Benefits of integrating palliative care: a qualitative exploration of the perspectives of palliative care providers in a tertiary health facility in Ghana

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Abstract

Background: Integration of palliative care (PC) services entails combining administrative, organisational, clinical and service elements to ensure continuity of care between all parties participating in the care network of patients. There is a need to understand the benefits of integrating PC to inform policy making and advance advocacy, especially in resource-constrained settings such as Ghana where PC is sub-optimally implemented. Yet, existing research in Ghana is sparse on what benefits are likely to be experienced as a result of integrating PC.

Objective: The study explored service providers' perspectives on the benefits of integrating PC in Ghana.

Design: The design was an exploratory descriptive qualitative research design.

Methods: A total of seven in-depth interviews were conducted using semi-structured interview guides. The data were managed using NVivo-12. Inductive thematic analysis was carried out following Haase's modification of Colaizzi's approach to qualitative research analysis. The study follows the COREQ guidelines and the ICMJE recommendations.

Result: Two main themes emerged: patient-related outcomes, and system/institution-related outcomes. For the patient-related outcomes, the following sub-themes emerged: restored hope, appreciated care and better preparation for the end of life (EoL). The emerging sub-themes under the system/institution-related outcomes include the following: early initiation of care, enhanced communication between primary healthcare providers and the PC team and strengthening staff capacity to provide PC services.

Conclusion: In conclusion, there are substantial benefits to be experienced from integrating PC. For the patients, it would restore shattered hopes, result in appreciated care and better preparation for the EoL. For the healthcare system, it would promote early initiation of care, enhance communication between primary healthcare providers and the PC team and strengthen service providers' capacity to provide PC services. This study, thus, furthers the case for a more integrated PC service in Ghana.

Keywords: cancer, integration, palliative care, qualitative research

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Background

The world has evolved through significant demographic and epidemiological transitions over the past decades. These transitions, which are exacerbated by the rise of the ageing population, increases in life expectancy, consumption of unhealthy diets and the surge in sedentary lifestyle, have culminated to a significant rise in the

incidence and prevalence of non-communicable diseases (NCDs).[1,2] According to the 2015 Global Burden of Disease report,[3] NCDs account for 71% (41 million) of all deaths across the world. Among the numerous NCDs that affect the human population, cardiovascular diseases, cancers, respiratory diseases and diabetes compositely account for over 80% NCD-related premature deaths.[3] Despite the universality of the problem of NCDs, sub-Saharan Africa has the highest burden as the region is reported to have experienced a 67% increase in disability-adjusted life-years due to the rise in NCDs.[4] Individuals suffering from one or more NCDs, particularly cancer, are likely to experience pains, psychological disorders and unfulfilled existential needs (i.e. the necessity of experiencing life as meaningful).[5] This is where palliative care (PC) becomes imperative to the management of NCDs, including cancers.

PC is

> An approach that improves the quality of life (QoL) of patients and their families' facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.[6]

Available evidence indicates that effective implementation of PC significantly improves the overall QoL of patients and their family.[7,8] Notwithstanding the effect of PC on the QoL, 86% of the global population in need of PC services do not have access to it,[9] thus signifying a high unmet need for PC across the globe. Within resource constrained settings such as Africa, only 5–11% of people in need of PC services receive it.[10] To address the high unmet need for PC services, there have been calls to integrate PC at various levels of healthcare service delivery.[10,11] Integration of PC services entails combining 'administrative, organisational, clinical, and service' elements to ensure continuity of care between all parties participating in the care network of patients.[11]

There is limited evidence that discusses the need for integrating PC services, opportunities for integrating PC, when to integrate and the barriers that challenge successful integration.[11–14] However, beyond these issues, there is a need to understand the benefits of integrating PC to be able to inform policy making and advance advocacy especially in resource-constrained settings like Ghana where PC is sub-optimally implemented. Yet, existing research in Ghana is sparse on what benefits are likely to be experienced as a result of integrating PC. The study aims to narrow this literature gap by exploring service providers' perspectives on the benefits of integrating PC in Ghana.

