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Integrated primary palliative care in Nigeria- perspectives of patients, families and providers

***Oladayo A. Afolabi^{1,5}, Kennedy Nkhoma¹, Olaitan Soyannwo², Akinyemi Aje³, Adesola Ogunniyi⁴, Richard Harding¹, Matthew Maddocks¹**

- 1. Cicely Saunders Institute of Palliative care, Policy and Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery and Palliative care, King's College London, London, UK**
- 2. Hospice and Palliative care department, University College Hospital, Ibadan, Nigeria**
- 3. Division of Cardiology, Department of Medicine, University College Hospital, Ibadan, Nigeria**
- 4. Division of Neurology, Department of Medicine, University College Hospital, Ibadan, Nigeria**
- 5. Department of Nursing Science, University of Maiduguri, Maiduguri, Nigeria**

***Corresponding author:**

Oladayo Ayobami Afolabi

Cicely Saunders Institute of Palliative care, policy and rehabilitation,
Faculty of Nursing Midwifery and Palliative Care,
King's College London,
Bessemer road, London, UK SE5 9RS
oladayo.afolabi@kcl.ac.uk

Abstract

Background: Palliative care should be integrated into primary healthcare systems within low- and middle-income countries to achieve Universal Health Coverage goals. We aimed to identify preferences and expectations for primary palliative care among people living with serious illness and their families and the readiness of primary healthcare providers to deliver primary palliative care in Nigeria.

Methods: Qualitative descriptive interview study with 48 participants: people living with serious illness (n=21) and their family caregivers (n=15), healthcare providers (n=12). Data were analysed using thematic analysis.

Results: Three major themes were identified. 1.) Engaging patients and families. 2.) Managing patients and families' expectations and preferences. 3.) Addressing staffing related issues. Patients and families have existing trust and bonds from using primary healthcare but lack individual agency necessary for person-centred care decisions. They expect an easily accessible service, opportunities for social interaction and adequate communication. Development of healthcare providers is needed to ensure an appropriate clinical response, manage interprofessional trust and ensure clear role delineation.

Conclusions: Our findings have identified specific approaches to implement the WHO policy on integrated primary palliative care. Palliative care integration within primary healthcare in Nigeria can be achieved through building information and communication skills of healthcare providers, engaging and empowering patients to exercise their agency in care decisions, and adequately delineating healthcare providers' roles to ensure staff work within their competencies and training.

Keywords: Palliative care, Primary healthcare, universal health coverage, serious illnesses

Key message

This paper describes how palliative care can be integrated within existing primary healthcare system in a low- and middle-income country. Results suggest that primary palliative care integration may be constrained by primary healthcare providers' response to serious illnesses and attitudes to death, interprofessional distrust and the patients' lack of agency.

Running title: Primary palliative care Nigeria

BACKGROUND

By 2060, the number of deaths with serious health-related suffering in the last year of life in low and lower-middle-income countries will be 5.14 million and 16.84 million respectively(1). This is an increase of 155% and 87% respectively compared to the year 2016. In Africa, the WHO project a 403% increase in cancer mortalities; a 213% rise in kidney disease-related mortality; an increase in chronic obstructive pulmonary diseases mortality by 255% and a 316% increase in cardiovascular disease-related deaths (including stroke) between 2016 and 2060(2). Patients living with these serious illnesses and their families report pain, suffering, poor quality of life and physical, psychological, social and spiritual needs that are amenable to palliative care(3, 4).

In low- and middle-income countries, palliative care can improve outcomes for patients and their families and saves costs(4). However, in the majority of these countries, palliative-care services remain either non-existent, largely fragmented within, or operate outside of national health systems(5, 6). For example, Nigeria has 23,640 healthcare facilities within the public health system, of which, 85.8% are primary, 14% secondary and 0.2% are tertiary. However, Nigeria is classified in Category 3a (*only isolated palliative care provision*) of the global palliative care atlas(6) and has only 17 reported palliative care facilities (mostly tertiary hospital specialist palliative care teams) catering for a population of ~190 million(7). This

isolation and centralisation of palliative care neglects the primary healthcare base of the health system, reducing access to relief from pain and suffering(8).

