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The state of palliative care in South Africa: A case of Mthatha hospices Eastern Cape Province

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ABSTRACT

Despite the recognized importance of palliative care by the government, healthcare professionals, and communities, there are concerns that patients with chronic illnesses in South Africa are not receiving adequate care and commitment from healthcare systems. This paper examines the state of palliative care in South Africa, focusing on hospices in Mthatha, grounded in the Ubuntu philosophy, which emphasizes human-centered care. The qualitative case study involved 13 participants, including terminally ill patients and health workers. Semi-structured interviews and thematic analysis were used to gather insights, thoughts, and feelings about palliative care. The findings highlighted that hospice provided biopsychosocial services such as counseling, wound care, and therapy. Common chronic illnesses include Human Immune Deficiency Virus / Acquired Immunodeficiency Syndrome, cancer, pulmonary tuberculosis, and congestive heart failure. The challenges identified include staff shortages, patients' denialism, crime and insecurity, and inadequate financing, all hampering the delivery of holistic and effective care. The study concludes that hospices provide end-of-life care and support patients in managing their illnesses, emphasizing the need for a comprehensive approach to palliative care. It recommends government subsidies to cover home care, hospice services, and inpatient palliative care facilities, establishing care guidelines, and a framework for evaluating patient outcomes, satisfaction, and the quality of care delivered to ensure high-quality, comprehensive palliative care services for all patients.

KEY TERMS: palliative care, hospice, chronic illnesses, healthcare, Human Immune Deficiency Virus / Acquired Immunodeficiency Syndrome, South Africa

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INTRODUCTION

Hospices undeniably play a pivotal role in supporting patients with terminal illnesses, making it imperative to deliver high-quality palliative care that assists both patients and their families. Palliative care is an essential component in the healthcare framework and a comprehensive model centred on alleviating symptoms, pain, and stress associated with life-threatening conditions. This type of care is provided by various professionals inclusive of physicians, chaplains, nurses, and social workers, ensuring a holistic approach to delivering compassionate and effective patient care. This study therefore seeks to investigate the status of palliative care in South Africa, particularly in hospices in Mthatha, using a qualitative exploratory and descriptive approach. It explores the insights, thoughts, and feelings of chronically ill patients and palliative care professionals. The study is crucial as South Africa continues to struggle with the burden of chronically ill patients in need of palliative care. The paper covers the continuum of care within the South African healthcare system, the emergence of palliative care services, data gathering, and analysis methods, presentation of findings, discussions, conclusions, and recommendations.

BACKGROUND

Palliative care is a specialized branch of medicine that focuses on providing relief and support to individuals living with chronic illnesses, aiming to improve the quality of life for patients and their families by addressing physical, emotional, social, and spiritual needs (Afolabi et al., 2021). It emerged as a response to the limitations of traditional medical care, which focused primarily on treating and curing diseases, often neglecting the overall well-being of patients (Welgemoed & Lerm, 2020). Palliative care represents a shift towards a more holistic, patient-centered approach, emphasizing the importance of relieving pain and suffering alongside disease management (Wong & Yu, 2021). From an African point of view, palliative care is shaped by cultural, spiritual, and traditional beliefs; hence, caring for the sick and dying is a collective responsibility of family members and the community (Welgemoed & Lerm, 2020). This care is provided by administering traditional medicine, ancestral rituals, and spiritual consultations. Death is considered a transition and not an end of life (Glyn-Blanco et al., 2023). Hence, open discussion about death is sometimes considered taboo.