Methods

Design

In this study, an exploratory descriptive qualitative research design was employed. The authors were interested in exploring perspectives, utilising text to describe the data and give interpretation to the results, rather than attempting to generalise the results from the study, hence, the choice of the study design.[15]

Setting

This study was conducted at the PC unit of the Korle Bu Teaching Hospital (KBTH). KBTH is the largest tertiary health facility and a major referral centre for cancer cases in Ghana.[16] It is also the first health facility in the country to provide specialist PC services. KBTH receives referrals from its immediate communities and also extends to peripheral regions. In addition to providing home care for patients with terminal illnesses, the PC unit at KBTH offers in-patient and out-patient consultations to patients in all hospital departments.[17] These in-patient consultations are scheduled for Monday, Wednesday and Thursday. The PC unit conducts home visitations every Tuesday. It is noteworthy the services provided at the PC unit are not limited to only cancer patients; individuals with HIV, sickle cell disease, chronic kidney disorders, cardiovascular diseases and other life-limiting conditions benefit from the services of the PC unit.

Sample

Purposive sampling technique was used. This sampling approach was used to ensure diversity in the participants' professional backgrounds, years of seniority, experience with providing PC services and depth of knowledge of the subject under study.[18] The PC unit at KBTH has a dedicated team that consists of nine professionals. The team is made up of a geriatric nurse, community health

nurse (CHN), PC nurse specialist, pharmacist, family PC resident, general nurse, clinical psychologist and a social worker.[17] Over the course of 6 weeks, each member of the PC team received thorough training from the Institute of Hospice and PC in Africa in Kampala, Uganda. The training for this certificate programme is divided into a number of components. Participants in this programme receive training on pain and symptom management, performing spiritual assessments and how to handle the emotional distress of patients or caregivers. The cost of the training programme is entirely funded by the service provider. As a result, members of the PC team received the training at different times. Moreover, this training was a part of their work at KBTH. Seven of the nine PC service providers consented to participate in the study. The PC service providers were recruited based on two inclusion criteria: (a) they must be members of the PC team at KBTH and (b) they must have been working in the field for at least 2 years.[19]

Data collection

The interviews were conducted between 1 October to 31 December 2021 as part of a larger study that sought to explore service providers' perspectives about the integration of PC services. The interviews were conducted in-person at the PC unit located at the KBTH. To assist with the data collection, a semi-structured interview guide was used. Prior studies that examined the benefits of integrating PC served guided the design of the interview guide.[20,21] These studies informed the main questions and probing questions. Participants were provided with an information sheet that detailed the aims, procedure, potential benefits and discomforts from participating in the study, the duration of the study, as well as their right to anonymity, confidentiality, privacy and autonomy to withdraw from the study. The participants then provided both written and oral consent to participate in the study. The first author conducted all of the seven interviews; each interview was audio recorded and conducted in English. Interviews lasted between 24 and 54 min. We attribute the differences in the time to the level of experience of the participants.

Analysis

First, all of the seven audio data from the interviews were transcribed verbatim. After the transcription, the transcripts were imported into NVivo-12 for data management and analysis. The study followed an inductive thematic analysis process to analyse the data. Specifically, Haase's version of Colaizzi's method for qualitative research analysis was employed.[22,23] The imported transcripts were read three times to familiarise with the data. Coding of the data was done using the 'nodes' function of NVivo-12. The initial coding was done independently by the authors. Overlapping codes were discussed and a consensus was reached on how it should be categorised. Identified patterns across the coded data were categorised to constitute themes and subthemes. Relevant narratives were extracted and presented to reflect the main findings of the study.

Rigour

One of the hallmarks of qualitative research is its rigour and trustworthiness. In this study, rigour and trustworthiness was achieved by ensuring the credibility, confirmability and transferability of the study methodology. To ensure confirmability, two of the participants were followed up 1 week after the interview to confirm whether the results are reflective of what they intended to communicate. Also, there is an audit trail of the transcripts, interview guide, information sheet and informed consent forms for confirmability purposes. By providing a thorough explanation of the study's context and participants' characteristics, transferability was guaranteed. Regarding creditability, the study strictly followed the methodology. Also, only verbatim quotes from the participants were used. The study adheres to the World Medical Association Declaration of Helsinki,24 and follows the Consolidated criteria for reporting qualitative research (COREQ) guidelines.[25]

Results

All of the PC service providers were females. Their ages ranged between 30 and 59 years. In terms of the years of experience, it varied with the minimum years of experience being 2 years and the maximum being 9 years. The summary of the background characteristics is presented in Table 1.