Palliative care is integral to the achievement of the Universal Health Coverage goal, yet limited access puts the achievement of this goal at risk(8). Primary healthcare remains the base on which strong and sustainable health systems are built(9, 10), and should provide health promotion, prevention, treatment, rehabilitation and palliative care services(9). Specialist hospital-based palliative care alone cannot be relied upon to meet the burden of palliative care needs. Primary healthcare has enormous potential to sustainably increase access to quality palliative care(11) and the WHO affirms palliative care as an essential function of primary healthcare(12).

As international policy direction continues to emphasise integration of palliative care within primary healthcare(13, 14), there is need to understand how these recommendations can be adapted within different local contexts. Engaging with patients with serious illnesses, their families and primary healthcare providers can provide insights into the opportunities to integrate palliative care in a person-centred manner. Hence, this study aimed to identify preferences and expectations for primary palliative care among people living with serious illness and their families and the readiness of primary healthcare providers to deliver primary palliative care in Nigeria.

METHODS

Study design

This cross-sectional qualitative interview study is part of a larger sequential mixed-methods project to integrate palliative care within the primary healthcare level in Nigeria. This is underpinned by the pragmatist approach with the aim of identifying and solving problems.(15)

Study Participants and Setting

We sampled three populations: patients and family caregivers attending specialist outpatient clinics (i.e., palliative care, cardiology, neurology, pulmonology, and cancer radiotherapy outpatient units) at a national referral teaching hospital, and healthcare providers at three primary healthcare centres (1 urban, 1 rural-urban and 1 rural) in Ibadan, Nigeria.

Eligible patients were adults (aged at least 18 years) with a diagnosis of a serious illness ranked among the top 10 causes of mortality in Nigeria(16) and recognized as causing a high burden of palliative care need(17), including in Africa(3). These were tuberculosis (Multidrug-resistant (MDR), Extensively Drug-Resistant (XDR) and Post-Tuberculosis Lung disease(18)); ischaemic heart disease with a complication of heart failure (stage 3 and 4 of New York Heart Association Classification OR American Heart Association stages C and D); any malignancy which is life-threatening but unlikely to benefit from or not responsive to curative treatment and for which only conservative management is planned(19), usually stage 3 and 4 cancer; Stroke (acute, serious, and life-threatening stroke, including those patients for whom some reversibility is a realistic goal(20)). Of the two million annual deaths in Nigeria in 2016, these conditions accounted for 17.6% (374,800) of all-cause mortality in all ages and 1 in 3 (338,000) deaths in ages 30 years and above(21).

Inclusion and exclusion criteria for patients included:

- a score of 3-5 on at least two domains of the APCA POS(22),
- functional limitation in any of the six basic activities of daily living(23) that significantly affects daily function and quality of life

Family caregivers identified by the patient were aged 18 years and over and have been involved in day-to-day unpaid caregiving for the patient for at least six months. Healthcare providers with at least six months of experience in primary healthcare were eligible.

Recruitment and Sampling

Participants were recruited by purposive sampling. Patients and family caregivers who meet the inclusion criteria were informed about the study by their healthcare providers while attending clinic. Interested individuals then contacted OA to express their interest in participating. Interested patients also identified family caregivers who was approached by OA to discuss participation in the study. OA and OS met with facility managers in the selected primary healthcare facilities to distribute the recruitment flyers to primary healthcare providers. Interested professionals contacted OA to learn more about participating in the study.

For maximum variation of the sample (24, 25), different characteristics were considered including patient diagnosis, duration of serious illness, palliative care referral status (for patients and family caregivers), gender (family caregivers), and for staff, professional training and years of experience. Recruitment continued until data saturation was reached, i.e. the point at which identification of new themes during the iterative analysis added no new insight to achieve the study objectives(26).

Data Collection

Semi-structured interviews were conducted. by OA between January 2020 and March 2020 during clinic visits. OA is a male researcher and registered nurse. He is Yoruba (the same cultural background as most of the population in Ibadan), conversant with the dominant local language and understands important cultural cues and dynamics within conversations and dialogues. Our study-specific interview topic guide covered patients and families' experience of using primary healthcare while living with serious illness, healthcare providers experience supporting these patients and families, understanding of palliative care needs, priorities, and expectations for support for palliative care needs by primary healthcare. The guide was

piloted with three patients, two family caregivers and one primary healthcare provider then refined. Clarifications and probes were used during the interview to ensure adequate details were captured. Interviews lasted 20 to 75 minutes and were audio-recorded. Patient participants and family participants were interviewed separately unless a preference to be interviewed together was expressed. OA maintained an ongoing journal to enhance the reflexivity, transparency and auditability of the research.

