Factors Influencing Palliative Care Utilization Among Patients With Cancer: A Cross-Sectional Study

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Abstract

Background: Cancer remains a public health challenge in low-and-middle income countries (LMICs). Over 30% of those in need of palliative care (PC) worldwide suffer from cancer and 80% of patients with cancer in LMICs are diagnosed at advanced stages, by which time they can only benefit from PC services. The aim of this study was to determine factors influencing PC utilization among patients with cancer in KZN.

Methods: A cross-sectional descriptive study was used among patients who had been diagnosed with different cancers and attending Inkosi Albert Luthuli Central Hospital (IALCH), Addington Hospital, Pietermaritzburg Grey's hospital, Msunduzi and Chatsworth Hospices. A systematic random sampling technique was used to select participants. Structured questionnaires were administered to a total of 394 patients. The questionnaire included two open-ended questions and the generated data was analysed and presented into two formats; firstly, the textual data was entered into REDcap (v.8.11.7) and then exported to IBM SPSS Statistics (v.25) and recoded for emerging themes which were later presented in a graph format. Secondly, the thematic analysis was presented in textual format and supported with verbatims quotes.

Results: The mean (+SD) age of the 394 participants was 51.89 (+14.67) years and about 22.9% were within the age-group 41–50 years. Majority of participants were females (77.7%) and were unmarried (60.6%). Most of the participants' racial classification was black (81.5%) and 64.5% had primary education. More than four-fifths (82.7%) were unemployed, 55.8% lived in urban areas and 24.6% had cervical cancer. The analysis of the two open-ended questions incorporated into the questionnaire revealed five themes as major barriers preventing cancer patients from seeking PC services.

Conclusion: Lack of knowledge and awareness about cancer symptoms and PC services could be addressed by better education of the public. Hence, utilization of PC could be maximized, thereby providing a better quality of life for the sufferers and their families until the end of life's journey. The study also provides information that can be used to strengthen and/or to develop PC guidelines addressing PC issues. **Keywords:** Cancer, Palliative care, barriers, utilization, KwaZulu-Natal

Background

Recent statistics revealed that cancers cumulatively rank as the leading cause of death worldwide, with the mortality rates outpacing that of HIV and AIDS, TB and malaria combined (1). The LMICs currently account for slightly more than half of all new cancer cases each year and these countries are projected to carry as high as over 80 percent of the global cancer burden by 2030 (2). However, only five percent of all global resources being spent on cancer are allocated for use in LMICs, therefore contributing to severe inequities in cancer management worldwide (1, 3). If the issue of resource allocation remains unaddressed, the rising rates of cancer will continue to impose a considerable burden on the health and socio-economic stability of sub-Saharan Africa (SSA) (4).

The increase in prevalence of cancer cases may be attributed to different factors including aging and an increase in the world population (5). An increase in the adoption of cancer-causing behaviours like smoking especially in the developing countries has amplified the prevalence of the disease (6). The result has been a double disease burden in developing countries as communicable diseases are still a serious health problem that these countries are grappling with (7). In Nigeria, 60–70% of patients with cancer present for treatment late. This is mainly due to the belief that many patients have concerns regarding the origin of their conditions (8). A lot of patients attribute their cancer to spiritual forces (9). Also, because many cancer patients die even after receiving conventional western medical treatment (10), other cancer patients tend to be discouraged from using western medicine, and therefore resort to complementary and alternative medicine (CAM) treatments, prayers or faith to obtain healing (11). Furthermore, poverty, lack of information and almost non-existent specialized care have also resulted in over 95% of cancer cases being diagnosed at the late or advanced stages of the disease (12, 13). The increase in incidence of cancer has been exacerbated by increased incidence of HIV, most notably Kaposi's sarcoma (14, 15).

SSA health systems are mainly orientated towards care for acute illness and maternal and child health (16). For most of the cancer patients in Africa, the unavailability of (i) anticancer drugs, (ii) oncology specialists, (iii) radiotherapy centres and (iv) PC services means limited chances of survival and increased mortality rates (17). Although infectious diseases are still the leading cause of death in SSA, the emergence of non-communicable diseases (NCDs), notably cancer, presents a significant challenge for healthcare systems (18).