Regarding the main findings of the study, two main themes emerged: patient-related outcomes, and system/institution-related outcomes. For the patient-related outcomes, the following subthemes emerged: restored hope, appreciated care and better preparation for the EoL. The emerging

Table 1. Participants' socio-demographic characteristics.

Participant ID	Age (years)	Speciality	Years of experience
SP1	30–34	Geriatric nurse	2
SP2	30–34	CHN	8
SP3	55–59	PC nurse	9
SP4	50–54	Pharmacist	9
SP5	35–39	Family PC resident	9
SP6	35–39	General nurse	9
SP7	30–34	PC nurse	2.5

SP: service provider; CHN, community health nurse; PC: palliative care.

sub-themes under the system/institution-related outcomes include the following: early initiation of care, enhanced communication between primary healthcare providers and the PC team and strengthened staff capacity to provide PC services.

Patient-related outcomes

Restored hope. It is evident from the thematic analysis that integrating PC restores the lost hopes of patients. According to the participants, patients were often terrified about the prognosis of their condition. As such, many of them had lost hope. However, integrating PC helped service providers to educate patients about their condition and help them to keep a positive outlook. One of the service providers made this narration as a testimony of how integrating PC was beneficial to patients:

> There were others too that had been told that they had only two months to live. Their hopes were shattered. All they thought about was an impending death. However, because of the integrated care that we provide here where we try to meet the spiritual and psychosocial needs of the patients, they regained their hope and zeal to continue living. I had one patient who will tell me that, 'Madam . . . the kind of care you provide has given me hope because I was going to die within a month'. That is the testimony. (SP3_IDI)

> Some of the patients have no one to care for them and listen to their concerns. However, here at Korle Bu, we have counselling sessions and home visit sessions integrated into the PC services that we provide. This offers us the opportunity to listen to the patient and then help them to better understand their condition and keep fighting to live. (SP1_IDI)

Appreciated care. The participants' responses revealed that integrating PC resulted in a situation where patients and their families have a better appreciation of the care provided to them. That is, by integrating various service delivery approaches including home visitation, in-patient and out-patient care led to patients being more appreciative of the care they receive. This is what some service providers had to say:

> When we integrate palliative care, the patients become more appreciative of the care. For me, I will try to quote my patients words. They say that if they had started with the team, then their illness would have been healed. That is what one patient's husband told me. For the patient and their families, integrating palliative care makes the care cost effective because they would not waste money in herbal centres and on curative treatment. Rather, they would come directly for palliation. (SP6_IDI)

> Most of them end up appreciating the care we provide to them because we use different approaches in our integrated care to meet their needs. They can even lay their hands on you and bless you because of how important PC has been in their disease trajectory. (SP2_IDI)

Better preparation for the EoL. Preparation for the EoL is one of the critical decisions and phases for many cancer patients. The participants

indicated that integrating PC enables patients to make peace with themselves and with their loved ones. According to the participants, the various physical, psychological and spiritual assessments performed by the PC team as part of the service provision helped the patient to make shared decision with their family concerning advance planning, bereavement and death. Some participants narrated the following:

> Sometimes, the patient comes and they are very weak, and do not know their diagnosis or prognosis. So, when they come and we tell them about that. Even though it is painful, they learn to appreciate the fact and put things in order. So, there are times that patients will come and then after briefing them, they go back to call their lawyers and then make plans for bereavement. (SP4_IDI)

> There is one woman who said that I know I am going to die, but I thank you for giving me this opportunity for me to have insight into my condition. Now, I can prepare my family. She said she felt brave to prepare her family. Some of them are able to prepare their funerals, write their memoirs, do their will and pay their funeral at the funeral home. Some had children outside; they gave them open ticket to come when they die and then go back within two weeks, maximum. (SP3_IDI)

System/institutional outcomes

Early initiation of care. In the perspective of the service providers, integrating PC has the potential to promote the early initiation of care. The participants asserted that referral of patients for palliation often delayed at the point of the primary healthcare provider. This was either because primary healthcare providers interpreted PC as EoL, or that they were fixated at providing curative care. Such systems create delays in referral and results in lapses in the early initiation of PC. Therefore, by integrating PC services, primary healthcare providers would have better understanding of the aims and the need to refer on time. Hence, resulting in early initiation of care.

