



**Nursing Care of Patients at the End of Life in Sub-Saharan Africa:
A Rapid (Systematic) Review**

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Abstract

Introduction: Palliative and end-of-life care is a relatively new healthcare discipline that originated as a response to the inadequate provision of mainstream services for the care of patients at the end of life. A literature review to identify and synthesize research evidence about the nursing care of patients at the end of life in hospitals of Sub-Saharan Africa was conducted. **Aim:** The article explored what published research evidence exists about the nursing care of patients at the end of life in hospitals in Sub-Saharan Africa. **Methods:** The literature search was carried out using 4 electronic databases; these are Citation Index for Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE (OVID) and Web of Science. **Results:** Two hundred and fifty-eight articles were related to Sub-Saharan Africa. One hundred and eighty-three articles were rejected because they were not related to adult, and studies not conducted in a hospital. Seventy-five articles were further screened based on the title and abstract, 58 were excluded. Full texts of the remaining 17 articles were finally scrutinised, and 12 articles were found relevant for the study. Six themes were identified: nurses' knowledge and perception about palliative and end-of-life care; nurses experiences of care at the end of life; nurses emotional stress when caring for patients at the end of life; barriers to palliative and end-of-life care provision; nurses' perception of dying; and family caregivers experiences of care at the end of life. **Conclusion:** The review reveals most of the studies were centred on HIV/AIDS, even though other conditions have similar needs for palliative care such as cancer, renal failure, heart failure, diabetes mellitus, liver diseases, and chronic respiratory diseases. However, most of the studies were conducted in South Africa, and based on the sample characteristics and other limitations such as sample size and study settings, the results are not generalisable beyond the participants and the study settings. The study recommends in-service training and education for caregivers. Enhancing communication skills of nurses when caring for patients at the end of life, appropriate skills development, education of student nurses on nursing care of patients at the end of life, update courses for registered nurses and more research on nurse's experiences of nursing care of the terminally ill patients as well as research into palliative and end of life care.

Keywords: *Nursing Care, End of Life Care, Sub-Saharan Africa, Rapid Review*

Introduction

This literature review explored what published research evidence exists, identified and synthesised research evidence about the nursing care of patients at the end of life in hospitals of Sub-Saharan Africa. The literature review followed an approach similar

to that of Grant and Booth (2009). A form of evidence assessment using systematic review methods to search and synthesise existing research literature. The methodology involves a careful focus on the review question, using broader or less sophisticated search strategies

than the traditional systematic review (Grant & Booth, 2009).

The Aim of the Review

To identify and synthesise research evidence on the nursing care of patients (adult) at the end of life in hospitals in Sub-Saharan Africa.

Review Question

What evidence is there about nursing care delivered to patients (adult) at the end of life in hospitals in Sub-Saharan Africa?

Search Terms

Table 1: Search Terms

<p>1- "End of life" OR 2- "End of life care" OR 3- "Palliative care" OR 4- "Terminal care" OR 5- "Terminal illness" OR 6- "Care of the death" OR 7- "Care of the dying" OR 8- "Care of the dying patient" OR 9- "Dying with dignity." 10-1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9</p>	<p>11- "Nursing care" OR 12- "Nursing practice" OR 13- "Hospital care." 14-11 OR 12 OR 13 15-10 AND 14 16-"Sub-Saharan Africa" AND 15</p>	<p>17-Angola 18-Benin 19-Botswana 20-Burkina Faso 21-Burundi 22-Cameroon 23-Cape Verde 24-Central African 25-Republic 26-Chad 27-Comoros 28-Congo B 29-Congo DR 30-Côte d'Ivoire 31-Djibouti 32-Equatorial Guinea 33-Eritrea 34-Ethiopia 35-Gabon 36-The Gambia 37-Ghana 38-Guinea 39-Guinea-Bissau 40-Kenya 41-Lesotho 42-Liberia 43-Madagascar 44-Malawi 45-Mali 46-Mauritania 47-Mauritius 48-Mozambique 49-Namibia 50-Niger</p>	<p>51-Nigeria 52-Réunion 53-Rwanda 54-Senegal 55-Sierra Leone 56-Somalia 57-South Africa 58-Sudan 59-Swaziland 60-Tanzania 61-Togo 62-Uganda 63-Western Sahara 64-Zambia 65-Zimbabwe 66-17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 67- 16 AND 66</p>
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Selection Criteria

