have anything "at the moment we don't have anything. We are-; we wish we can help but we can't, the hospital doesn't have anything. (Participant 52 Zimbabwe)
	Quote 30	"Then the pressure is too much, people, patients are too much, pressure too much on the doctor. If it was not that I am a nurse, when the doctor was listing and made a mistake, I noticed but the layman they don't know. I quickly called him, he says no oh you know that is not the one you take, so that is what me, I noticed." (Participant 23, Nigeria)
	Quote 31	"Yes in every, every visitation you pay consultation fee because that is the first thing they will, like the one I pay today now, 1060, 1060 naira this is the one, so they will first of all demand for the 1060 naira then you pay them then they take our scale, they take our scale reading, our weight before they can attend to us." (Participant 8, Nigeria)
	Quote 32	"When I am in a lot of pain that's why I said these days, I don't go very often because the pain stopped. So, when I am in pain, that is when it is most important. In fact, we talked about it with the people that take care of me here, all the rest that we must keep going to hospice because at one time we were told I don't need to take the morphine anymore, we could cut off the relationship and I said no because tomorrow I might be in a lot of pain so we should go on and continue. They give very good counselling, they also ask questions, how are you doing this and this, they give advice and they give other tablets to help and so and so let's keep on. So I think all the time, from the time you start going there that's why as I said, the frequency has decreased but as I told them let's continue going because I think even the counselling is something you need, now those people in Mahindye [where the hospice is located] they are experienced both in, knowledge and dealing with patients, so they can continue to advise, if you do this, if you do this, you will be ok. . . . So, these things are ongoing. From the time you start with them until the Lord calls you. Even if you got cured miraculously I think you'd be a good thing to continue with them." (Participant 59, Uganda)
	Quote 33	"Ever since I got to this condition I think, they are part of my life now. And I need them all the time, but mostly when I am in a crisis. (Participant 46, Uganda)
	Quote 34	"They are very important because of the care and the treatment they give to me and the way they value my life. They are important all the time." (Participant 48, Uganda)
	Quote 35	"After interacting with the palliative care doctors, I realized that I need them even more than when I only have the pain because they encourage me and they talk to me on various occasions so I think, I think I would need to have the palliative care help as more frequently as I can if they're readily available." (Participant 42, Uganda)
Quote 36	"I am a Muslim like I have told you. . . so sometimes aah eeh this condition of mine can put you in such a position when you really want some spiritual guidance, and aah like I have told you that when I met the palliative care doctor, they even found out my faith and encouraged me to remain faithful to Allah, to pray, who can help me try to talk about the goodness of Allah and maybe sometimes these conditions, that is Allah who brings and it is Allah who takes away, then maybe it would also be some good thing to talk about so that my "Iman" grows, aah in the faith and then sometimes you feel the peace of mind when you talk to someone about the goodness of Allah and maybe it can even bring some miracles for you." (Participant 42, Uganda)	
Quote 37	"the point where it is very important, as it is, is that of-; what is very essential to my life if I have to speak about my own condition. The thing is called a colostomy bag. Ah, as for catheters, they-; they are not able to get them. Nonetheless, I wish they were able to get them. The colostomy bag, aaaaaah. The colostomy bag, urine bag and the-; the-; the pain killers which I get. And the gauzes, I don't-; the-; the gauzes-; the cotton stuff which I use to clean this and that. Those things are very important to me absolutely. (Participant 26, Zimbabwe)	

and existential ways. The impact of cancer in the physical and social domains was reported by most participants with the two domains being intertwined. The major physical issues reported were symptoms including pain, physical weakness, and immobility (quote 1). For some participants, physical symptoms led to declining physical functioning, leading to them being bedridden and being forced to depend on others for daily care (e.g., bathing and obtaining food) and for

accessing health care facilities (quote 2). Physical symptoms that involved sexual organs, such as a patient with penile cancer reporting having an ulcer on their penis, had a detrimental impact on intimacy with their spouse. Some participants had to move their children away from their homes to relatives' homes to protect the children from witnessing the suffering they were experiencing due to uncontrolled physical pain (quote 3).

The social and societal impacts of cancer arose from restrictions to participation following the loss of physical function, such as participants' inability to continue income-generating activities. Loss of income had wide-ranging negative impacts where participants were the primary income source for a family, including, for example, the inability to pay school fees and to pay for medical costs (quote 4) and a lost sense of identity and purpose (quote 5). One participant reported considering dissaving, deliberating whether to sell their house to pay for surgery, but later opted against it. As participants lived longer with cancer, they described gradual increases in loneliness and isolation, leading some to feel they were a burden on their family and friends (quote 6).