> Having an integrated palliative care system is important for the entire continuum of care because it will prevent delays in referral and help us to start with care provision right from the point of diagnosis. (SP2_IDI)

> Ideally, the departments and general health care providers should refer cancer patients to the palliative care unit early but they don't do that . . . But if the integration of palliative care is done effectively; it will reduce delays in the referral of patients. We will be able to initiate care very early; preferably right from the diagnosis of the patient (SP5_IDI)

Enhanced communication between primary healthcare providers and the PC team. PC is an interdisciplinary care that thrives on effective communication. The participants reported that by integrating PC care, primary healthcare providers and the PC team would have a harmonious relationship that would foster an enhanced communication between both parties. The following quotes reflect the perspective of the participants:

> The primary healthcare providers are the ones who do the diagnosis before referring the client to us. But there are times that we would have wished for them to refer, but in their judgment, it is not yet time for palliative care to come in. However, if we have an effective integrated system, members of the palliative care team would be attached to each department where we receive cases. So, we would be able to easily come to a consensus about the patient. (SP7_IDI)

> It will ensure that we have an effective communication with the primary healthcare providers of the patients. We can easily share information about the patient and make critical decisions concerning the patient's health needs. (SP2_IDI)

Strengthened staff capacity to provide PC services. From the thematic analysis, it is indicative that integrating PC has the potential to strengthen the staff capacity to provide PC services. In the perspective of the participants, integrating PC is not limited to only the services provided, but also extends to its inclusion in the preservice training curriculum of all healthcare providers. According to the participants, when PC is integrated in the curriculum of healthcare education, it would create a large pool of generalist PC providers who will provide primary PC services to patients before they are later referred for specialist PC services. Such actions have the potential to increase the staff strength and augment their capacity to provide PC services.

> I think for the past five or six years, the medical students in the final year are introduced to palliative care during the family medicine sessions . . . If this continues, we would have a lot of generalist palliative

> care providers. That will be a game changer because we will eliminate delays in referral and improve on early initiation of care. (SP4_IDI)
>
> Currently, PC is partly integrated into the educational curriculum for medical students and those reading pharmacy. In the long run, it is going to pay off because our staff strength will increase significantly. Also, these increases in staff strength will be accompanied by skills and expertise to deliver PC services to those who may need it. (SP7_IDI)

Discussion

This study sought to explore service providers' perspectives on the benefits of integrating PC in Ghana. The findings revealed two major benefits of integrating PC, namely, patient-related outcomes and system/institution-related outcomes. It is indicative from the study that the integrating PC has the potential to restore the shattered hopes of the patient. This is consistent with previous studies that have shown that the benefits of integrating PC services included an improvement in the life of patients in relation to their goals, expectations and concerns.[26,27] Possibly, this could be attributed to the point that healthcare providers try to present death as a natural life event that should be accepted.[28] Patients gain a sense of worth, accomplishment and fulfilment that leads to an improvement in their lives, and in relation to their goals, expectations, standards and concerns. Another plausible explanation for this could be that effective PC integration follows a system of conducting an impeccable assessment and counselling of patients and their relatives.[29] Therefore, patients are more likely to receive accurate information about their illness and its prognosis, enabling them to accept their status and avoid having unwarranted or unreasonable expectations about PC services.

Consistent with previous literature,[30–32] this study revealed that integrating PC has the potential to result in patients and their families being appreciative of the care that they receive. The findings align with Anyane *et al.*[30] whose study revealed that in a teaching hospital in Ghana, the integration of PC led to a state of appreciated care on the part of patients. A possible explanation for this could be that, integrating PC would involve the use of person-centred approaches that embodies characteristics such as kindness, friendliness and gentleness.[32] These characteristics when exhibited as a result of integrating PC would probably lead to patients being more receptive to care and appreciating the care that they receive. While being appreciative of the care received is a positive development, the result also suggests a misunderstanding of the role of PC. The accounts of the participants indicate that patients were of the view that PC could cure their cancer. This perception is contrary to the tenets of PC that 'neither to hasten nor to postpone death'.[33]

From the participants' perspective, integration of PC helped them to accept their condition and make preparations for the EoL. The result aligns with previous studies that have reported that integration of PC enhances preparations towards the EoL.[20,34] For example, the result is consistent with the findings of Ndiok and Ncama[20] whose study revealed that integrating PC promoted meaningful EoL (i.e. preparing for the EoL). One likely factor that could explain this finding could be that, through PC integration, patients receive psychosocial and existential care that mentally prepares patients to be at peace with their condition and make advanced decisions concerning death, bereavement as well as decisions to help their families to grieve in a proper manner. This aligns with previous studies that showed that cancer patients often suffer from significant spiritual and existential anguish, which can be defined as a condition characterised by morbid suffering associated to hopelessness, futility, meaninglessness, disappointment, regret, death fear and a disturbance of personal identity.[35,36] However, through PC integration, the patient is psychologically prepared to persevere through the anguish and have a better EoL care.