This contrast requires complex interventions that can be sustained throughout the continuum of care (19). PC offers a realistic public health approach to cancer care where most people with cancer present at healthcare facilities at the incurable disease stage, and where disease modifying treatment is not accessible to most of them (19,20). Paice et al., (20) highlighted that appropriate pain treatment and access to analgesics are both essential in PC and should be prioritized as a public health matter, from a national and global perspective (21). If this is not done, an escalating proportion of the world's population will continue to live with pain unnecessarily and will furthermore die in pain (22,23). Therefore, the aim of this study was to determine factors influencing PC utilization among patients with cancer in KwaZulu-Natal (KZN), South Africa.

Materials And Methods

Study design and population

This was a cross-sectional study with a total of 394 cancer patients recruited during the period of November 2018 to March 2019 from the targeted healthcare facilities in KZN; namely: IALCH, Addington Hospital, Grey's Hospital, Msunduzi Hospice and Chatsworth Hospice. The criteria for patients to be considered for inclusion in this study were that they: (i) had to be aged 18 years and above; (ii) had to have a confirmed cancer diagnosis; and (iii) willing to participate in the study. The study sites were

selected through purposive sampling (based on the oncology units offering PC services in the province). Study participants were recruited using the systematic random sampling technique until the calculated sample size was achieved.

Sample size

To assess the outcome of interest, assuming 95% confidence and an acceptable margin of error of 5%, and maximum variability, i.e. 50% (given unknown prevalence), a sample size of 384 participants was required. The sample was further increased to 394 to account for contingencies such as that of non-response or recording error. Increasing the sample size reduced the type I and type II errors and known and unknown confounders' effects. The power ($1-\beta$) (the % chance of detecting difference) of the study was set at 80%.

Recruitment and data collection

Prior to the commencement of the study, nurses working in the oncology unit identified cancer patients in accordance with the eligibility criteria. All eligible participants who met the study criteria were enrolled into the study using a systematic random sampling technique. The systematic random sampling technique implies that the interval may be in terms of time, space or order. For instance, an element appearing after every 30 minutes, or present at a distance of two metres, or every 5th element present on a list, would be recruited (24).

Structured questionnaires were used to collect data. Within the questionnaire, we included open ended questions on factors influencing PC utilization among patients with cancer, as follows:

- What are the main barriers that prevent the community members from seeking PC?
- What do you think can be done by healthcare providers to make PC services in the healthcare facilities appealing?

The purpose of the study was explained, the study information sheet was shared, and the informed consent form was signed by the potential participants prior to administering questionnaires. The questionnaires were administered to each individual participant by the research team, using a private room, in order to ensure that their identity and confidential information were protected. The questionnaires took about 10–15 minutes to complete. None of the participants reported feeling discomfort or distress during the questionnaire administration.

Data analysis

The two open-ended questions from the questionnaire generated data that was analysed and presented into two formats; firstly, the textual data was entered into REDcap (v.8.11.7) (25), exported to IBM SPSS Statistics (v.25) (26) and then recoded for emerging themes which were later presented in a graph format.

Secondly, the thematic analysis was presented in textual format and supported with verbatims quotes. Data was further checked for possible errors and missing values and any errors were corrected before analysis. For descriptive analysis, socio-demographic data was summarized into a table that included age, gender, marital status, ethnic group, level of education, employment status, geographical area and cancer diagnosis.

Results

Quantitative findings

Participants’ socio-demographic characteristics

The mean ($\pm$ SD) age of the 394 participants was 51.89 ($\pm$ 14.67) years and about 22.9% were within the age group 41 – 50 years. The majority of participants were females (77.7%) and were unmarried (60.6%). Most of the participants’ racial classification was black (81.5%) and 64.5% had primary education as their highest level of education. More than four-fifths, 82.7% were unemployed, 55.8% lived in urban areas and 24.6% had cervical cancer, the most common type of cancer among the participants (Table: 1).