Data Analysis

Interviews were transcribed, translated verbatim, pseudonymised, and uploaded to NVivo version 12(27). Translated transcripts were back-translated and verified against the audio files by OA for accuracy, consistency, fidelity and to optimise interpretation. Where translated quotes formed key segments of analysis, a second translator (OS) reviewed content to ensure that the meaning of participant responses was maintained.

Analysis was undertaken by OA and KN using thematic analysis(28). Data analysis started after the first three interviews and proceeded iteratively. OA read the interview transcripts repeatedly to familiarise with the data and develop a preliminary understanding of themes within individual cases and across the data set. OA inductively identified themes from the data which were reviewed by KN, and OS independently, new themes were created, existing ones were revised and a mutually agreed coding frame was developed and applied to all remaining transcripts. Transcripts were coded line by line; patterns and themes of particular salience for participants and across the data set were identified and analysed at the semantic or explicit level(25, 28). While the data was coded for convergence of participants' perspectives, deviant or non-confirming themes were also coded. The analysis was reviewed by MM and RH plus project expert advisory group (GW, CE and VS) and clinical experts in

Nigeria (OS, AA and AO) at regular intervals. Main themes were developed based on a summary of coded themes to form an overall coherent story.

RESULTS

Sample characteristics

Of the 29 patients, 17 carers and 12 healthcare professionals who expressed interest in the study, seven patients and two carers later declined and one patient was too fatigued. 48 participants (21 patients, 15 family members and 12 primary healthcare providers) were interviewed.

Table 1 highlights the demographic characteristics of the participants. Patients were living with cancer (n=7); heart failure (n=5) tuberculosis (n=5) or were post-stroke (n=4). Healthcare providers were nurses (n=7), doctors (n=3), or community healthcare extension workers (n=2) (Table 1).

Main findings

Three main themes were developed: engaging patients and families, managing patients' expectations, and addressing staffing related issues (

Figure 1).

Figure 1 illustrates the themes and subthemes and how these are interlinked as factors to be considered in the development of the new integrated primary palliative care intervention. The coding tree and supporting quotes are in Table 2.

Engaging patients and families

Patients, family caregivers and healthcare providers identified opportunities and potential constraints for palliative care delivery existing within current primary healthcare structures.

The desperation of patients and families for support

After living with and enduring unresolved symptoms and other concerns related to serious illnesses patients and family caregivers were desperate for any available support to improve their quality of life, including palliative care. They described challenges in trying to access care for their concerns between their specialist appointments. They also expressed fears of taking inappropriate actions that might further complicate their health which often results in them presenting at the emergency unit.

Patients and families' current use and existing trusting bond within primary healthcare

For less financially-privileged participants, public primary healthcare facilities were usually their first point of call before attending the tertiary hospital where the diagnosis of a serious illness was made. More financially-privileged individuals described their use of private primary healthcare facilities as both their first point of call for minor illnesses and last resort when systemic problems sometimes make it difficult to access care at a tertiary healthcare centre.

Participants described their existing trust and bond with primary healthcare providers established from ongoing use of these accessible facilities situated nearby. They believed that engaging in communication relating to diagnosis, what to expect from illness course, what

supports are available and how to prepare within the context of serious illnesses would be less challenging.

Patients and families' lack of agency

When asked their priorities and what support they would like from a palliative care intervention delivered within primary healthcare, patients and their family caregivers often responded that healthcare providers should decide what kind of support to provide. Most patients described not being knowledgeable enough and would defer to what the healthcare providers judge as necessary to meet their needs. Even for those patients who wished to exercise their agency, the communication challenges they faced in interacting with their current healthcare providers meant their involvement and opinions in decisions made by healthcare providers were minimal.

Managing patients and families' preferences and expectations

Ease of access and use

Patients and caregivers described the need for any intervention to be easily accessible in terms of proximity to home, with a conducive and welcoming environment, short waiting times and prompt response. This was often discussed in the context of their current experience with seeking care at tertiary healthcare centres.