Participants reported that in the communities in which they lived there was a very limited understanding of cancer and its causes, often resulting in participants being stigmatized by community members and their families, most notably reported by participants in Uganda and Zimbabwe. Cancer was thought to be contagious and there was an assumption from communities that participants with cancer had HIV. Stigmatization was reported commonly by those who had visible physical symptoms from cancer such as swelling and disfigurement. Participants chose instead to hide from their community and isolate themselves to avoid encounters that were distressing for participants (quote 7). Participants reported being referred to as 'that person with cancer' instead of by their names. Participants also gave accounts of how living with cancer affected them psychologically. For example, participants reported feeling worried, hopeless and having low self-esteem due to a changing self-image (quote 8).

## **2) *The expectations and endeavors of palliative care to ameliorate the impact of cancer on physical, psychological and basic needs***

Multiple needs and expectations were expressed by participants regarding receiving palliative care. The most commonly expressed need across all countries was for medicines and other supplies such as colostomy and catheter bags (quote 9). The need for confidential and empathetic communication with health professionals was also expressed by participants across all countries. Participants wanted health care professionals to provide a safe environment where they could express themselves freely, where health care professionals talked to them, listened to them, and would maintain confidentiality, especially those relating to family challenges (quote 10; quote 11). Participants also expressed a desire for health professionals to provide facts on their diagnosis, cancer stage, and goals of any treatment. However, there were differences in preferences around disclosing prognosis, with some participants preferring prospective prognoses framed around maintaining hope, while others opted for direct and specific

timeframes in communicating prognosis to inform future decision-making (quote 12).

Participants expressed specific support they sought from palliative care services. Information about managing their disease, side effects of medicines, and how medication can interact with foods were common across participants (quote 13). Participants also expressed a need for social support where symptoms relating to their illness had reduced wider contact and interaction with their family and community. Participants sought financial support, including food (quote 14) and, in Nigeria and Zimbabwe, support with accommodation costs when accessing oncological treatments far away from their homes (quote 15). Psychological support was commonly referred to by participants in Zimbabwe and Uganda. Some participants needed counselling to make them feel valued and loved (quote 16). In Uganda, participants sought to interact with other people living with cancer as part of a counselling process to share experiences and access support from peers, such as approaches to managing relationship issues with family members (quote 17). Through access to palliative care services most participants across the countries anticipated any symptoms would be managed and improve, with hope that prior activities could be resumed (e.g., returning to education) (quote 18), and participants with children hoped they would be kept alive to care for their young children.

## **3) *Processes and preferences for interacting and communicating with palliative care services***

Modes of interaction with palliative care were varied, with participants visiting facilities, or having caregivers visit facilities on their behalf. Home visits by care teams were reported but only in Uganda and Zimbabwe where community-based palliative care provision was present. Typically, in-person visits to health facilities were conducted monthly, although more frequent visits were made based on need, such as when first diagnosed with cancer, when initiating treatments, or when participants experienced distressing symptoms (quote 19). For participants receiving chemotherapy, participants reported having regular reviews at the end of appointments with their oncologists, particularly in Nigeria (quote 20). Contact with services also leveraged mobile phones which were commonly used to maintain contact with palliative care services, either by participants themselves or through their caregivers. Phone calls, text and voice messaging, and sending pictures of physical problems to health professionals were common (quote 21). Participants or their caregivers typically initiated calls, but health professionals also contacted participants when they had missed an appointment, to check whether they had enough

medication, to discuss the status of their condition, or to invite them to training and social events (quote 22). Table 4 outlines specific drivers of participant contact with palliative care services, outlining differences between modes of in-person and remote contact.

#### 4) Restoration of hope in the context of limited resources

Across all countries participants reported receiving compassionate care from health care professionals that embodied mercy, sympathy, love, encouragement, and feeling welcomed (quote 23). In Zimbabwe, health care professionals had been receptive to the information given by participants and allowed them to

integrate their information into decision-making relating to their care (quote 24). Participants also reported improvements in the management of their symptoms (quote 25) and felt that services often responded quickly when they reported distress. Palliative care provided hope of extending life (quote 26) and reduced participants' fear of their illness (quote 27). Whilst largely positive, participants highlighted frustration with being unable to see the same health care professional to provide continuity (quote 28), frustration with frequent occurrences of medical supplies and medications not being available (quote 29), health care professionals being under pressure with potential consequences and errors that could have an impact on

Table 4  
Key Findings Relating to Existing Types of Contact Made with Palliative Care Services Using In-Person Visits and Digital Technology