Major barriers to palliative care utilization

Over a third (40%) of the participants reported lack of cancer knowledge and the pursuit of alternative treatment options, only a few reported stigma and discrimination (19%) and 4% reported long waiting periods for results of the accurate diagnosis or to be attended to by the doctor and for the date of the next appointment. In addition, participants reported lack of screening and diagnostic equipment (1%) and 25% cited socio-economic barriers, which include transport issues and employment status as factors contributing to the underutilization of PC services in KZN (Fig: 1).

Furthermore, when participants were asked about what could be done to improve the uptake of PC services, the majority cited that the Department of Health (DoH) should allocate enough resources for cancer awareness campaigns in the communities (45%). A total of 27% recommended that the DoH should improve healthcare services and only a few suggested quality in-service training and continuous professional development (CPD) for healthcare providers (8%). The analysis reveals that the majority of participants believed that when the above mentioned is prioritized, the number of premature deaths would decrease and that CPD on PC would enhance healthcare providers’ knowledge and practice (Fig: 2).

Table 1: Socio-demographic characteristics of participants (N=394)

Characteristics	Frequency	Percent
<i>Age (years)</i>		
<30	26	6.7
30–40	72	18.7
41–50	88	22.9
51–60	79	20.5
61–70	68	17.7
>70	51	13.2
<i>Mean age ($\pm$SD): 51.89 ($\pm$14.67)</i>		
<i>Gender</i>		
Male	84	21.3
Female	306	77.7
<i>Marital status</i>		
Unmarried	233	60.6
Living with partner	160	41.6
<i>Ethnic group</i>		
Black	313	81.5
White	19	4.9
Coloured	3	0.8
Indian	57	14.8
<i>Level of education</i>		
Never been to school	88	22.3
Primary	254	64.5
Tertiary level	26	6.6
<i>Employment status</i>		
Employed	67	17.0
Unemployed	326	82.7
<i>Geographical area</i>		
Rural	173	43.9

Urban	220	55.8
<i>Cancer diagnosis</i>		
Cervical cancer	97	24.6
Breast cancer	89	22.6
Other cancers	76	19.3
Kaposi's sarcoma cancer	57	14.5
Prostate cancer	21	5.3
Colon cancer	18	4.6
Anal cancer	13	3.3
Vulva cancer	13	3.3
Lung cancer	10	2.5

Figure 1: Barriers to palliative care utilization (N=394)

Figure 2: Patients' perspectives on how DoH can improve utilization of cancer palliative care (N=394)

Qualitative Findings

The five major themes on factors that affect cancer patient in utilizing PC services were identified and are discussed below: (1) lack of cancer knowledge and pursuit of treatment options, (2) stigma and discrimination, (3) long waiting periods for referral, diagnosis, treatment and care, (4) lack of screening and diagnostic equipment and (5) socio-economic barriers. Furthermore, participants stated what could be done by the government's health department to make PC services more appealing to patients. Under this theme, there were three major subthemes: (1) cancer awareness campaigns, (2) improved healthcare services and (3) CPD.

Factors Influencing Palliative Care Utilization Amongst Patients

Cancer knowledge and pursuit of treatment options

Knowledge and awareness about cancer symptoms, treatment options available and palliative care services were poor among patients with cancer. The available information focused on communicable diseases. With that being said, cancer patients were unable to seek PC because of limited general knowledge about cancer symptoms. The excerpts below attest to this assertion (Participants: 21 & 26).

"In 2012, I started noticing that I had a small pimple on my left foot that would not go away, I always thought something must have bitten me while I was in the bush. It kept growing as small pimples with a smelly pus over the years and I never thought it was a medical condition as I had decided to consult with a traditional healer to see if I could get umuthi (traditional remedy) to make it go away because I had also started thinking that I had been bewitched...because that is the only cure for unusual symptoms of sickness, especially us people from the rural areas who are far away from everything" (Participant: 21).

Most of the participants also spoke about not knowing that cancer can be manageable and if found at an early stage, some may be curable.

"Growing up in the village, we were not aware that cancer is manageable as we were only told that there is no cure for it and that when you have cancer it's a death sentence for you" (Participant: 26).

