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Social and health system complexities impacting on decision-making for utilisation of oncology and palliative care in an African context: a qualitative study

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Abstract

Background: There is a dearth of research focusing on identifying the social complexities impacting on oncology and palliative care (PC), and no study has explored how the healthcare system in Nigeria or other African contexts may be influencing utilisation of these services.

Aim: This study explored how social complexities and the organisation of healthcare influenced the decision-making process for the utilisation of oncology and PC in a Nigerian hospital.

Methods: This qualitative study used an interpretive descriptive design. Data was collected using semi-structured interview [guides](#) with 40 participants, comprising healthcare professionals, patients and their families. Thematic analysis was conducted to generate and analyse patterns within the data.

Findings: Three themes were identified: dysfunctional structural organisation of the healthcare delivery system; service-users' economic status; and the influence of social networks. The interrelationship between the themes result in patients and their family members decisions either to present late to the hospital, miss their clinical appointments, or not to seek oncological healthcare and PC.

Conclusion: This paper offers insights into the role of the healthcare system, as organised currently in Nigeria, as 'auto-inhibitory' and not adequately prepared to address the increasing burden of cancer. We therefore argue that there is a need to restructure the Nigerian healthcare system to better meet the needs of patients with cancer and their families as failure to do so will strengthen the existing inequalities, discourage usage and increase mortality.

Key words: [Africa](#); [Cancer](#); [Decision Making](#); [Health System](#); [Nigeria](#); [Oncology](#); [Palliative Care](#); [Qualitative study](#); [Social](#)

Introduction

The African Palliative Care Association (APCA), Hospice Africa, UK and other organisations, have continued to advocate for the availability of palliative care (PC) across Africa ¹⁻². Although successes in PC have been achieved across Africa, there is a sustained lack of access to this specialised service for many individuals. For instance, of the 40 million people in need of PC worldwide, 78% were assumed to live in low- and middle-income countries ³, implying that many people in these regions lack access to the PC which could improve their lives. Many studies have uncovered obstacles to PC in an African context, such as too few health professionals with PC training and education, lack of training opportunities, poor knowledge of, and attitudes towards, PC, professionals and service-users' lack of awareness, inadequate opioids, lay meaning-making of cancer/care and a lack of PC policies in most African countries ⁴⁻⁹. The rising costs of chemotherapy, drug resistance, and insufficient radiotherapy machines are some of the recognised challenges of cancer care in poorly resourced countries ¹⁰⁻¹¹. Again, cancer patients not only experience physical problems but also cancer-related social difficulties which impact on their mental health and quality of life ¹²⁻¹³. Although the need to provide support in addressing the social problems experienced by cancer patients has been increasingly recognised ¹³⁻¹⁴, how social challenges influence decision-making for utilisation of palliative care has not yet been sufficiently understood especially in African context. Thus, the research reported herein sought to address this issue as well as how the healthcare system in Nigeria influence the provision of oncology and PC.

The healthcare system is recognised to be an important contributor to health inequalities in African regions ¹⁸. Undoubtedly, there is diversity in the healthcare systems across Africa, but many similarities exist in terms of finance, governance and organisation ¹⁹. For instance, the financial systems of healthcare services are underfunded in most African countries, as displayed through lack of implementation of 'The Abuja Declaration 2001' signed by Heads

of State of the African Union, including Nigeria, which states that countries should allocate at least 15% of their total annual budget to improve the health sector¹⁷⁻¹⁸. Again, APCA has called for more research regarding palliation to improve the welfare of patients with cancer and other life-limiting illnesses². So, turning the spotlight on the experiences and perceptions of cancer patients, family caregivers and healthcare professionals (HCPs), this research explored how social complexities and the organisation of healthcare influence the utilisation of oncology and PC in a Nigerian hospital. Given the paucity of literature in this area, an in-depth study that focused on a single site was needed as the first step in theory development and the initial step in the development of evidence which may be applied or extrapolated to other similar context and settings in line with the principles of conceptual generation and applicability in qualitative research¹⁹⁻²⁰.

METHOD

Study design

An interpretive descriptive design was utilised in this study. Interpretive description is applied to develop clinical understanding, using an inductive analytical approach that allows for interpretation or explanation of patterns within human experiences and perceptions²¹⁻²².

Study setting

A hospital situated in the south-eastern region of Nigeria provided the study setting for examining oncology and PC. This site was purposively selected as it is the largest tertiary hospital with an established multi-oncology centre providing cancer care to approximately 40 million people from the five south-eastern states of Nigeria, as well as other surrounding states. Some of the services provided to patients and their family members during in-patients' ward round and out-patient consultations in the study site include pain/symptom management, counselling and bereavement support⁴, as similar to other African context²³. Source of referral

to PC unit is from other units, but often late primarily because patients present at advanced stage of their disease at the time of consultation ^{4,9}.