Mode	Drivers of Contact
In-person contact	<p>To consult on symptoms that could not be managed at home</p> <ul style="list-style-type: none"> <li>• "I mean there have been, I remember there was a time I couldn't urinate, and I had to come down in the night, I met a doctor and something was done for me. Anytime such happen whenever I get to the emergency section" (Participant 20, Nigeria)</li> <li>• "...situation where I would be in severe pain or those occasions when I bleed".</li> </ul> <p>(Participant 54 Zimbabwe)</p> <p>Honouring appointments given by a health professional</p> <ul style="list-style-type: none"> <li>• "When I have an appointment" (Participant 3, Nigeria)</li> </ul> <p>For medication refills and medical supplies (e.g. colostomy bags)</p> <ul style="list-style-type: none"> <li>• "Now that am not too sick, I mainly go there for my Colo...Bags... my bags, that is the main reason. . ." (Participant 41, Uganda)</li> </ul> <p>For emotional and psychosocial support</p> <ul style="list-style-type: none"> <li>• "In between consultations, I think I went there like twice minus an appointment. Yes, because I was getting some mental breakdown" (Participant 37, Uganda)</li> <li>• "To see them... because I like them... so sometimes I spare some times because I like them so much" (Participant 41, Uganda)</li> </ul> <p>To be able to explain their problems clearly</p> <ul style="list-style-type: none"> <li>• "I might get pain but when I feel that I cannot maybe share well the kind of pain I have on the phone. Because there is that information that you feel that you can't explain very well on the phone for someone to understand. And it feels like you need to go in person and explain in person everything so that that person understands you properly." (Participant 50, Uganda)</li> </ul>
Mobile phone	<p>When unable to attend physically because of distressing symptoms or lack of transport</p> <ul style="list-style-type: none"> <li>• "Yes, I get in contact with them. . . using my phone because sometimes I can get the pain, that I can't even, it can't allow me to move, to go there. So, I use my phone to contact them." (Participant 50, Uganda)</li> <li>• "Transportation is one of the reasons, like sometimes if I want to contact my consultant... I may not be able to contact her, especially because of transportation challenges, like now my leg, moving is very difficult sometimes so I have to call" (Participant 3, Nigeria)</li> </ul> <p>Appointment scheduling</p> <ul style="list-style-type: none"> <li>• "To ma. . .to make appointments ooh and the pharmacy." (Participant 42, Zimbabwe)</li> </ul> <p>To seek urgent advice on symptom control, medicines given and functioning of medical devices such as catheters and feeding tubes when at home</p> <ul style="list-style-type: none"> <li>• "I first feared their medicines because they would give us a lot of it, like 100 ibuprofen a packet, like giving us this, they say take ten tablets of this dexa. I said, how can I take this. So, if someone could give me... before taking I would call another one. When they are very many tabs there I say that I've been given this, should I take it?" (Participant 21, Uganda)</li> <li>• "...aah, so I need to call them; and at times maybe this feeding tube they fixed in me, that I use while eating, when it's kind of blocked." (Participant 34, Zimbabwe)</li> <li>• "So, my chemo at times I react to it, I will call them and they may say that it's normal, it's a normal problem people get and with time it will go and with time it wears off. For example, If I am not eating I will call them and they will say don't worry and I discover that with time everything wears off" (Participant 10, Nigeria)</li> </ul> <p>To get information on issues not discussed during the in-person visits e.g diet</p> <ul style="list-style-type: none"> <li>• "I consult them for issues like diet, what can, what I should add to my diet or what I shouldn't use. . ." (Participant 44, Uganda)</li> <li>• "But my young sibling is the one who usually contacts them [n the phone]. He usually talks to them mostly to relay information or he would also be learning from them." (Participant 7, Zimbabwe)</li> </ul>

patient care (quote 30), and a few participants in Nigeria being asked to pay for consultations prior to seeing health care professionals (quote 31).

Participants expressed different views on how palliative care was most important to them. Most participants suggested palliative care was important throughout their disease journey with one participant outlining its continuing role and relevance “...from the time you start with them until the Lord calls you” (quote 32). There were times when participants felt the intensity of palliative care involvement could be reduced, such as when they were symptom-free, but would want to be assured it is available should there be a re-emergence of symptoms (quote 33). Prominent aspects relating to the perceived role of palliative care included assisting participants to value their lives when living with cancer, providing access to information and support from health care professionals that extends beyond physical symptoms (quote 35), providing spiritual support irrespective of religious beliefs (quote 36), and providing essential medical supplies to manage their condition and its symptoms (quote 37).