- ❖ Research conducted in Sub-Saharan Africa
- ❖ Research involving adult patients receiving palliative and end-of-life care
- ❖ Papers related to care at the end of life
- ❖ Research conducted in hospital settings
- ❖ Research published in English

Methods

The literature search was carried out using 4 electronic databases; these are Citation Index

for Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE (OVID)

and Web of Science. Total search from the databases yielded 37620 articles, two articles extracted from Google Scholar were added and 14 duplicates removed. Two hundred fifty-eight articles were related to Sub-Saharan Africa. One hundred eighty-three articles were rejected because they were not

related to adult, and studies not conducted in a hospital. Seventy-five articles were further screened based on the title and abstract, 58 were excluded. Full texts of the remaining 17 articles were finally scrutinised, and 12 articles were found relevant for the study (See Figure 1).

Search Strategy

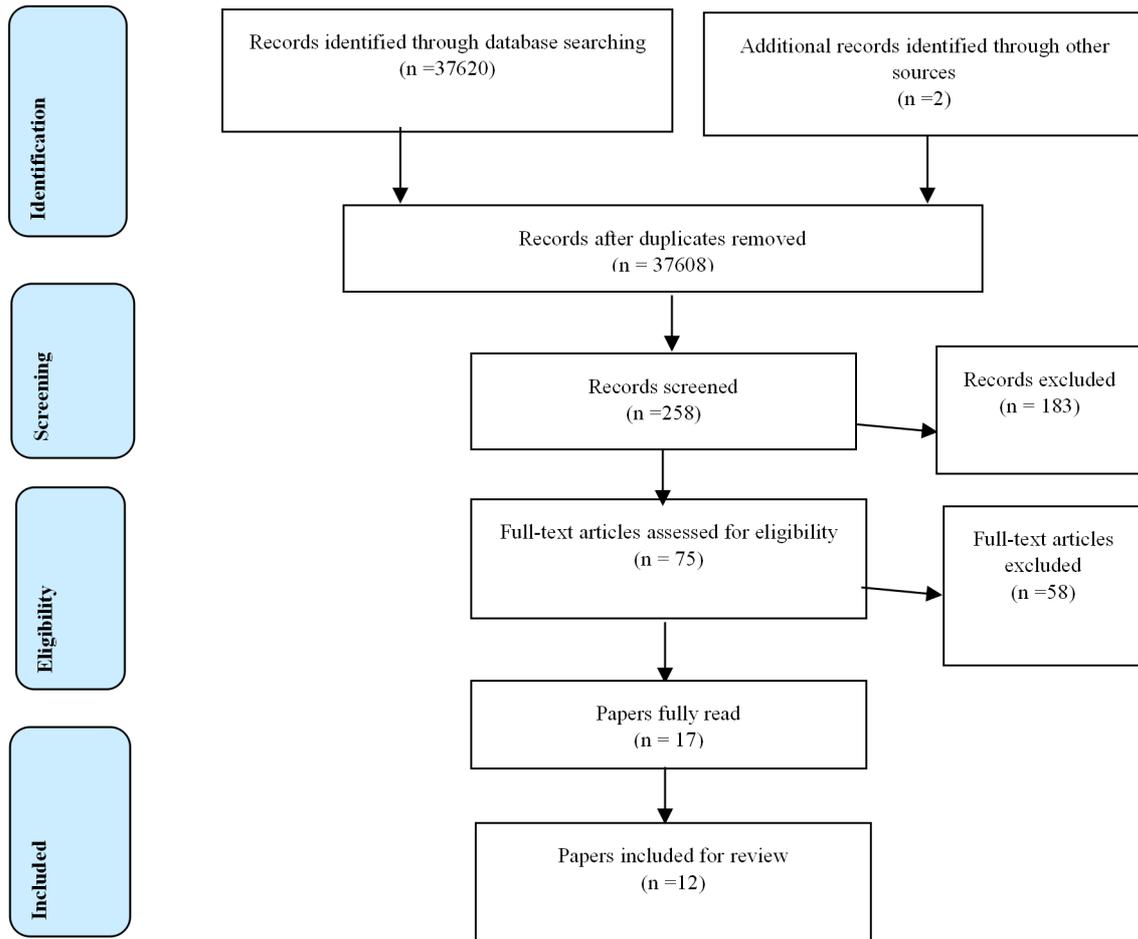


Figure 1: PRISMA flow for searched articles

Table 2: Summary of Reviewed Articles

AUTHOR YEAR COUNTRY	JOURNAL	ARTICLE TITLE	AIM	METHOD	SAMPLE SIZE	REPORTED MAIN FINDINGS	NOTES AND CRITIQUES
BAM AND NAIDOO (2014) SOUTH AFRICA	<i>Curationis</i>	Nurses experiences in palliative care of terminally ill HIV patients in level 1 district hospital	To explore and describe the lived experiences of nurses caring for patients with terminal HIV illness	Qualitative research, using the interview	Ten nurses	Themes: Conceptualization of caring and terminal illness, experiences of caring, factors hinder palliative care, a mechanism for adjusting in caring for terminally ill,	There is no ethical approval for the study, the location of interviews was not mentioned
BESTER ET AL. (2006) SOUTH AFRICA	<i>Health SA Gesondheid</i>	Professional nurses' experience of the dying process of the terminally AIDS patient	To explore and describe the nurses' experience of the dying process of the terminally AIDS patient	Qualitative research design using an in-depth interview	Ten professional nurses	Categories: Experience regarding the course of the dying process, Medical treatment during the dying process, Specific behavioural needs for patients, Specific behaviour of the nurse, Nurses' emotional experiences, Value judgement by the nurse	No ethical approval for the study, Number of participants not clearly stated, venues of the interview were not mentioned
COENEN ET AL. (2007) (ETHIOPIA, INDIA, KENYA AND UNITED STATE)	<i>Oncology Nursing forum</i>	Nursing intervention to promote dignified dying in four countries	To describe a nursing intervention to promote dignified dying as identified by nurses in four countries	Qualitative analysis of an open-ended question	560 nurses from four countries	Themes: Symptom management, Communication, Family care, Spiritual comfort, Environmental management	Design/method not clearly defined