Participants

Participants were provided with an information sheet about the study and an opportunity to ask questions. They were given a minimum of 24 hours and up to one week to make their decision about participation. Of the 50 participants approached for this study, three healthcare professionals and five patients and two of their family members refused, gave reasons which included lack of time and no financial incentives. Those who accepted signed a written consent form. Overall, there were 40 participants, comprising 11 HCPs from the PC unit (three doctors, four nurses, two medical social workers, a physiotherapist and a pharmacist), 9 HCPs from the oncology unit (five doctors and four nurses), 10 patients and 10 family carers from the five states in south eastern Nigeria that sought either oncology care and/or PC. These participants met the following inclusion criteria:

- HCPs who had experience of providing PC and/or were decision makers about care of cancer patients; or
- Patients living with cancer and/or who were receiving oncology care and/or PC, and were considered to possess the capacity to provide informed consent; or
- Family members who were the key carer of the patient who was receiving oncology care and/or PC

Ethical approval

The Hospital Research Ethics Committee at the studied hospital granted ethical approval for this study on March 2016 and this was renewed in March 2017 with reference number: NHREC/01/2008B-FWA00002458-1RB00002323.

Data collection

Information was generated through semi-structured face-to-face interview guides conducted by the lead author (DA). Interview guides were specific for each group of participants, were designed using past literature and pilot tested. Prior to each interview session, the steps to ensure confidentiality and anonymity was re-affirmed. Interviews with the participants were conducted discretely either in their offices, meeting room or bedsides at their convenient time. Each interview commenced with a specific open-ended question for each group of participants, as shown in Table 1, below.

Insert table 1

The open questions were followed by probing questions based on participants' responses, in order to gain an in-depth understanding of emerging ideas and patterns. Interviews were conducted between March and June 2016. Following the analysis of data, further interviews were conducted with the same participants (15 HCPs, 7 patients and 8 family caregivers) between March and May 2017 to achieve data saturation. Each interview lasted between 45 and 90 minutes, was digitally recorded and later transcribed verbatim by DA anonymously.

Data analysis

Thematic analysis was conducted in accordance with the six steps outlined by Braun and Clark²⁴, to identify and analyse patterns within the collected data²⁴⁻²⁵. Firstly, the interview transcripts were read several times whilst listening to the digital recordings, to ensure accuracy and to gain familiarisation with the data. Secondly, all the transcripts were imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11) and coded by DA to generate several initial codes. This was followed by a search for relationships among the many codes to generate categories (initial pattern/theme), which were reviewed by the co-authors to confirm their accuracy and fit. Finally, the categories were reviewed by all authors and were independently organised until consensus was achieved, following critical discussion amongst

the research team, to arrive at patterns that represented single ideas. Member checking and reflexivity were additional approach utilised to ensure the rigour of this research. The three themes identified are shown in Figure 1 below.

Insert Figure 1

Findings

Theme 1: Dysfunctional structural organisation of the healthcare delivery system

The three-tier structure of Nigerian healthcare system was perceived by all the HCPs to be problematic. For instance, the primary healthcare level was said to be ineffective, while the secondary and tertiary levels were perceived to be muddled and politicised:

The primary healthcare system is not functional, secondary health care is disarrayed due to poor management. The simple cases that would have been managed in these centres come here to increase our workload. The tertiary hospitals are politicised...

(Doctor 1)

Primary healthcare centres have collapsed, general and teaching hospitals are not sufficiently funded by those in authority. They also embezzle the limited fund...

4)

Although primary care centres (which should be the first point of access to healthcare) existed, it was perceived to have ‘collapsed’ and were ‘not functional’, due to lack and/or mismanagement of fund by decision-makers. This clarifies why patients sought care at the tertiary healthcare level without first accessing care at primary or secondary levels. Participants also cited a lack of policy to guide the operations of non-orthodox centres (spiritual and traditional healing services, patent medicine dealers, church-based healers and prayer houses) that operate alongside the three-tier government recognised structure of healthcare system:

There are orthodox centres and there are so many non-orthodox centres (spiritual healers, traditional healers, prayer houses and church-based healers) but without a policy to guide and coordinate their activities (Doctor 8)

The absence of policy and guidelines for effective functioning of the Nigerian plural healthcare system made it difficult for cancer patients and their families to know where to seek care:

People kept referring us to different traditional centres and I became confused about the right place to go... (Patient relative 9)

This extract suggests that cancer patients patronised non-orthodox centres due to the lack of a functional structured pathway for oncology and PC in Nigeria. This implies that the lack of coordination of medical pluralism had put these cancer patients at risk of making wrong choices, thereby receiving wrong care for their illnesses. Most of the patients and family carers repeatedly emphasised challenges they experienced in knowing the right place to seek care. For instance:

...it is difficult to know the right place to go when someone is sick. I took the herbal mixture and went for prayer... (Patient 10)

I went for spiritual cleansing before I came to this hospital. Knowing the right place to go wasn't easy... (Patient 3)

Most of the HCPs underscored that many of the cancer patients presented late for oncology and PC, because of the dysfunctional structure of the health system. For instance, Doctor 1 said:

Some of these patients come here when their illness has advanced, due to ill-functioning and numerous structural pathways of our health system

Although, the defective heterogeneous system of healthcare delivery impacted negatively on the utilisation of oncology and PC, patients' economic status also influenced their decision-making.

Theme 2: Service-users' economic status

Most of the patients were reportedly constrained from seeking care by their lack of money. For instance:

My husband and I are unable to raise money to commence chemotherapy (Patient 7)

My husband has no money to pay... (Patient 9)

The above quotations indicate the context overwhelmingly determined by the capacity of patients with cancer to pay for their care. Unfortunately, most service-users were less likely to pay, due to poverty and the huge financial requirements for cancer management:

No single person can afford the cost of cancer treatment especially the poor people (Doctor 7)

High cost of care for this illness has made me poorer... (Patient 5)

It is, therefore, plausible to argue that low economic status and the high cost of cancer treatment and palliation rendered patients and their families vulnerable to poorer access to services and, consequently, to poorer health and wellbeing. For example:

I will discontinue chemotherapy and will not go for radiotherapy because I can no longer afford the cost (Patient 8)

Most of the time, patients refuse treatment for lack of money to pay for it (Nurse 9)

In light of this, patients either presented late to the hospital, missed their clinical appointments, or did not seek oncology and PC:

*It's been a long time since I first notice this illness but had no money to attend hospital
(Patient 9)*

*Many patients come during the advanced stage of their disease and often tell us that
lack of money made them to either miss their hospital appointments or not to attend
(Nurse 10)*

Thus, financial ability to pay for care was a criterion considered by some of the service users in their decision to seek PC, and this illustrates how the payment mechanism in the Nigerian healthcare system resulted in patients having limited access to oncology and PC. Expressively, most service-users reported they patronised traditional services as an alternative to oncology and PC because it was less expensive:

*I went to herbalist and prayer houses because it was affordable. If I had enough money,
I would rather have sought care in the hospital ... (Patient 1)*

This patient's choice, as with others in the study, for oncology and PC was based on economic constraints, rather than preferences. The social context of the decisions made by patients was another contributory factor, as presented next.

Theme 3: Influence of social networks

The decision about whether or not to use oncology and PC was shaped by information and recommendations received by cancer patients from friends, neighbours and family members:

*Some of my friends and family members recommended that I should go for herbal
treatment, while some said that I should visit prayer house (Patient 7)*

This illustrates how cancer patients felt supported by members of their social networks, especially through the provision of information that played a role in their health-seeking

behaviour. However, this social network was detrimental, because it discouraged the use of oncology and PC:

I rejected doctors' advice and went back home with my daughter because my mother told me to bring her for traditional care (Patient relative 1)

I even advised my sister that we should visit a man of God for prayers contrary to the advice of the doctors and nurses (Patient relative 7)

Most patients and their relatives rejected the medical advice for oncology and PC; instead, they accepted lay advice from members of their social networks to seek non-orthodox care. However, some network members provided positive advice that encouraged the use of oncology and PC:

My husband took me to the hospital but some of my friends suggested that I should visit a prophet and a prayer house, but I refused their advice because I am educated (Patient 4)

The decision in favour of oncology and PC was upheld by some patients, despite the conflicting advice from other individuals from the same social connections. The patients' educational status seemed to have influenced their acceptance of advice to either use or not to use PC.

DISCUSSION

The healthcare system in Nigeria was found to comprise both orthodox and non-orthodox pathways, with multiple subdivisions in each category, in agreement with existing literature about Nigerian healthcare system²⁶⁻²⁸. The research reported here revealed, for the first time that the organisation of the healthcare system caused difficulties related to patient's decision-making about care, and confusion about the appropriate place for care, which negatively influenced the use of oncology care and PC. Thus, it can be construed that the heterogeneous

healthcare system in Nigeria and particularly the ineffective orthodox three-tier pathway for the healthcare delivery has made access to oncology and PC unnecessarily complex.