Quality of care and Staffing

Patients and family caregivers emphasised the need to improve the quality of care and the skills of primary healthcare providers. Patients highlighted the need for the palliative care provided at primary healthcare facilities to be aligned with their specialist care received at the tertiary level, fearing differing opinions or treatment. Family caregivers felt that the less-

pressured environment of primary healthcare mean patient monitoring may be better provided.

Finding shared experiences, social interaction and respite

All groups of participants highlighted the role of primary healthcare space in facilitating opportunities for social interactions and shared experiences. As patients and caregivers interact with one another, this helped them to cope with social stigma of serious illnesses which are usually shrouded in mystery. Patients and carers also described the anticipated psychosocial benefits from having better access to palliative care including reduced social isolation and an opportunity to leave the house and share their concerns. Carers emphasised the current lack of home care support and their expectation of respite to help them deal with burn-out and to relieve them of their obligation while they recuperate mentally.

Information, education and communication

Patients and family caregivers highlighted the importance of receiving education about the illness- causes, course and consequences, including clear and focused communication around treatment and support plans. They highlighted the difficulty they faced in communicating with specialist providers, and the need for a less pressured environment with providers who can communicate using understandable language, listen to their concerns and educate them. Participants expected healthcare providers' attitude and approach to communication to be open, patient, and supportive. They emphasised this can foster a sense of shared understanding of their needs and goals of care, manage their expectations concerning the course of the illness and plan appropriately for eventualities.

Addressing staffing-related issues

Inconsistent perception of the competence and function of PHC

Some patients and carers feared that the primary healthcare level was staffed by lay healthcare workers and that care was rudimentary and of lesser quality compared to secondary and tertiary care. However, others, in agreement with healthcare providers, reported that primary healthcare facilities are already staffed by qualified healthcare providers (i.e. nurses and doctors) supported by trained community health workers. However, healthcare providers acknowledged that the facilities do not always have the appropriate staffing ratio, with shortages of nurses and doctors in many facilities. They felt that the resulting pressure sometimes affects care quality and highlighted the need to be trained to provide palliative care for patients.

Inter-professional distrust about working within competencies

The participants' responses also revealed a constant tension between healthcare provider cadres due to the lack of a clear definition of roles, responsibilities, and limits of competence. This distrust is majorly directed at the community health officers and community health extension workers (CHOs/CHEWs). Nurses were concerned that CHOs/CHEWs see themselves as equally competent as nurses despite having different training. This creates an atmosphere of rivalry with the patients at the receiving end. Doctors and nurses reiterated their worries about the competence of the CHOs/CHEWs to deliver care out of hours, to deliver care for patients with serious illnesses, to follow designed care plans and to work within the limits of their competence. They provided instances where they have been forced to cover up problems created by the CHOs/CHEWs.

There was also a pattern of vertical interprofessional distrust within the healthcare system. Healthcare providers suggested that tertiary and secondary level providers do not trust them to competently deliver care for patients with serious illnesses and hence fail to refer patients

back to them after stabilising any exacerbations. This meant they usually did not hear back from patients referred to the higher level of care.

Primary Healthcare providers' response to serious illnesses

Healthcare providers explained that their first response to patients with serious illnesses is to refer them to other levels of care for treatment. They highlighted that they currently only have resources to support some patients with HIV or TB. Orientation of primary healthcare towards the treatment of minor acute and not chronic illnesses has informed the perception of the limits of their care at this level. Therefore, some healthcare providers did not feel they have a role to play in the ongoing management of patients with serious illnesses. Others explained that this response is due to challenges such as lack of focus on long term management, reluctance to deal with dying patients, potential administrative and legal implications from patients dying at primary healthcare and shortage of qualified nurses and doctors.

'We already do this somehow'

Some healthcare providers acknowledged that they have no prior knowledge of palliative care. They variously described it as pain management, rehabilitation, relief of symptoms or end-of-life care. However, they felt that they already perform some palliative care activities e.g. managing physical symptoms such as uncomplicated pain, nausea and diarrhoea, delivering health education to patients, and providing counselling support to families.

DISCUSSION

Our findings highlight the expectations and preferences of patients and family caregivers in the delivery of palliative care within primary healthcare in terms of prioritising information, communication, education and social spaces. Adequate palliative care integration at the primary healthcare level must capitalise on patients' current use of primary healthcare facilities and existing bonds; address healthcare providers understanding of their roles in the ongoing management of persons with serious illnesses and families at this level, and ensure delineated competency-based roles and responsibilities to foster interprofessional trust for collaboration.