Stigma and Discrimination

The findings revealed a prevailing expectation that people with cancer would experience stigma and discrimination. Therefore, they delayed in reporting symptoms because of expectations, based on previous experience, that they would be stigmatized as having multiple partners and blamed for their illness (Participant: 53).

"I remember when I first got the news that I had vulva cancer, people thought it must have been because I have been sleeping around with their men. Some of the family members would not come visit me like they normally did, I don't know whether it's because of the smell or they just don't want to associate themselves with someone who has cancer of the vagina as the rumor says, I have been sleeping around" (Participant: 53).

Long waiting periods for referral, diagnosis, treatment and care

While early access to PC is seen as helpful to support advanced care planning, to support patients and their families and to promote better symptom management, long waiting periods remain an important barrier to cancer PC. Participants highlighted how long waiting hours to be attended to in a health facility, long waiting periods for the next appointment and long waiting periods for an accurate diagnosis had affected their confidence in the SA healthcare system (Participant: 62).

“The whole of SA is disgusting, can you imagine having to beg the nurse to make a referral for you because the pain is getting worse each day and you cannot take it anymore, after being referred to a government hospital, when you get there you have to wait for hours to be attended to by a doctor?... I think they do not even start on time to do their consultations because we get there as early as possible, around 7:00 am. When you finally get a chance to be seen by a doctor, you sometimes do not get the accurate results for your presenting problem and have to go back home and wait again for other three to six months for the next appointment, which doesn't make sense because the disease does not stop growing and spreading, especially this one to be precise”(Participant: 62).

Lack of screening and diagnostic equipment

It has been said that early detection both by screening and early clinical diagnosis is an important intervention to control cancer in LMICs. The main objective of cancer screening and early clinical diagnosis (through improved awareness and health services infrastructure and accessibility) is to detect cancer cases early enough to provide the least toxic and least expensive curative treatment. Most of the participants stated how they were affected by the lack of resources, such as screening machines and diagnostic equipment in KZN healthcare facilities (Participant: 82).

“One of the reasons why I'm now this sick it is because I have been transferred from one hospital to another because some of these hospitals do not have enough cancer screening machines. I get checked and given Paracetamol for pain which barely makes a difference...what I'm trying to say is that if they had discovered at an early stage that I had cancer I would not be in so much pain and I would not be running around for cancer management...There was also a time where I needed pain medication, but I was told that they were out of medication and I had to buy from my own pocket, which is also another issue” (Participant: 82).

Socio-economic barriers

Socio-economic barriers were also reported to play a major role in the healthcare practices and experiences of KZN cancer patients. Limited monetary resources, fear of unemployment and lack of insurance coverage were viewed as contributing to delays in medical care seeking (Participant: 77).

“To be absent from work because you have to go for cancer treatment is something else...because when you finally get back to work, you find that your employer has replaced you with someone else...meaning you will now have to start job hunting again which takes a lot of effort and exposes you to another[kind of] stress you do not need, especially when you are sick with cancer” (Participant:77).

Patients’ perspectives on what could be done to make cancer palliative care services appealing

Participants from the three hospitals and two hospices we visited highlighted that enhanced cancer awareness campaigns for the general population, improved healthcare services and CPD for healthcare providers would assist in strengthening knowledge and awareness about cancer symptoms and PC services available (Participants: 27, 40, 44, 49, 50 & 53).

Awareness campaigns

Most of the participants suggested that health literacy about NCDs especially cancer, should be done within the hospitals while the patients are waiting to be attended to. There should also be information counters with flyers written in both IsiZulu and English. This would keep the patients updated and they would know about their disease (Participants: 27 & 40).

“We need monthly awareness campaigns done by the CCGs, and they should deliver accurate information, by doing so everybody gets to understand their diagnosis and no one would feel ashamed about being diagnosed with NCDs if we talk about these openly...DoH should utilize CCGs because they are able to take the services to the communities” (Participant: 27).

“CCGs should also be able to do community outreach for patients who are too ill and [thus] unable to travel” (Participant: 40).

Improved healthcare services

Many participants pointed out that KZN hospitals lack properly trained palliative healthcare providers and patients are nursed in large open wards with little privacy. In addition, participants stated that access to screening and essential treatment services was poor. A combination of different approaches involving education, awareness, advocacy, legislation, vaccination, screening, early diagnosis and treatment should be used to prevent suffering and death due to cancer.