## Discussion

We provide narrative accounts of people living with advanced cancer in Nigeria, Uganda and Zimbabwe, outlining their experiences and expectations of palliative care, its importance and role in the management of their condition, when palliative care has the greatest impact, and its unique contribution to the quality of their lives. This is the first study drawing together and compiling experiences and expectations of palliative care services across multiple countries in the sSA region. Whilst there was variation in the levels of palliative care development across the three countries, there was commonality in the experiences of and preferences for palliative care delivery. Wide-ranging physical, psychological, social and financial impacts on participants were outlined, with prominent expectations of palliative care services to provide medications and supplies to manage their condition. Participants reported and sought confidential and empathetic communication from staff, alongside seeking common gaps in awareness and understanding of their diagnosis, cancer stage, and goals of treatment. Individual differences and variation in participant preferences were evident relating to disclosure of prognosis. Participants sought a diverse array of services, including those to manage symptoms, provide counselling, and assist with financial support. For the latter, this included the provision of food and assistance with accommodation costs when long-distance travel was necessary for accessing oncological treatments. Participants also reported varying expectations around the modality of communication used by providers, with in-person consultations

preferred when an initial diagnosis was being shared, when initiating treatments, or when experiencing distressing symptoms, compared to the use of remote contact via mobile phone, for example, for scheduling appointments. Participants outlined experiences of receiving compassionate and responsive care despite its delivery in the context of prominent constrained resources leading to limited relational continuity with professionals, disruptions to medication supplies, and staff operating at capacity.

Participants expressed multidimensional needs whenever they interacted with palliative care services, mirroring the multidimensional impact that living with cancer had on them; a finding aligned with existing literature exploring the experience of living with cancer within the sSA region.<sup>5-9</sup> These findings align with reviews of the experience of people living where a wide range of unmet needs are commonly reported across a multitude of world regions and countries of differing levels of economic development.<sup>48</sup> This study highlighted prominent physical and social needs, as commonly reported with advanced disease.<sup>49</sup> While participant needs were met around the management of their disease, the wider impact of stigmatization within their local communities and families was not addressed. Stigma remains high in both clinical settings and amongst the general public and is known to negatively influence cancer patients' psychosocial and treatment outcomes.<sup>50</sup> Local community engagement is required to improve public awareness and understanding of cancer and palliative care. Palliative care provision across low-resource settings may be well placed to explore approaches that draw on the expertise and knowledge of both health workers and community volunteers who are embedded into and provide important roles in the delivery of palliative care services in community settings.<sup>51,52</sup> Public engagement is a critical component of normalizing conversations about death and dying, with a need for public health, governmental, community-based, faith-based, and consumer organizations to provide a role in the provision of fact-based information about care options and to discourage misinformation.<sup>53</sup> There is a need for future research to determine how public engagement can be achieved effectively to reduce the stigma associated with conditions including cancer,<sup>54</sup> including identifying optimal ways in which different aspects of the palliative care workforce can contribute.

Financial concerns were notable for participants, including treatment costs and loss of work due to illness. Health care provision in the participating countries is financed with out-of-pocket expenses of people experiencing illness and chronic disease that commonly leads to impoverishment.<sup>55</sup> The health systems of the three countries operate in a context where the average poverty rate (i.e., the proportion of people

whose income falls below the poverty line) is 41%.<sup>56</sup> The need for financial support with food and accommodation suggests widening the remit of palliative care provision to include efforts to meet basic needs such as food.<sup>6,57</sup> However, broader financial support and guidance is required to avoid the catastrophic financial impact a diagnosis of advanced cancer can have on vulnerable people in low-resource settings, with palliative care involvement associated with avoidance of dissaving (e.g., selling assets to cover medical treatment costs).<sup>58</sup> Such an approach would align with Universal Health Coverage aspirations of an essential package of palliative care proposed to enable access to quality pain and symptom management while preventing financial hardship and impoverishment.<sup>13</sup> Implementation of this proposed package needs to occur concurrently with efforts to develop and enhance social welfare and protection programs in the participating countries. Currently, the International Labour Organization advocates for and is supporting the implementation of a basic social protection package in Africa that includes basic health care, basic income transfers in case of need and basic education; deemed plausible and affordable to provide to all the poor in Africa.<sup>59</sup> Progress is being made in implementing elements of the package in other sSA countries including Ghana, Kenya and Rwanda.<sup>60</sup>