This ineffective structural organisation was perceived to emanate from leadership failure in terms of insufficient and mishandling of resources by the government authorities, who have responsibility of managing the healthcare system. The findings may not be surprising, especially to people familiar with Nigeria's socio-political circumstances, since several scholars and international agencies have documented that Nigerian bureaucracy is riddled with nepotism, incompetency, misappropriation of funds, and other forms of corruption²⁹⁻³². The findings about defective heterogeneous system of healthcare delivery in Nigeria suggest the need for policy to synchronize the orthodox and non-orthodox structures. This may also be relevant to other Sub-Saharan African countries since they operate similar plural healthcare systems.

In addition to the plurality of the Nigerian healthcare system, it was also found that poor socio-economic circumstances of cancer patients and their families rendered them more vulnerable, conditioned by the users' payment for the service that operated in Nigeria, thereby restricting access to oncology and PC. However, previous studies have [shown](#) that cancer patients from other African countries, such as Kenya and Ethiopia, received either free care or government subsidised payment for care^{33, 11}, thereby protecting their right to use oncology and PC. This is contrary to cancer patients in Nigeria, who exclusively pay for their service without healthcare insurance or government subsidy. Moreover, 'situational poverty' created by the high financial cost of cancer management made most of the cancer patients unable to afford treatment. Therefore, these patients resorted to non-orthodox care, reflecting the findings of previous studies¹¹, because it was perceived to be a cheaper alternative even when oncology and PC was preferred. This finding revealed the need to make oncology and palliative care free for the population that needs such services in Nigeria and other countries with the minority of

individuals having health insurance coverage. The findings also agreed with the recommendation by African Palliative Care Association ², that cancer patients should be given the opportunity to discuss their social and practical needs, with the options to address them identified and implemented.

Finally, it was revealing that social relationship was fundamental to decision-making concerning use of oncology and PC. Cancer patients predominantly accepted the advice to use non-orthodox care from people within their social networks. However, few patients accepted advice from HCPs for the use of oncology and PC but mainly those who possess higher educational status. Further study, adopting a quantitative method, would also be necessary to test the correlation of education attainment, social networks, and economic status in utilisation of oncology and PC among the larger population in an African context.

Study limitations

This study was limited to a single hospital, consequently the sample may not be representative of the population of patients with cancer and the clinicians that provide care to such a population. Although the conclusions are not broadly generalisable, the findings can be transferred to similar contexts.

Study implications

Firstly, this paper offers a new understanding that healthcare systems, as organised currently in Nigeria are not adequately prepared to address the increasing burden of cancer. There is lack of equity in access to oncology and PC as well as no financial-risk protection for patient contrary to the principles of universal healthcare coverage³⁴. Findings also showed that choices made by cancer patients and their families, primarily driven by poverty, increases mortality, as patients who could have been treated become terminally ill. Therefore, policy-makers could use the findings as evidence to contemplate restructuring of the Nigerian healthcare system to

promote access and eliminate difficulties in decision-making regarding appropriate places to seek care.

Secondly, the government, international and local donor organisations could use the findings from this study as evidence to prioritise creation of financial and tangible support for cancer treatment and palliation, as doing so will improve the uptake of oncology and palliative care.

Conclusions

Issues concerning the uptake of oncology and PC in a Nigerian society were found to be complex, as they stemmed from economic conditions, social relationships and dysfunctional healthcare system rooted in bureaucratic system failures. The findings contribute to a new understanding, that oncology and PC will not thrive in a society such as Nigeria and other countries with plural and dysfunctional healthcare systems. Nigeria and other countries should be societies where someone with cancer can have access to oncology and PC, regardless of their socio-economic background or other circumstances. We, therefore, argue that failure to either to make oncology and PC ‘free for all’ or to create a health insurance policy to cover cancer care in Nigeria and other countries, especially in the African continent could strengthen the existing inequalities, discourage usage and increase mortality. An integrated community case management programme³⁵ could be adopted for PC, whereby community PC volunteers will be initiated in all Nigerian states, provide them with training and on-going support to identify and manage minor symptoms in collaboration with PC team. This will facilitate partnership, sense of ownership, early identification and community support which will enhance utilisation of PC and minimize confusion about the appropriate place for care. Finally, we recommend partnership between government, NGOs and healthcare providers to encourage access to oncology and palliative care at affordable cost.

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