“The situation in the state hospitals is really terrible, we have to travel from one hospital to another because some don’t have cancer screening machines, some don’t have oncology specialists/ palliative care specialists, and some don’t even have enough medication in stock...what do you call that? DoH really need to do something about this depressing situation in this region because so many people are

dependent on public hospitals for their disease management and if this is also not improved how are we supposed to trust them?” (Participant: 44).

Continuous professional development

Most participants agreed that education and training for healthcare providers must address issues concerning how to communicate effectively with patients and their family members, how to involve patients in decision making early in the course of their illness and how to ensure that the advanced care planning goals are met. An in-house education program for healthcare providers about available PC services and how healthcare providers can work with consultative teams to provide such services to patients with life-limiting illnesses may help to achieve such ends (Participants: 49, 50 & 53).

“Healthcare providers are always in a rush, they don’t have time to offer emotional support, and they don’t acknowledge patients’ concerns – if we can’t address our concerns to them, who should we direct them to?” (Participant: 49).

“Healthcare providers need to be taught the spirit of ubuntu (humanity), they have no respect for a sick person...they do not listen to our concerns, their only focus is managing cancer pain and not acknowledging other concerns. When you leave the consultation room, you feel discouraged, not knowing where to turn to – but doctors and nurses are supposed to make you feel better under these circumstances” (Participant: 50).

“When a nurse is unable to tell whether you need more check-ups or not, it becomes a problem because you get discouraged to even go further as nurses sometimes would say: it’s just a rash it will soon go away, and you really did not have to come all the way for this” (Participant: 53).

Discussion

The results of this study are in line with the emerging and existing international and SSA literature on factors influencing PC utilization among patients with cancer. We found that there were several barriers to progressive utilization of PC, and these included age, stigma and discrimination. In addition, there were socio-economic barriers which included employment status and level of education. Furthermore, participants emphasized what could be done by the DoH to make PC services appealing in KZN: among other things, cancer awareness campaigns were most often cited.

As indicated by the WHO (28), the number of people currently in need of PC is high with 94% of them being adults. Our findings indicate that as one advances in age, the possibility for the need to utilize PC is

significantly increased. This concurs with the study findings by Ciemins et al., that focused on healthcare utilization in California Pacific Medical Center's PC (26,29).

Their study showed that among the elderly, utilization increased with age and this was due to the increased prevalence of chronic illnesses like cancer (29). Among other barriers to the utilization of PC, participants reported how fear of being stigmatized and discriminated against often prevents many patients from seeking needed PC services for any cancer diagnosis. Participants further mentioned that many people with cancer have been evicted from their homes by their families and rejected by their friends and colleagues. Our findings are consistent with the results of earlier studies, which found that a particular group sampled in Botswana, 40% of cancer patients had experienced stigma (30). Further to the scientific evidence, it was reported that doctors from SSA are usually reluctant to pass bad news to patients on any health matter, especially regarding cancer as this puts patients at risk of being stigmatized and discriminated against (31).

In addition, this current study demonstrated that socio-economic barriers to PC utilization were reported most often by the participants. Our findings were similar to other studies done across the sub-Saharan countries which found that socio-economic inequalities contribute to and shape people's health seeking behaviour adversely (32). This negative effect of people's socio-economic realities on their health behaviour is not different in PC. Screening participation is higher amongst people with advanced socio-economic status. Such socio-economic status includes material resources (e.g. income), social status (e.g. occupation) and level of education (33). For example, recent US data shows a strong association between self-reported mammography participation and both education and income (34). Similar associations with income and education were found in Great Britain (34).

Furthermore, lack of cancer knowledge and pursuit of treatment options was most pronounced among those living in the least affluent areas and those who had primary education as their highest level of education. The positive relationship established implies that as one moves from a low level of education to a higher level of education, there is a significant increase in utilization of PC progressively. These results concur with the study findings of Hirai et al., who found that, despite the inequities present, the number of years of education did improve the prevalence rates of seeking healthcare, even among the poor (35). This is also because as people become more educated they are able to identify their healthcare needs and seek them (36). Education levels have been shown to often influence the occupation of an individual and this will directly translate to income earned and ability to afford the healthcare services (37).