According to Bigna and Noubiap (2019), the worldwide burden of life-threatening diseases, such as cancer, Human Immune Deficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS), and non-communicable diseases, has been enormous in Africa in the last decades. An estimated forty million individuals worldwide require palliative care annually, of whom the majority live in low- and middle-income nations, including sub-Saharan Africa (WHO, 2020). According to Welgemoed and Herm (2020), palliative care is widely recognized as ethically, morally, and legally sound. However, South Africa lacks a structured system or legislation guiding end-of-life care. Palliative care focuses on managing symptoms, enhancing comfort, and alleviating emotional distress for terminally ill patients and their families, making it essential for addressing end-of-life suffering. Research shows that the need for palliative care in South Africa grows annually (Drenth et al., 2018). Therefore, additional healthcare facilities and outlets, such as community and home-based care, must be developed to address this demand. South Africa has eight hospital palliative care programs, with two dedicated to children's needs. Notably, 150 hospices provide palliative care across all nine provinces in South Africa, and eight of these institutions are in the Eastern Cape Province (Drenth et al., 2018). Despite the presence of these institutions, there are concerns that patients suffering from life-threatening illnesses are not receiving adequate attention and commitment from healthcare systems, against its significance in the healthcare continuum (World Health Organization, 2020). Notably, while palliative care facilities have been developed in South Africa, they are not funded by the government, making them expensive and inaccessible to the vulnerable population who require them the most (Welgemoed & Herm, 2020). These operational gaps lend credence to the Ubuntu Philosophy and its fundamental principles of survival and compassion as a theoretical framework in this study (Boboyi, 2024).

According to Ngubane & Makua (2021), Ubuntu philosophy extends beyond physical care to encompass other values such as social justice, equity, and long-lasting human relationships. Therefore, Ubuntu is about restorative justice, where healing and reconciliation are more prominent than punishment. Mugumbate et al., (2020) advance the Ubuntu philosophy to maintain the essence of collective responsibility and solidarity that are fundamental values of African culture and identity. Through the lenses of Ubuntu, survival is defined as the ability to derive strength and comfort from one's family and community to endure difficult situations. Palliative care allows families and communities to provide and gain strength from terminally ill patients (Mnyandu, 2018). Palliative care enables individuals in their final hours to live positively rather than merely facing death, thereby fostering sustained connections with their family members. Moreover, compassion, as advocated in *Ubuntu*, is central to the process and provision of palliative care services. It helps alleviate suffering and encourages patients to die with dignity (Mnyandu, 2018). Against this backdrop, access to palliative care services remains a contentious issue in South Africa, given the daunting challenges of poverty, inequality, and unemployment, especially in rural areas. These socioeconomic disparities contribute to unequal access to health care, with palliative care services

being affected most. This is because low-income patients face challenges such as a lack of insurance coverage, financial constraints, and limited knowledge about available services (Nelson et al., 2021). Moreover, stigma associated with chronic illnesses may prevent patients and families from seeking or accepting palliative care services (Flieger et al., 2020).

Consequently, this study sought to examine the state of palliative care in hospices in Mthatha to establish their effectiveness and challenges. To achieve this aim, the following questions were answered:

- What palliative care services are available for chronically ill patients in hospices in Mthatha?
- How effective are the palliative care services rendered to chronically ill patients?
- What challenges are encountered by the hospices rendering palliative care services?

METHODOLOGY

The study employed a qualitative research approach to explore the insights, thoughts, and feelings of terminally ill patients and healthcare workers regarding the state of palliative care. This approach was chosen for its ability to capture personal experiences and perspectives through dynamic interaction (Keikelame & Swartz, 2019). The research was both explorative and descriptive, using a case study design focused on a small, specific sample of 13 participants, including terminally ill patients and healthcare workers from two hospices in Mthatha. Purposive sampling, a non-probability sampling method, was used to select participants with substantial knowledge and experience in palliative care, ensuring rich, relevant data without aiming to generalize findings to a broader population.

Data was collected using a structured interview guide with in-depth, semi-structured interviews featuring open-ended questions. These interviews were conducted at the participants' locations and included both face-to-face and telephone conversations. Observations were made alongside the interviews, with responses recorded on paper and via mobile phone for those who consented. Mock interviews were conducted to refine the interview questions, which were tailored separately for patients and healthcare providers.