Alongside ongoing physical and social needs, information needs were prominent among participants before accessing palliative care.<sup>61–63</sup> Limited information prior to accessing palliative care could have led to unrealistic expectations relating to outcomes from care.<sup>64</sup> This has important implications for health care provider education programs that should emphasize the provision of information to people prior to referral to palliative care services. Once accessing palliative care, however, participants largely reported positive experiences. This was influenced by being in receipt of compassionate care, improved symptom management, timely access to services when needed, and opportunities to be reviewed by health care professionals with different skills. This experience of receipt of care, and sensitive handling of participants' needs align with accounts of people accessing palliative care in South Africa.<sup>65</sup> In our study, factors driving positive experiences with palliative care for a range of diseases align with findings from other countries outside of sub-Saharan Africa.<sup>25–33</sup> Common aspects in the philosophy and approach of palliative care have perceived benefits for people accessing care, irrespective of the development level of a country. This study provides insight into valued attributes of care based on the expectations and experiences of people living with advanced cancer in the participating countries. These findings may have relevance in guiding the further development of palliative care provision in Nigeria, Uganda and Zimbabwe

alongside guiding refinements to quality criteria to audit existing delivery of care. Furthermore, research is required to support the 'unravelling' of each country setting to better understand their contextual nuance.<sup>66</sup> Doing so will facilitate further sharing of lessons around the delivery of palliative cancer care across settings in which there exist limits to care delivery. For example, the ability of providers in this study to sustain confidential, empathetic and compassionate care in the context of financial shortages and underdeveloped infrastructure could guide practice across the region and internationally where similar constraints on resources exist.

Participant views of when palliative care matters were concordant with current models of palliative care provision in participating countries, as a continuum of care from diagnosis to death and increasing intensity of palliative care services based on need and in times of crises. It was noted that for some people, digital technology such as mobile phones was being used alongside in-person contact. Such approaches can enable flexible and dynamic delivery of care whilst also overcoming disparities in access related to most providers being based in urban locations.<sup>67</sup> Exploring the use of digital technologies for palliative care delivery in sSA provides an opportunity to determine whether benefits demonstrated in high-income settings can be achieved in the context of sSA, including increased access to continued care and follow-up, the provision of information to improve health literacy, and providing options for accessing care providers when face-to-face visits to palliative care services are not possible.<sup>68–71</sup> This aligns with WHO recommendations for developing digital health approaches to overcome health system challenges including the availability and accessibility of services.<sup>72</sup>

### **Strengths and Limitations**

This study was conducted concurrently in three sSA countries with a large and diverse participant sample. Sampling criteria included both men and women, with half of each recruited to the study. Whilst data collection was undertaken across three countries simultaneously, training was provided by the lead research team to local teams, who were familiar with their country contexts and local languages, and validation checks of transcripts took place regularly. Due to the breadth of in-depth, rich data collection across multiple stakeholder groups in the parent study, this secondary analysis focuses on solely the perspectives of people living with advanced cancer. Limitations of the study include that the parent study had a different primary aim, which means further elaboration and seeking of specific responses to address the focus of this study was not possible. Previous analysis and reporting of findings from the project have been used to guide the derive

requirements of digital technologies for palliative cancer care,<sup>39</sup> with the experiential aspects of living with advanced cancer and interaction with palliative care used to guide the analysis and presentation of separate and novel data in this study. Whilst a wide range of cancer types were included, one-third of the study sample included women with breast cancer. Whilst this represents a dominant cancer type in the study sample, the prevalence may reflect the extent of people living with breast cancer with it being the leading malignancy in African females and the most common cancer globally.<sup>73,74</sup> While this study recruited participants living with advanced cancer, we sought the views of those already engaged with palliative care services. Future research is needed that draws on community participation and engagement to elicit perspectives that can inform the provision of equitable care that addresses the social determinants of health amid serious illness, particularly for vulnerable and excluded groups.<sup>75</sup>

### **Conclusion**

Determining the experiences and expectations of patients with serious illness can guide the response and adaptation of care delivery. We identified multiple and varied needs of people living with advanced cancer and accessing palliative care in Nigeria, Uganda and Zimbabwe, alongside their expectations and preferences around care delivery. Wide-ranging physical, psychological, social and financial impacts on participants were outlined. These concerns were largely met with compassionate and responsive care from palliative care services. However, this occurred in the context of constrained resources, impacting aspects of person-centered care, including limited relational continuity of care between participants and health professionals, disruptions to medication supplies, and staff operating at capacity. Furthermore, the enduring financial burden of living with advanced cancer and the social stigma experienced by participants can provide steer in two areas of further research. Firstly, they reflect experiences across all participating countries that warrant further exploration and potential intervention development including, in the case of cancer and palliative care-related stigma, exploring augmentation of the palliative care workforce to facilitate community engagement. Secondly, this study directly informs an evolving notion of person-centered care that reflects the needs and experiences of people with advanced cancer and serious illness reflected from multiple countries in sub-Saharan Africa.