Of significance is the discussion around what could be done to make the PC services appealing. The findings from this study indicate that the majority of participants would like to have more cancer awareness campaigns to keep them updated about what to look for in terms of cancer symptoms and PC services. Scientific evidence documented that while many members of the public had heard of the concept of PC, there was a clear lack of familiarity and awareness of what PC really means (38).

Our findings were in line with what was documented by other studies which found a range of approaches, such as publicity campaigns, posters, talks, open days and clear signposting from healthcare professionals, which were suggested to enhance cancer PC awareness (39).

Strengths

A particularly strong aspect of this study was the inclusion and exclusion criteria, as this helped to ensure that the population would possess similar characteristics to future intervention participants. Furthermore, it is valuable that the participants were of different gender, varying levels of affluence and from urban and rural areas, as this ensured a range of opinions were considered. Whilst PC may be gaining traction in medical practice, it needs to be properly introduced to patients, so that they can understand it and appreciate its potential contribution to optimal patient care.

Limitations

Whilst this study represents one of the largest recent studies assessing factors influencing PC utilization among patients with cancer, it has several limitations; the use of open-ended questions within the questionnaire allowed participants to express themselves in their own words, so that different participants provided different degrees of detail, questioning the comprehensiveness of the results. Secondly, while the questionnaire was based on a review of the literature and subject to content validity by experts, it was not tested formally for reliability. Finally, whilst factors influencing PC were explored, religion and culture were not explored.

Conclusions

The results from this study imply that knowledge levels about cancer symptoms, PC and related services were generally poor among cancer patients who participated in this study. However, lack of awareness was most pronounced among those living in the least affluent areas and those who had primary education as the highest level of education. Low levels of understanding highlight the need for a parallel approach ensuring that PC is more integrated into healthcare systems, alongside a continued public health approach to PC to eliminate social taboos and ensure such services are sought out when required. Furthermore, the study provides information that can be used to strengthen and/or develop PC guidelines addressing PC issues.

Declarations

Abbreviations

PC: Palliative care, LMICs: Low-middle-income countries, KZN: KwaZulu-Natal, SSA: sub-Saharan Africa, CPD: Continuous Professional Development, IALCH: Inkosi Albert Luthuli Central Hospital, DoH:

Department of Health, NCDs: Non-Communicable Diseases.

Ethical approval and consent to participate

The study was approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee (**REF: BE374/18**) and DOH National Research Ethics Committee (**KZ_201810_039**). The ethics committee approved the written informed consent forms which were obtained from all the participants prior to participating in the study.

Availability of data and materials

Data from this study is the property of the Province of KwaZulu-Natal, Department of Health and University of KwaZulu-Natal and cannot be made publicly available. All interested readers can access the dataset from DoH National Research Ethics Committee from the following contacts: Directorate, Health Research and Knowledge Management, physical address: 330 Langalibalele street, Pietermaritzburg, P/Bag X9051, Tel: +27 33 395 2805 Fax: 033 394 3782 and UKZN-BREC from the following contacts: The Chairperson, Biomedical Research Ethics Administration Research Office, Westville Campus, Govan Mbeki Building University of KwaZulu-Natal P/Bag X54001, Durban, 4000 KwaZulu-Natal, South Africa Tel: +27 31 260 4769 Fax: +27 31 260 4609 Email: BREC@ukzn.ac.za.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

MSD designed the study, data collection, MSD, SBD & TGG carried out the analyses, and MSD wrote the paper. MSD analyzed data and TGG supervised the write up of the manuscript; TGG supervised the study and analysis. TGG reviewed and modified the original manuscript. All authors read and approved the final version of the manuscript.

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Figures

Figure 1: Barriers to palliative care utilization (N=394)

Figure 1

Barriers to palliative care utilization (N=394)

Figure 2: Patients' perspectives on how DoH can improve utilization of cancer palliative care (N=394)

Figure 2