Following Braun and Clarke's (2006) six-step method, thematic analysis was used to interpret the data, allowing the researchers to identify and formulate themes based on the participants' responses. Braun and Clarke (2019) refined their thematic analysis approach, improving definitions and reorganizing stages for greater consistency. While flexibility remains a strength, it can lead to inconsistent application, affecting replicability and standardization. Despite these challenges, thematic analysis continues to be widely used, with ongoing critiques calling for better accuracy, consistency, and balance between flexibility and analytical depth. The study adhered to strict ethical guidelines, including obtaining **informed consent** from all participants and hospice managers, ensuring voluntary participation, and maintaining privacy, **anonymity, and confidentiality**. Participants were assured that their information would be used solely for research purposes, with real names omitted from the records. Adherence to these ethical principles was crucial, given the sensitive nature of the participants' health statuses and the importance of respecting their rights and dignity throughout the study.

LITERATURE REVIEW

The literature review provided a comprehensive background on palliative care services, focusing on hospices for chronically ill patients. It explored key concepts, principles, and global practices, with a particular emphasis on South African hospices. The review was informed by studies examining the availability, effectiveness, and challenges of palliative care. It aimed to address three research questions: (i) What palliative care services are available for chronically ill patients in hospices in Mthatha? (ii) How effective are these services? and (iii) What challenges do hospices face in providing palliative care? The review helped frame the study's objectives and identified gaps for further exploration.

Literature shows that palliative care significantly improves the emotional well-being of patients. Lemke (2021) found that palliative care interventions reduce anxiety and depression in individuals with advanced cancer. According to Rid et al. (2015), palliative care prioritizes patients' goals, aids in understanding treatment plans, manage pain and symptoms, and reduces unnecessary hospitalizations. By addressing patients' emotional needs, palliative care enhances overall satisfaction with care.

Palliative care also extends support to families. Aoun et al. (2015) reported that families of patients receiving palliative care experienced reduced caregiver burden, better communication with healthcare professionals, and improved bereavement support. This highlights the importance of involving families in palliative care to enhance coping mechanisms and support during grieving.

However, despite the benefits of palliative care, access remains limited. For instance, Hawley (2018) notes that the benefits of early integration of palliative care with disease management are missed by many people living with a chronic illness, and these services are only provided in the last phase of their illness. Moreover, another study shows that few of those needing palliative care in South Africa receive it. Gerber et al. (2021) identified a

shortage of palliative care nurses, particularly in rural areas, limiting access to adequate care. The absence of standardized guidelines and protocols contributes to inconsistent care quality. Communication difficulties among healthcare professionals, patients, and families complicate palliative care provision. Literature shows that challenges in discussing prognosis, treatment options, and end-of-life decisions can lead to dissatisfaction, unmet needs, and misaligned treatment goals (Aoun et al., 2015; Rid et al., 2015). These studies highlight that palliative care is crucial for enhancing symptom management, addressing emotional needs, supporting families, and reducing hospital readmissions. Therefore, palliative care improves the quality of life for patients with chronic illnesses and their families' well-being. However, these studies are limited to a Eurocentric and biomedical framework, with no focus on Afrocentric, cultural, and traditional practices towards care for the dying. This study employs the Ubuntu framework to address such gaps.

FINDINGS

The key findings are presented in the section, beginning with participants' demographic data, the health care professional's ratio to patients, the provision of coordinated care, and challenges, including unsafe communities and limited access to palliative care.

Demographic data of participants

Thirteen volunteers from two hospices, both patients and health care workers, took part in the study. Of the participants, 77% (ten) were women, and 23% (three) were men. The split by age was as follows for the females: 46.2% (six) aged 30-40, 15.4% (two) aged 41-50, 30.8% (four) aged 51-60, and 7.6% (one) aged 61-70. This implies that terminal illness is common above the age of thirty, and increased access to palliative care services is required. It was discovered in the study that 61.5% (eight) of the participants were unemployed, 23.1% (three) employed, 7.7% (one) were self-employed, and 7.7% (one) were pensioners. In terms of marital status, 38.5% (five) were single, 30.8% (four) married, 23.1% (three) divorced, and 7.6% (one) widowed. These results point to serious socioeconomic issues, where most of the participants were unable to pay for private care, and further, there is no spouse in most instances, leaving the children, family members, or community volunteers to assume caregiving responsibilities. The research also noted low rates of male participants, which implies that gender roles might deter men from accessing palliative care services.