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Ethics approvals for the larger study<sup>30</sup> were obtained from the Institutional Review Boards of the University of Leeds (Ref: MREC 18–032), College of Medicine University of Lagos (Ref: HREC/15/04/2015), Uganda Cancer Institute (Ref: 19–2018), Medical Research Council of Zimbabwe (Ref: MRCZ/A/2421), and the Uganda National Council of Science and Technology (Ref: HS325ES). The project was aligned with the Medical Research Council's good research practice guidelines and H3Africa framework for conducting ethically responsible biomedical research. Participants provided written consent for anonymised transcribed data from their audio recordings to be published.

### **Data Availability**

The authors have full control over the primary data for this study. The data analyzed in this study are stored online in OneDrive folder at the University of Leeds, King's College London, Makerere University, African Palliative Care Association, University of Zimbabwe and the University of Lagos. As per the ethical committee approval from all the countries involved, this dataset is subject to ethical restrictions, and the informed written consent of study participants does not include the publication of raw data in terms of interview manuscripts.

### **Supplementary materials**

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2022.08.022](https://doi.org/10.1016/j.jpainsymman.2022.08.022).

## References

1. Sleeman KE, De Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health* 2019;7:e883–ee92.
2. Open society foundations palliative care as a human right. 2016.
3. WorldHealthOrganisation, Guide to cancer early diagnosis. 2017.
4. Jedy-Agba E, McCormack V, Adebamowo C, et al. Stage at diagnosis of breast cancer in sub-Saharan Africa: a systematic review and meta-analysis. *The Lancet Global Health* 2016;4:e923–ee35.
5. Harding R, Powell RA, Namisango E, et al. Palliative care-related self-report problems among cancer patients in East Africa: a two-country study. *Support Care Cancer* 2014;22:3185–3192.
6. Herce ME, Elmore SN, Kalanga N, et al. Assessing and responding to palliative care needs in rural sub-Saharan Africa: results from a model intervention and situation analysis in Malawi. *PLoS One* 2014;9:e110457.
7. Tapera O, Nyakabau A. Limited knowledge and access to palliative care among women with cervical cancer: an opportunity for integrating oncology and palliative care in Zimbabwe. *BMC Palliat Care* 2020;19:1–9.
8. Olaitan S, Oladayo A, Ololade M. Palliative care: Supporting adult cancer patients in Ibadan, Nigeria. *J Palliat Care Med* 2016;6:258.
9. Nnandi DC. Palliative care: the Nigerian perspective. In: Mollaoğlu M, ed. *Palliative Care*, London, United Kingdom: IntechOpen book series; 2019. p. 146.
10. Olaleye O, Ekrikpo U. Epidemiology of cancers in sub-Saharan Africa. *Cancer in sub-Saharan Africa*. Cham, Switzerland: Springer; 2017. p. 3–19.
11. Harding R, Selman L, Agupio G, et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. *Eur J Cancer* 2011;47:51–56.
12. Afolabi OA, Nkhoma K, Maddocks M, et al. What constitutes a palliative care need in people with serious illnesses across Africa? A mixed-methods systematic review of the concept and evidence. *Palliat Med* 2021;35:1052–1070.
13. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *Lancet North Am Ed* 2018;391:1391–1454.
14. Temel JS, Greer JA, El-Jawahri A, et al. Effects of early integrated palliative care in patients with lung and GI cancer: a randomized clinical trial. *J Clin Oncol* 2017;35:834.
15. Rhee JY, Luyirika E, Namisango E, et al. *APCA atlas of palliative care in Africa*. 2017.
16. Downing J, Grant L, Leng M, et al. Understanding models of palliative care delivery in sub-Saharan Africa: learning from programs in Kenya and Malawi. *J Pain Symptom Manage* 2015;50:362–370.
17. McKenna H, Hasson F, Keeney S. Surveys. In: Gerrish K, Lacey A, eds. *The research process in Nursing*, Chichester, United Kingdom: Wiley-Blackwell; 2010. p. 222.
18. Giusti A, Nkhoma K, Petrus R, et al. The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review. *BMJ Global Health* 2020;5:e003330.
19. African palliative care association, *APCA standards for providing quality palliative care across Africa*. Kampala, Uganda: African Palliative Care Association; 2010.
20. Powell RA, Harding R, Namisango E, et al. Palliative care research in Africa: consensus building for a prioritized agenda. *J Pain Symptom Manage* 2014;47:315–324.
21. Lateef F. Patient expectations and the paradigm shift of care in emergency medicine. *J Emerg Trauma Shock* 2011;4:163.
22. Black A, McGlinchey T, Gambles M, et al. The ‘lived experience’ of palliative care patients in one acute hospital setting—a qualitative study. *BMC Palliat Care* 2018;17:1–10.
23. World Health Organization. *WHO global strategy on people-centred and integrated health services*. Geneva, Switzerland: World Health Organization; 2015.
24. Hasson F, Nicholson E, Muldrew D, et al. International palliative care research priorities: a systematic review. *BMC Palliat Care* 2020;19:16.
25. Sampson C, Finlay I, Byrne A, et al. The practice of palliative care from the perspective of patients and carers. *BMJ Support Palliat Care* 2014;4:291–298.
26. Masel EK, Kitta A, Huber P, et al. What makes a good palliative care physician? A qualitative study about the patient’s expectations and needs when being admitted to a palliative care unit. *PLoS One* 2016;11:e0158830.
27. van Klinken M, de Graaf E, Bressers R, et al. What do future hospice patients expect of hospice care: expectations of patients in the palliative phase who might be in need of hospice care in the future: a qualitative exploration. *Am J Hospice Palliat Med* 2020;37:439–447.
28. Tamirisa NP, Goodwin JS, Kandalam A, et al. Patient and physician views of shared decision making in cancer. *Health Expect* 2017;20:1248–1253.
29. Jager M, de Zeeuw J, Tullius J, et al. Patient perspectives to inform a health literacy educational program: a systematic review and thematic synthesis of qualitative studies. *Int J Environ Res Public Health* 2019;16:4300.
30. Philip RR, Venables E, Manima A, et al. “Small small interventions, big big roles”—a qualitative study of patient, care-giver and health-care worker experiences of a palliative care programme in Kerala, India. *BMC Palliat Care* 2019;18:1–10.
31. Hudson BF, Best S, Stone P, et al. Impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review. *BMJ Open* 2019;9:e027323.
32. Hughes NM, Noyes J, Eckley L, et al. What do patients and family-caregivers value from hospice care? A systematic mixed studies review. *BMC Palliat Care* 2019;18:1–13.
33. Ngwenya N, Kenten C, Jones L, et al. Experiences and preferences for end-of-life care for young adults with cancer and their informal carers: a narrative synthesis. *J Adolesc Young Adult Oncol* 2017;6:200–212.
34. Lewington J, Namukwaya E, Limoges J, et al. Provision of palliative care for life-limiting disease in a low income country national hospital setting: how much is needed? *BMJ Support Palliat Care* 2012;2:140–144.