DEKKER ET AL. (2012) SOUTH AFRICA	<i>Journals of pain & palliative care pharmacot herapy</i>	“What is killing me most”: Chronic pain and the need for palliative care in the Eastern Cape, South Africa	To investigate patient experiences and health care provider attitudes towards chronic	Mixed method approach using questionnaire and in-depth interview	Patients - 45 Doctors - 7 nurses – 11 Physiotherapist – 3 Occupational	Themes: pain and patient experiences, predictors of pain, pain prescription patterns, Palliative care training, and providers	No basis for sampling, No justification for the chosen design

			pain and palliative care		ional therapist – 3 Social worker – 1 Pharmacist – 1	understanding of palliative care.	
FADARE ET AL. (2014) NIGERIA	<i>Annals of Medical and Health Sciences Research</i>	Perception of Nurses about Palliative care: Experience from south-western Nigeria	To explore nurses knowledge and attitude toward palliative care	Questionnaire-based cross-sectional study	120 Nurses	Experience-46% practice for >10 years, Knowledge-71.8% said palliative care is about pain medicine, 55% geriatric medicine, 90.2% active care of the dying, 64.6% rehabilitation medicine	Random sampling was used instead of quota sampling, The number of participants not clearly stated.
GYSELS ET AL. (2011) SSA	<i>BMC palliative care</i>	End-of-life care in Sub-Saharan Africa: a systematic review of the qualitative literature	To synthesise qualitative research on end-of-life care in SSA to inform policy, practice and further research	Systematic review	51 articles	The burden of the end of life care, Training, support needs, and tools, Place of care, Good death versus bad death and stigma, Bereavement, Culture-specific experiences and approaches to symptoms, illness, death and caring	
KASSA ET AL. (2014) ETHIOPIA	<i>BMC Palliative care</i>	Assessment of knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospitals in Addis Ababa	To assess the knowledge, skills, attitude and associated factors with palliative care in nurses working in selected hospitals in Addis Ababa	A cross-sectional quantitative study using questionnaire	365 nurses	Knowledge-76.2% of the respondents had poor knowledge, Attitude- 76% had a favourable attitude towards palliative care	
KELL AND WALLEY (2009)	<i>BMC palliative care</i>	Palliative care for HIV in the era of antiretroviral	Understand the perceptions of nurses of palliative	Qualitative semi-structured interviews	Ten nurses and six key	Themes: palliative care: end of life or chronic care,	No justifications of choice of