The ratio of healthcare providers to patients

To have a clear picture of the status of the palliative care services in Mthatha, it is crucial to know the number of professionals vis-a-vis the demand for care. When the patients were asked if they received prompt responses upon placing their requests, the responses suggested that the healthcare providers were not consistently prompt. The lack of consistency in immediate response indicates a shortage of healthcare providers in these facilities. This critical gap was illustrated by Participants 10, 2, and 8, who decried that: They do not always respond quickly because there are about 80 of us with only two nurses (P10). I live far from the hospice, so sometimes when I do not feel well, they send a nurse from our local clinic (P2). The nurses visit three times a week, so I am unsure what would happen if I fell ill on a day they do not visit (P8).

These findings underscore that the available palliative care providers are fewer than the patients in demand of the services. This discrepancy concerns whether the services rendered are adequate, affordable, and effective in managing the magnitude of the illnesses. For instance, the 3-day frequency of rendering services (as alluded to by the participant) clearly indicates inadequate staffing at these hospices, hence compromising the quality and objectivity of palliative care. These sentiments highlight the necessity of prioritizing the recruitment and posting of palliative care professionals in hospices to enhance the effectiveness and efficiency of patient care in the study area.

Provision of coordinated care

The primary goal of hospices is coordinating care services to ensure patients' needs are met. This study established that the hospices provided coordinated services such as re-initiation of treatment after defaulting, tracking and delivering medication, and educating immediate family members on home care skills. Participants 2 and 8, being happy beneficiaries of these services, narrated the following: The nurses do not only make sure that I am fine they also reassure my family and give them hope (P8).

When I failed to collect my treatment from the local clinic, the hospice nurses traced me, counselled me, and educated me about the importance of adhering to my treatment. They also enlisted my sister to support and remind me to take my medication daily (P2).

The study established that some patients felt that the services effectively managed the illnesses' pain and other

severe symptoms. This was achieved through regular provision of medication and physical exercise. To illustrate this sense of effectiveness, participant 2 affirmed that; Palliative care services are effective because they ease pain for a short period (P2).

Moreover, participants 6,7,9 and 10 attested that palliative care manages their illnesses, especially by controlling symptoms. For instance, P7 and P9 opined that: It helps to improve our quality of life. It focuses on managing our symptoms and supporting us (P7). It helps us to feel less pain. We are given medication and other exercises (P9).

Furthermore, the study revealed that palliative care services were considered effective because they provide emotional and spiritual support, which is instrumental in managing stress and depression. Consequently, they promote healthy living and prolong the lives of the patients. To attest to these findings, the participants had the following to say: Palliative care services provide emotional support, and they help to reduce anxiety, stress, and depression. We get counseling through support groups; they also dress my wound twice a day since it got worse (P8). There are pastors from different churches that come every Sunday for an afternoon service (P10)

At the hospice, we have a pastor providing us with spiritual comfort, social workers offering us counseling, and the nurses offer us care (P4).

These findings suggest that the hospices in the study area attempt to render holistic care for their patients by involving other significant stakeholders such as family members, social workers, and spiritual leaders.

The study also revealed that the patients are accorded physical support, such as being fed and bathed. This is instrumental in managing the pains and enhancing the feelings of being cared. To illustrate this, Participants 4 and 6 said: Our healthcare providers give us respect; they are not rude, and they love us (P4). They give us food, bathe us and give us treatment (P6)

The study also established that the staff at the non-profit palliative care facility were in the process of implementing a policy to increase the frequency of patient visits. This finding indicates that hospices provide end-of-life care and actively support newly diagnosed patients in adhering to their treatment regimens.

Challenges affecting palliative care

The study established the following as key hurdles affecting the effective delivery of palliative care services in the study domain: limited accessibility, crime and insecurity, patient denialism, and financial constraints.