The concept of palliative care was new to many of the participants interviewed for this study. Most patients and families contextualised their expectations within their current experience of attending specialist clinics. These clinics are based on rigid appointment schedules which do not align with the unpredictable and fluctuating nature of many problems associated with serious illnesses, leaving patients and families without adequate support. The clinic environments are also highly-pressured and make quality communication difficult to attain, leaving patients and families disoriented with their conditions. The healthcare providers also showed varied understanding of palliative care, palliative care needs and their role in providing palliative care at the primary healthcare level.

Patients emphasised the need for easily accessible and flexible support that is less-pressured. They want clarity about the breadth of concerns that can be discussed with healthcare providers and quality information, education and communication to help them understand the causes, course and consequences of their illnesses and treatments. These findings underscore earlier studies that show that patients with serious illnesses and their families want adequate information, communicated with clarity, accuracy, and sensitivity (3).

The healthcare provision structure contributed to these challenges faced by patients with serious illnesses in accessing support for palliative care needs. Previous authors have reported dysfunctionalities in the structure of the Nigerian healthcare delivery system concerning the provision of palliative care(29). Our study builds on this with opportunities for the integration of palliative care within primary healthcare despite the challenges. Patients and families highlighted that their previous use of the primary healthcare facilities helped build therapeutic bonds and trust with the healthcare providers at this level. This aligns with earlier findings that social relationships are crucial to the decision-making of patients about the use of palliative care and oncology services in Nigeria(29).

Participants raised several constraints that may hamper the integration of palliative care within the current primary healthcare structure. Patients relinquishing their agency and deferring to the healthcare providers for the decisions about their care may constrain the provision of person-centred palliative care driven by patients' preferences and concerns. The low health literacy of the patients and the years of healthcare providers paternalistic attitudes to care within this setting(30) might have reinforced this lack of agency. This implies that patients are seldom involved in participating in the decisions about their care plan, and instead follow decisions made by healthcare providers. Often patients expected the healthcare providers to know what support they need; however, healthcare providers were constrained by limited understanding of palliative care, limited resources, high workload and paternalistic attitudes. To deliver palliative care within this setting, healthcare providers will need to support patients' agency and involvement by giving information to and, engaging patients to participate in care decisions.

The primary healthcare system in many low and middle-income countries has been largely focused on minor acute illnesses usually related to infections and maternal and child health services(31). This has resulted in a transactional approach to service delivery and the

diversion of care for patients with serious illnesses away from this level. The response of many primary healthcare providers to patients and families presenting with serious illnesses is onward referral with minimal engagement. Ineffective referral feedback from the higher level of care can mean the patients may never be seen again at the primary healthcare level, even when back home in the community with ongoing problematic symptoms and concerns(32). For palliative care to function appropriately within the primary healthcare in Nigeria, there is a need to re-orientate healthcare providers about the roles of primary healthcare in managing people with serious illnesses and change the perception that primary healthcare is for the provision of rudimentary care. It is also imperative to revamp referral feedback from the higher levels of care to primary healthcare to ensure that ongoing support is available to patients in between secondary and tertiary clinic appointments. This is important as primary palliative care must continue to work together with specialist providers to ensure patients and families receive the appropriate level of care.

Quality palliative care delivery thrives on a strong multidisciplinary approach. The chronic suboptimal staffing of nurses and doctors at the primary healthcare level means community healthcare workers and community health extension workers (whose training was geared towards health promotion and first aid for acute conditions) have now become the backbone of staffing for primary healthcare(33). Our findings revealed some interprofessional distrust among the healthcare providers with nurses and doctors expressing doubts about the community health workers' knowledge, competence to provide care for patients with serious illnesses and discipline to work within the limits of their competence.

Previous interventions within primary healthcare in Nigeria successfully trained community healthcare workers to deliver stepped-care interventions within the task-shifting framework(34-36). To deliver palliative care within primary healthcare in low and middle-income countries, wide-scale engagement to clarify the roles and responsibilities of the

community health officers and community health extension workers and their fit within the organisational structure at the primary healthcare level is important. This can improve task shifting, interprofessional harmony and reduce the burden on acute care.

Methodological reflection

To our knowledge, this is the first study to consider how to integrate palliative care for a broad range of serious illnesses within primary healthcare on the African continent. We employed a robust design and maximum variation sampling to ensure the perspectives of patients, family caregivers and healthcare providers were heard.