LESOTHO		therapy availability: perspectives of nurses in Lesotho	care in Lesotho Discuss the need for palliative care through analysis of the components of the WHO definition		informants	The need for palliative care, Integrated management of adolescent and Adult Illness (IMAI) as a tool for palliative care provision	methodology and sample selection
MACHIRA ET AL. (2013) KENYA	<i>International Journal of Palliative Nursing</i>	Impact of an educational pain management programme on nurse' pain knowledge and attitudes in Kenya	To implement and evaluate a pain management programme for a nurse in Kenya	Quasi-experimental pre-post-test design	27 nurses	Kenyan nurses' pain knowledge and attitudes are far from ideal (47.5%),	No pilot study was conducted to test the applicability of the instrument to Kenyan nurses
SMIT (2004) SOUTH AFRICA	<i>Journal of Advanced Nursing</i>	HIV/AIDS and the workplace: perceptions of nurses in a public hospital in South Africa	Investigate the perceptions and experiences of nurses in the public health sector with regard to their attitudes towards caring for patients with HIV/AIDS	In-depth semi-structured interviews	Nurses - 35	Themes: Helplessness, Emotional stress, and fatigue, Fear, Anger and frustration, Empathy and Self-fulfilment	Design of the study not defined, name of the university that approved the ethical clearance was not mentioned.
VAN GURP ET AL. (2015) NIGERIA	<i>PLoS ONE</i>	Telemedicine's potential to support good dying in Nigeria: A qualitative study.	To conceptualise good dying and or good death among Nigerian health care professionals in palliative care and explore how telemedicine fit the palliative care practice	Qualitative study using focus group	Doctors – 11 Nurses – 7 Pharmacists – 5 Medical social worker – 1 ICT staff – 3	Themes: Good dying and or good death, Barriers to palliative care provision, Telemedicine in a Nigerian care	
VAN ROOYEN	<i>Health SA Gesondheid</i>	Caring for terminal AIDS	Explore and describe	Qualitative, exploratory, descriptive,	13 Care givers	One theme: Challenges experience by	The identity of caregivers

ET AL. (2009)		patients: The experiences of caregivers in a palliative care institution	how caregivers in a formal setting (palliative care institution) experience caring for patients dying from AIDS, and develop broad guidelines for support and optimising nursing care for patients dying from AIDS	and contextual research with a phenomenological approach		caregivers in dealing with dying patients Five sub-themes: Emotional challenges for caring of the dying patients, Differences in death and dying of adults compared to children, Rationalisation of death and dying, Strength to cope with death and dying from having faith in God, caring for the dying is self-fulfilling and meaningful despite the sadness	not define, no ethical approval, no justification for the purposive sampling which was based on the researcher's assumption
SOUTH AFRICA							

Quality Assessment

Of the twelve articles included in the review, seven were qualitative studies, three quantitative, one mixed-method and one was a systematic review. A traditional approach to assessing more than one study by the narrative discussion was used (Hawker, Payne, Kerr, Hardey, & Powell, 2002) (see Table 2).

There were certain limitations in some of the qualitative studies (Bam and Naidoo, 2014 and Bester *et al.*, 2006); these include lack of reports of ethical approval from ethical reviewing board or committee and ethical considerations. In some of the articles study design and approach were not specified (Coenen *et al.*, 2007 and Smit, 2004), sample size selection not justified Dekker *et al.* (2012), and the locations of the interviews were not mentioned Bam and Naidoo (2014) Bester *et al.* (2006). Characteristics of caregivers were not defined in one of the studies and were selected based on the assumption of the researcher Van Rooyen *et al.* (2009).