Limited access to palliative care

The study revealed that palliative care services were not readily accessible in the study area. Few facilities offered such services, and the high demand attracted some admission fees. This study showed that the private facility charged R2100 fees monthly. Looking at the socioeconomic status of the participants in this study, this amount of money would be costly, especially when the patient is incurring other treatment costs. These costs imply that patients cannot access the services without adequate funds, hence limiting the accessibility of palliative care. These costs are illustrated in the participant's P10 and P6 sentiments: Yes, because it is a non-profit organization, we pay R2100 monthly (P10).

Yes, when I came, they explained to me and my family that they give palliative care services. So, I paid R700 for registering and R2100 every month (P6).

These findings suggest that access to palliative care services in Mthatha is limited. Patients must either have the financial means to afford the fees at the NPO or rely on robust family support for home-based care.

Crime and insecurity

The study established that the facilities providing palliative care operate in unsafe communities. The healthcare providers reported that it was unsafe to visit some communities because of criminal activities. Notably, the lack of a proper road network in such areas makes it unconducive for vehicles, especially during rainy seasons. Therefore, healthcare providers feel unsafe walking in such places for fear of mugging and vandalism of their vehicles. Participant 11's sentiments highlight this plight as she decried that: It becomes difficult to visit unsafe communities, especially in winter we fear for ourselves and the vehicles. We report our home visits to the chief before we come so that they are aware of protecting us (P11, Palliative care provider).

This finding suggests that geographical factors, such as unsafe locations and poor road conditions, pose significant barriers to accessing palliative care services. Therefore, to improve service delivery, the security and safety of healthcare providers must be prioritized.

Patient's denialism

The study established that patients are also challenging to deliver effective palliative care. Denialism is one aspect revealed in this study. When patients are in denial, they become irrational and begin defaulting on treatment, hence undermining the efforts to manage their illnesses. Failure to accept their health conditions would inhibit them from accepting the assistance provided by healthcare providers. Participants 12 and 13, healthcare providers, encapsulated this dilemma by noting the following: Patients come here with a mindset that they are going to die soon, so they refuse to take their medication (P12, Palliative care provider).

Patients sometimes do not want to accept their diseases, so they become very difficult to work with. Others also accuse us of making them sicker with the medication (P13, Palliative care provider).

This finding indicates that patients fail to acknowledge their chronic illnesses and remain in denial of their situation. This is detrimental to the financial cost of the treatment and care and the motivation of the healthcare providers to continue offering their services.

Financial constraints

The study revealed that patients incur additional personal amenities and diet costs. It was established that the paid fees were insufficient to cover all the needs of the patients. Some of the personal expenses include adult diapers, airtime, snacks, and toiletries. The financial constraints for the facilities and individual patients are a serious concern for the quality of services rendered. The following participants verbatim attest to the financial struggles experienced by the patients and the hospices: The money does not cover all my needs as I also need diapers during the month (P1). It is not enough. Our families visit twice a week, so I need airtime to talk to them over the phone (P7).

We have to buy our own toiletries, and my medication increases my appetite, so I need to have my own snacks during the day (P10).

Additionally, the participants also revealed that the food is sometimes displeasing. This implies that they needed money to buy food of their choice. However, this was not affordable due to insufficient money to cover the expenses. The complaints about the state of food suggest that the hospices would also be operating on 'shoestring' budgets to provide basic services, not the expected conformant for the patients. The sentiments of P3 lay bare the possible financial challenges of the hospices: It is not enough to cover all our needs. Sometimes we eat food that does not have vegetables (P3).

These findings show the dire financial situation of palliative care facilities in the study area. This financial situation calls for the hospices to strategically fundraise to ensure they provide the highest standard of care for terminally ill patients as expected.