Some limitations may affect the interpretation of our findings. The local language in which some of the interviews were conducted does not have a direct interpretation for palliative care, and the term was new to many of the participants, including healthcare providers. This might have limited the participants' expression of their thoughts. Nevertheless, our topic guides were influenced by a comprehensive framework of palliative care needs in Africa(3) to explore different areas of palliative care need with the participants. Additionally, OA, a native speaker of the local language and conducted all the interviews. The results were also presented to local experts to enhance contextual interpretation of the findings. Also, majority of the participants interviewed were Yoruba. This may limit the interpretation of this study, considering Nigeria's ethnic and religious diversity. However, the themes in the findings are related to institutional factors rather than individual needs, and as such, the influence of ethnic or religious differences on the relevance of the findings will be minimal.

This paper focused on service delivery and human resource for health as two of the six WHO building blocks of the health system. This is not to undermine other building blocks which might support the integration of palliative care within primary healthcare, but these are

usually already defined within the context of the health system. Further work on, for example, leadership and governance, and healthcare financing remain important.

Conclusions

Our findings demonstrate the considerations needed to integrate palliative care within primary healthcare to address the multidimensional needs of patients with serious illnesses and their families. Such integration must emphasise clear role descriptions for primary healthcare providers to ensure an appropriate response to patients with serious illnesses and encourage interprofessional trust. Primary healthcare providers need training and support to foster quality communication, education and information for patients and families. This can strengthen patients' understanding of their symptoms and expression of multidimensional concerns, and their agency and involvement in care decisions. Policies and continuous professional development must emphasise the critical role and function of primary healthcare providers in palliative care for patients with serious illnesses.

DECLARATIONS

Ethics Approval and Consent to Participate

Ethical approvals were sought and obtained from Kings College London Ethical Review Board (HR-18/19-13585) and the University of Ibadan/ University College Hospital Ibadan Research Ethics Committee (UI/EC/19/0422). The research process and data collection procedures adhered to sound ethical principles. Fully informed consent was sought from all participants in the study.

Consent for publication

Not Applicable

Availability of data and Materials

The summary table of themes and supporting data has been included as a supplementary file. Anonymised copies of interview transcripts conducted for the current study are available from the corresponding author upon reasonable request and subject to ethical review.

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

OA: design of the work; acquisition, analysis, and interpretation of data; drafting and substantial review of manuscript

KN: design of the work; acquisition, analysis, and interpretation of data; drafting and substantial review of manuscript

OS: acquisition and interpretation of data; review of manuscript

AA: acquisition and interpretation of data; review of manuscript

AO: acquisition and interpretation of data; review of manuscript

RH: design of the work; acquisition, analysis, and interpretation of data; drafting and substantial review of manuscript

MM: design of the work; acquisition, analysis, and interpretation of data; drafting and substantial review of manuscript

All authors approved the final version of the paper to be published.

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Table 1: Demographic characteristics of participants

	Patients (n=21)	Family caregivers (n=15)	Healthcare professionals (n=12)
Gender	<i>n</i>	<i>n</i>	<i>n</i>
Male	6	7	3
Female	15	8	9
Total	21	15	12
Age in years (Mean ± SD)	54.48 ± 12.99	40.73 ± 16.74	
Profession			<i>N</i>
Medical Doctors			3
Nurses			7
Community health officers or extension workers (CHOs/CHEWs)			2
Total			12
Diagnosis	<i>n</i>	<i>n</i>	
Cancers	7	5	
Heart failure	5	5	
Tuberculosis	5	1	
Stroke	4	4	
Total	21	15	
Years of experience within PHC [Median (Range)]			22 (15-26)
Educational level	<i>n</i>		
No education	4		
Primary	3		
Secondary	6		
Tertiary	8		
Total	21		

<i>Relationship to patient</i>		<i>n</i>
Son		4
Daughter		4
Spouse		6
Others (Daughter-in-law)		1
Total		15
<i>Marital status</i>		<i>n</i>
Single	3	
Married	9	
Widowed	8	
Divorced	1	
Total	21	
<i>Palliative care referral</i>		<i>n</i>
Yes	1	1
No	20	14
Total	21	15
<i>Duration of Serious illness (years)</i>		<i>n</i>
0-5	7	
6-10	8	
10 and above	6	
Total	21	