Beyond the patient-related outcomes, this study revealed that there are some system/institution-related outcomes to be experienced as a result of integrating PC services. Among the emerging system/institution-related outcomes was the benefit of early initiation of care. The findings are consistent with the results of a related study by Davis *et al.*[37] that showed that integrating PC reduced delays associated with referrals and improved early initiation of care. Similarly, Ferrell *et al.*[38] have also reported that the integration of PC reduces referral delays while promoting the early initiation of care right from diagnosis. Probably, this result may be explained from the perspective that an integration of PC counteracts the commonly held belief that PC is equivalent to EoL

care,[39] hence, motivating primary healthcare providers to refer patients for palliation at the point of diagnosis.

A related study has shown that within the context of providing PC services, there is often a lack of communication and consensus building between primary healthcare providers and the PC team; that made it difficult to comprehend and agree on the needs of the patients and the goal of care.[40] However, the findings of this study suggest that integrating PC has the potential to resolve this challenge by enhancing communication between primary healthcare providers and the PC team. The result corroborates the findings of earlier studies that have found interdisciplinary communication between primary healthcare providers and the PC team to have improved as a result of integrating care.[20,21]

The study also revealed that integrating PC had the potential to strengthen the staff capacity to provide PC services. Ndiok and Ncama[20] have also reported that PC integration provides an opportunity to have well-trained nurses in PC. In the context of this study, the findings could be explained by the point that, there is currently some level of inclusion of PC in the preservice curriculum of medical students. Moreover, students of medicine and pharmacy run rotations in PC as part of the preservice training. This is essential to facilitate early initiation of care, reduce delays in referral and improve the overall quality of service delivery.

Strength and limitations

The strength of the study lies in its methodology. That is, the research design used provides a rich in-depth exploration of service providers' perspectives about the benefits of integrating PC. Also, the use of Hasse's adaptation of Colaizzi's approach to qualitative research analysis was appropriate for the type of research design employed in this study. A sample size of seven may be considered to be small even in qualitative studies; notwithstanding, those who participated in the study were key informants who had received special training in PC, have worked in providing PC services for years, and have gained the expertise and knowledge in PC. Hence, they were the right people to provide insights into the perceived benefits of integrating PC. Nonetheless, there were some limitations to the study. Only members of the PC team were included in the study. Hence, the findings may not be reflective of the perspectives of patients and primary healthcare providers as they were not included. Also, because the study relied on only in-depth interviews, the findings may not necessarily be reflective of the group perspective, but rather reflect more of the individual perspectives.

Conclusion

Integrating PC services has potential benefits for patients and the healthcare system of Ghana. For the patients, it would restore shattered hopes, result in an appreciated care and better preparation for the EoL. For the healthcare system, it would promote early initiation of care, enhance communication between primary healthcare providers and the PC team and strengthen the capacity of service providers to execute the task of providing PC services. In conclusion, there are substantial benefits to be experienced from integrating PC. This study, thus, further provides the case for a more integrated PC service in Ghana.

Declarations

Ethics approval and consent to participate

This study adheres to the World Medical Association Declaration of Helsinki, COREQ guidelines and the ICMJE recommendations. The Institutional Review Board of the University of Cape Coast (ID number: UCCIRB/CHLS/2021/18) and the KBTH Scientific and Technical Committee of the Korle Bu Teaching Hospital (ID number: KBTH-STC 000108/2021) granted ethical approval for this study. All of the participants provided written and oral consent to participate in the study.

Consent for publication

Not applicable.

Author contributions

Joshua Okyere: Conceptualisation; Data curation; Formal analysis; Investigation; Methodology; Software; Writing – original draft; Writing – review & editing.

Kwaku Kissah-Korsah: Formal analysis; Methodology; Supervision; Writing – review & editing.

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Availability of data and materials
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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