DISCUSSION

Indeed, palliative care is critical in the continuum of the healthcare system for chronically ill patients. This type of healthcare is crucial for South Africa due to high cases of terminal illnesses such as HIV/AIDS, cancer, and pulmonary tuberculosis. As outlined in the Hospice Palliative Care Association (2023), palliative care facilities are designed to support patients diagnosed with chronic illnesses without cure. This study showed that hospices in Mthatha offer these essential services, including medication and treatments, psychological support through counselling, and spiritual and physical support. The cluster of these services enables the patients to manage the physical pains, and the emotional and spiritual agonies associated with the illnesses. These findings suggest that hospices attempt to provide holistic patient care, proving their indispensability to the healthcare system. Providing care and love for chronically ill patients aligns with the *Ubuntu* Philosophy, which emphasizes the need to care for and share each other burdens because our being and existence are interlinked. This perfectly supports the efforts of families to provide adequate support and care for their ill relatives.

Moreover, the community is responsible for caring for the weak and the needy. This community responsibility to care situates the hospices' critical position in providing palliative care. The efforts by hospices to make palliative care effective are developmental towards actionizing *Ubuntu* philosophy as the culturally defining philosophy of co-existence in the study area.

However, the lack of adequate facilities and the high cost of palliative care services renders them inaccessible to the vulnerable patients who need them most. The findings of this study reflect the National Policy Framework and Strategy on Palliative Care (2017) report, which found that palliative care is not uniformly available within South African public health facilities. This gap has led to private facilities providing critical services, shifting the cost burden to the patient and the family. These private facilities suffer staffing shortages, which impedes the ability of healthcare providers to respond promptly to palliative care requests. Hawley (2018) highlights the shortage of trained staff as a significant barrier to the effective delivery of palliative care, leading to limited accessibility and quality.

The study identified several challenges faced by hospices in delivering palliative care to terminally ill patients. Patient denialism is a serious challenge because it results in treatment defaulting and, ultimately, poor health

outcomes. Importantly, lack of funds is detrimental to the quality and accessibility of palliative care in the country. Chronic illnesses are expensive in treatment and management, so hospices require adequate financing to cater to medical and patients' personal needs. South Africa is a crime-prone country, and the study established that healthcare providers are sometimes afraid of making home visits, hence stifling efforts to deliver home-based care services. With these challenges abound, the status of palliative care in the study area is at a crossroads. This is because the demand for the services is relatively high, while the capacity for the hospices is not fully supported.

CONCLUSION

The status of palliative care in the study area is ambivalent. This is because while the hospices are found rendering biopsychosocial services such as counseling, wound care, medication, and spiritual well-being, there are eminent challenges. These challenges include inadequate funds, patient denialism, shortage of healthcare providers, and crime and security. However, despite all these challenges, the findings suggest that palliative care is effective as participants candidly and vividly illustrated how they managed their pains and symptoms, found hope for themselves and their families, and prolonged their lives. This underscores the importance of palliative care services in improving the quality of life for patients with chronic illnesses. Given the increasing demand for palliative care, it is imperative to prioritize resource allocation, investment in developing and training the healthcare workforce, and advance efforts in awareness and advocacy. Implementing these measures will ensure that individuals with life-limiting illnesses receive comprehensive, compassionate, and patient-centered care in accordance with the principles of *Ubuntu* and the right to quality healthcare for all.

RECOMMENDATIONS AND IMPLICATIONS FOR SOCIAL WORK

The findings of this study are significant to social work as a helping practice. Social workers often find themselves at the intersection of healthcare services and the clients (patients). Social worker's understanding of palliative care in South Africa is critical for advocacy, lobbying, and referral of clients. For instance, social workers working with HIV/AIDS patients may need to work with hospices during the last stages of life for the clients. Social workers are primary palliative care stakeholders who collaborate and partner with other professionals to deliver quality and accessible services.

Having the established challenges that may hinder the effectiveness of palliative care, the study makes the following recommendations:

- The hospices should strategically pursue government funding and private sponsorships to ensure that palliative care services remain accessible to all individuals in need. Government subsidies would help generate additional financial resources, enabling a more balanced ratio of healthcare providers to patients.
- Establishing and implementing a national policy ensures access to high-quality and comprehensive palliative care services for all patients, regardless of age, diagnosis, or location.
- Resources should be adequately allocated to support the expansion and sustainability of palliative care programs across hospitals, nursing homes, and community-based settings. This includes funding for training palliative care specialists, infrastructure development, and educational initiatives.

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