35. Selman LE, Higginson IJ, Agupio G, et al. Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centred study. *Health and Quality of Life Outcomes* 2011;9:1–14.
36. Selman L, Higginson IJ, Agupio G, et al. Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study. *BMJ* 2009;338.
37. Afolabi OA, Nkhoma K, Maddocks M, et al. What constitutes a palliative care need in people with serious illnesses across Africa? A mixed-methods systematic review of the concept and evidence. *Palliat Med* 2021;35:1052–1070.
38. Bates MJ, Mphwatiwa T, Ardrey J, et al. Household concepts of wellbeing and the contribution of palliative care in the context of advanced cancer: A Photovoice study from Blantyre, Malawi. *PLoS One* 2018;13:e0202490.
39. Nkhoma KB, Ebenso B, Akeju D, et al. Stakeholder perspectives and requirements to guide the development of digital technology for palliative cancer services: a multi-country, cross-sectional, qualitative study in Nigeria, Uganda and Zimbabwe. *BMC Palliat Care* 2021;20:4.
40. Okunade K, Bashan Nkhoma K, Salako O, et al. Understanding data and information needs for palliative cancer care to inform digital health intervention development in Nigeria, Uganda and Zimbabwe: protocol for a multicountry qualitative study. *BMJ Open* 2019;9:e032166.
41. McKenna H, Hasson F, Keeney S. Surveys. In: Gerrish K, Lacey A, eds. *The Research Process in Nursing*, Chichester, United Kingdom: Wiley Blackwell; 2010. p. 222.
42. Hinds PS, Vogel RJ, Clarke-Steffen L. The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qual Health Res* 1997;7:408–424.
43. Ruggiano N, Perry TE. *Conducting Secondary Analysis of Qualitative Data: Should We, Can We, and How?*, 18. Cape Town, South Africa: Qualitative Social Work; 2019. p. 81–97.
44. Okunade K, Nkhoma KB, Salako O, et al. Understanding data and information needs for palliative cancer care to inform digital health intervention development in Nigeria, Uganda and Zimbabwe: protocol for a multicountry qualitative study. *BMJ Open* 2019;9:e032166.
45. Stewart and Kamins, *Secondary Research. Information Sources and Methods (Volume 4, 133 pages)*, in *Organization Studies*. 1986. p. 95-95.
46. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Method* 2013;13:117.
47. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–357.
48. Wang T, Molassiotis A, Chung BPM, et al. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care* 2018;17:96.
49. Cleeland CS, Zhao F, Chang VT, et al. The symptom burden of cancer: evidence for a core set of cancer-related and treatment-related symptoms from the eastern cooperative oncology group symptom outcomes and practice patterns study. *Cancer* 2013;119:4333–4340.
50. Akin-Odanye EO, Husman AJ. Impact of stigma and stigma-focused interventions on screening and treatment outcomes in cancer patients. *Ecancermedicallscience* 2021;15:1308.
51. MacRae MC, Fazal O, Donovan J. Community health workers in palliative care provision in low-income and middle-income countries: a systematic scoping review of the literature. *BMJ Global Health* 2020;5:e002368.
52. Loth CC, Namisango E, Powell RA, et al. From good hearted community members we get volunteers” – an exploratory study of palliative care volunteers across Africa. *BMC Palliat Care* 2020;19:48.
53. MacKenzie AR, Lasota M. *Bringing life to death: the need for honest, compassionate, and effective end-of-life conversations*. Virginia, USA: American Society of Clinical Oncology Educational Book; 2020. p. 476–484.