Table 2: Analysis coding and supporting quotes

Themes and subthemes	Illustrative quotes
Managing patients' and families expectations and preferences	
Ease of access and use	<ol style="list-style-type: none"> 1. 'Somebody like me would prefer to go to where I would be attended to immediately rather than queue in a bigger place like this. If the quality of what I would be getting in primary health care is okay, and quality drugs, you know, just like that...' - Patient with heart failure 2. the way I came for this check-up, it's a matter of just going there for them to check me up and if there's anything that they can't handle, they'll refer. Then in fact, assuming it was that place I went to, this is almost eleven now and I got here by eight o'clock, there would be nothing wrong for me to have left that place at most ten o'clock. Patient with stroke
Quality of care and staffing	<ol style="list-style-type: none"> 1. 'If we do that at the primary healthcare level, are we going to be consistent with the care being provided by the consultants? Are we going to be consistent with it?' - Patient with cancer 2. Well, if you raise. If you want to, you raise the standard, the quality of health care standard you want to dispense to the

	<p><i>public, once, we raise the public's interest, I mean, it would make the public have confidence in their output. But if it is what they have now, nobody wants to risk his/her life to go to where you can't find doctors, qualified nurses, I would not go to such places. I wont. Patient with heart failure</i></p>
<p>Finding shared experiences, social interaction and respite</p>	<ol style="list-style-type: none"> 1. <i>'it is good. You know she is getting older. If she has a place she can be going closer to home and not just sitting at home on her concerns. It will be good. If she comes she will be able to explain her perspectives and you can discuss with her as well. That opportunity to even get out of the house will help her a lot. It is a good thing.'</i> - Carer of patient with heart failure 2. <i>People will come. Even if you think the elites will not come, those who are not elites will come. They will find out that we can gather in this place, myself and the other women can meet and even discuss our issue. Hen hen so how does it happen to you, what is the thing that you do.</i> - Patient with cancer
<p>Information, education and communication</p>	<ol style="list-style-type: none"> 1. <i>'It will be very helpful because even the way you are talking and explaining things, it is different from the doctors here and if we can hear the explanations, it will help us to be more conscious of what we need to do to support mama and to understand her condition.'</i> - Carer of patient recovering from stroke 2. <i>Once it has been treated fully I don't know what happens. I didn't even know that after it has been completely treated it reoccurs. I thought that once I use all the drugs it clears off but it came back again.</i> – Patient with MDR TB
<p>Engaging patients and families</p>	
<p>Desperation for support</p>	<ol style="list-style-type: none"> 1. <i>'Yes. No matter how little the support is, no matter how little the care will be, she will be very glad and grateful for anybody that will help her.'</i> - Carer of patient with cancer 2. <i>They said I have the heart thing. Is it possible to find a solution? Can we find a solution? If there is no solution, rather than for me to be a spectacle of pity, God should rather deliver me and take me to him. There is no enjoyment, there is no sleep. There is no food.</i> -Patient with heart failure
<p>Patients and families current use and existing trusting bond within primary healthcare</p>	<ol style="list-style-type: none"> 1. <i>'But you know family doctors now, they have been the ones we go to for malaria, typhoid, cough and cold, so he has created a bond with the family and I feel like based on that, the family will listen to him more than just anybody that just comes.'</i> – Carer of patient with cancer 2. <i>'When this illness just started, it was also the health centre that I went to before they discovered that it was this type of</i>