54. Rosenberg JP, Mills J, Rumbold B. Putting the ‘public’ into public health: community engagement in palliative and end of life care. *Progress in Palliat Care* 2016;24:1–3.
55. Leive A, Xu K. Coping with out-of-pocket health payments: empirical evidence from 15 African countries. *Bull World Health Organ* 2008;86. 849-56C.
56. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Method* 2013;13:1–8.
57. Kohi TW, von Essen L, Masika GM, et al. Cancer-related concerns and needs among young adults and children on cancer treatment in Tanzania: a qualitative study. *BMC Cancer* 2019;19:1–9.
58. Jane Bates M, Gordon MRP, Gordon SB, et al. Palliative care and catastrophic costs in Malawi after a diagnosis of advanced cancer: a prospective cohort study. *The Lancet Global Health* 2021;9:e1750–e1e57.
59. InternationalLabourOrganisation. *Social protection in Africa*. [cited 2022 01/03/2022].
60. Devereux S and Cipryk R. *Social protection in Sub-Saharan Africa: a regional review*. 2009.
61. Heins M, Hofstede J, Rijken M, et al. Palliative care for patients with cancer: do patients receive the care they consider important? A survey study. *BMC Palliat Care* 2018;17:1–7.
62. Mekuria AB, Erku DA, Belachew SA. Preferred information sources and needs of cancer patients on disease symptoms and management: a cross-sectional study. *Patient Preference and Adherence* 2016;10:1991.
63. Mohabbat-Bahar S, Bigdeli I, Mashhadi A, et al. Investigation of stigma phenomenon in cancer: a grounded theory study. *Int J Cancer Manag* 2017;10:e6596.
64. Ghandourh WA. Palliative care in cancer: managing patients’ expectations. *J Med Radiat Sci* 2016;63:242–257.
65. Vasileiou K, Smith P, Kagee A. The way I am treated is as if I am under my mother’s care”: qualitative study of patients’ experiences of receiving hospice care services in South Africa. *BMC Palliat Care* 2020;19:95.
66. van Zyl C, Badenhorst M, Hanekom S, et al. Unravelling ‘low-resource settings’: a systematic scoping review with qualitative content analysis. *BMJ Global Health* 2021;6:e005190.
67. Oleribe OO, Momoh J, Uzochukwu BS, et al. Identifying key challenges facing health care systems in Africa and potential solutions. *Int J Gen Med* 2019;12:395.

68. Phongtankuel V, Adelman RD, Reid M. Mobile health technology and home hospice care: promise and pitfalls. *Prog Palliat Care* 2018;26:137–141.
69. Ostherr K, Killoran P, Shegog R, et al. Death in the digital age: a systematic review of information and communication technologies in end-of-life care. *J Palliat Med* 2016;19:408–420.
70. Mills J. Digital health technology in palliative care: Friend or foe? *Progress in Palliative Care* 2019;27:145–146.
71. Huxley CJ, Atherton H, Watkins JA, et al. Digital communication between clinician and patient and the impact on marginalised groups: a realist review in general practice. *Br J Gen Pract* 2015;65:e813–ee21.
72. World Health Organization. WHO Guideline: recommendations on digital interventions for health system strengthening, WHO. Geneva: WHO; 2019 Editor.
73. Sharma R. Breast cancer burden in Africa: evidence from GLOBOCAN 2018. *J Public Health (Oxf)* 2021;43:763–771.
74. Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2021;71:209–249.
75. Rosa WE, Elk R, Tucker RO. Community-based participatory research in palliative care: a social justice imperative. *The Lancet Public Health* 2022;7:e104.