	<i>illness. It is the small hospital that I went to before I knew that this type of illness has started. -Patient with heart failure</i>
Patients and families lack of agency	<ol style="list-style-type: none"> 1. <i>'I believe that's your work. You are the one that will know what is good for us, especially with the kind of treatment she needs.'</i> - Carer of patient with heart failure 2. <i>'No. since it is not my work, it is the doctors that will say what to do. They will say what to do.'</i> - Patient with cancer
Addressing staffing related issues	
Inconsistent perception of the competence and function of primary healthcare	<ol style="list-style-type: none"> 1. <i>'That will be good. At least it will be closer to home. However, I do not know whether the doctors and nurses there will be able to handle my condition because even the general hospital that I went referred me here. That said, if they will be able to attend to me at least that will reduce the burden a lot.'</i> - Patient with cancer 2. <i>'They should not see primary as rudimentary, as a level that the people there knows nothing. It is a wrong misconception, a very bad one. In my life I have done well over 800 surgeries, herniorrhaphy, over 800 hundred without complications and I have done that at primary care. No mortality. Nothing.'</i> - Doctor at primary healthcare
Interprofessional distrust about working within competency	<ol style="list-style-type: none"> 1. <i>'It's not to say we can't treat them, but hmmm... and it's when we that are registered are around and some of these people that are capable. If another person mishandle them that will cause another problem for them, and they are not...we cannot say we are proud of most of the care work that they do here and be able to monitor them. That is where the problem is.'</i> - Nurse at primary healthcare 2. <i>'Because some higher level of care, they don't want that patient to come to primary care. As in they would be doubting..., will they do what I want them to do?'</i> - Doctor at primary healthcare
Primary healthcare providers' response to serious illness	<ol style="list-style-type: none"> 1. <i>'And as you also know, in primary health care, we try as much as possible to avoid any form of death. We are not here to just be recording death -death. If a patient needs an higher care, let the patient go as much as possible.'</i> – Doctor at primary healthcare 2. <i>'We have 3 categories of health care, so we don't go beyond our own boundary, we have limitations, to treat minor ailments. The primary health care is here to treat primary ailments, like malaria, cough, diarrhea, measles, and things like that. Not chronic ones, we are not liable to treat it. So if we have any such cases like that, we have to refer. We know our boundary, so we don't go beyond our boundary'</i> - Nurse at

	primary healthcare
We already do this somehow	<ol style="list-style-type: none"> 1. <i>'At least if we have malaria patient, the relatives too, they are disturbed, they have anxiety, and so on. And we take care of it. So if these patients too are around us, we know how to take care of it, if we can allay the fear of those other patients, we can allay their own fear too.'</i> – Nurse at primary healthcare 2. <i>Ha ha we can do that. We used to do that a lot. Some may not even... some people came down here and we started counselling, they were so happy to be able to talk.</i> – Nurse at primary healthcare

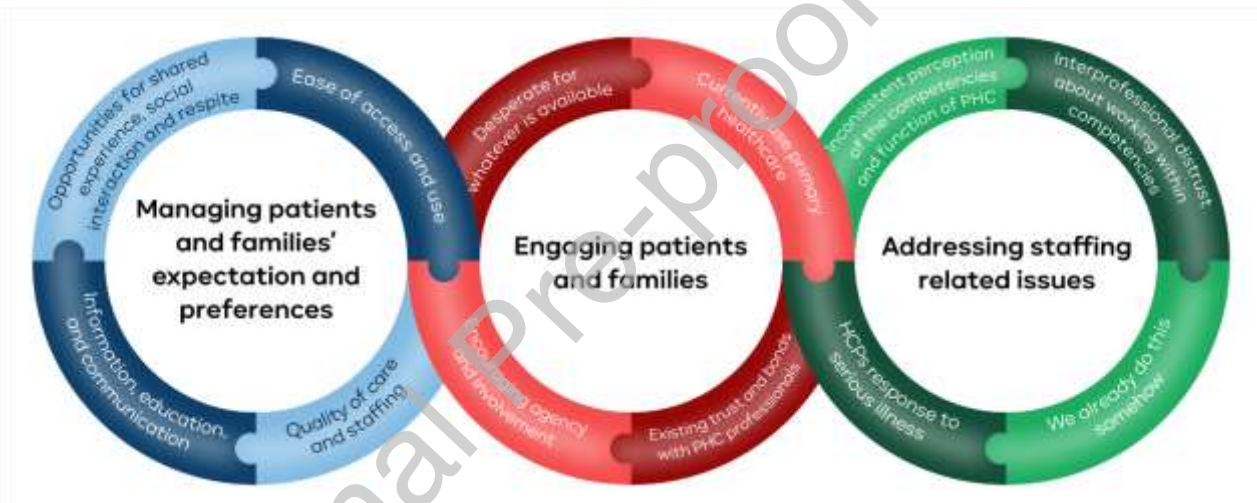


Figure 1: Considerations for integrating palliative care within PHC

Blue- Subthemes of Managing patients and families' expectation and preferences
 Red- Subthemes of Engaging patients and families
 Green- Subtheme of Addressing staffing related issues