In the three quantitative studies, two (Machira *et al.*, 2013, and Fadare *et al.*, 2014) have

questionable generalisability due to small sample size, selection bias and no pilot study was not conducted. This may affect the internal and external validity of the results. Also, one of the studies (Fadare *et al.*, 2014) was a cross-sectional survey among different categories of nurses in a hospital, yet a random sampling method was used to select respondents instead of a quota sampling, thus affecting the distribution of the respondents. The mixed-methods study (Dekker *et al.*, 2012) has a small sample size limiting the power of detecting statistically significant differences, while the convenience sampling approach prevents a fair representation due to selection bias. In the systematic review (Gysels *et al.* 2011) there was no summary table to show the articles reviewed, show up only the locations for data collection, participants and illnesses.

Findings

Of the twelve articles in the review, five were from South Africa (Bam & Naidoo, 2014; Bester, Du Plessis, & Greeff, 2006; Dekker, Amon, le Roux, & Gaunt, 2012; Smit, 2005;

Van Rooyen, Williams, & Ricks, 2009), two from Nigeria (Fadare *et al.*, 2014; van Gurp *et al.*, 2015), one from Lesotho (Kell & Walley, 2009), one from Ethiopia (Kassa, Murugan, Zewdu, Hailu, & Woldeyohannes, 2014) one from Kenya (Machira, Kariuki, & Martindale, 2013) and one systematic review (Gysels, Pell, Straus, & Pool, 2011). As noted above, seven of the studies were qualitative (Bam & Naidoo, 2014; Bester *et al.*, 2006; Coenen, Doorenbos, & Wilson, 2007; Kell & Walley, 2009; Smit, 2005; van Gurp *et al.*, 2015; Van Rooyen *et al.*, 2009), three articles were quantitative studies (Fadare *et al.*, 2014; Kassa *et al.*, 2014; Machira *et al.*, 2013), one mixed-method (Dekker *et al.*, 2012) and one systematic review (Gysels *et al.*, 2011).

Five of the reviewed articles were related to the care of patients with HIV/AIDS (Bam & Naidoo, 2014; Bester *et al.*, 2006; Kell & Walley, 2009; Smit, 2005; Van Rooyen *et al.*, 2009), one article each related to palliative care experience, chronic pain, and death and dying respectively (Dekker *et al.*, 2012; Fadare *et al.*, 2014; van Gurp *et al.*, 2015). Four of the remaining papers report studies on experiences, two on knowledge and attitude, one each on perception, and experiences amongst nurses and conceptualisation of a good death and dying.

Six themes were identified from the studies and presented as follows:

- ❖ Nurses' knowledge and perception about palliative and end-of-life care
- ❖ Nurses experiences of care at the end of life
- ❖ Nurses emotional stress when caring for patients at the end of life
- ❖ Barriers to palliative and end-of-life care provision
- ❖ Nurses' perception of dying
- ❖ Family caregivers experiences of care at the end of life

Themes

Nurses' Knowledge and Perception about Palliative and End-of-Life Care

There is a range of understandings of palliative and end-of-life care among nurses in

Nigeria. This is evident in a study of 100 nurses' perceptions of palliative care in South-Western Nigeria by Fadare *et al.* (2014), where results show that 71.8% of the respondents said that palliative care is about pain medicine, 55% felt that it is about geriatric medicine, 90.2% said it is about active care of the dying, and 64.6% said it is synonymous with rehabilitation. These results raise concerns about the level of knowledge of nurses about palliative and end-of-life care since a significant proportion (46%) of the respondents have had more than ten years of experience working with patients with palliative and end-of-life care needs (Fadare *et al.*, 2014). Kassa *et al.* (2014) in their study on the assessment of knowledge, attitude, and practice, and associated factors towards palliative care among nurses working in selected hospitals in Addis Ababa show that the majority of the respondents (76%) had poor knowledge of palliative care. This finding reflects a study in Kenya by Machira *et al.* (2013) in which the majority of the nurses (93%) reported no knowledge of palliative and end-of-life care. In a qualitative study among nurses in Lesotho by Kell and Walley (2009) some nurses described palliative care as chronic care, while other responses included the following:

*"It is care given to a patient at home."
"I think it's the care that is given for HIV-positive patients, going together with TB."
"With the palliative care, I don't know anything" (Kell and Walley, 2007 p.3)*

The latter study further shows that knowledge of palliative and end-of-life care is training dependent because two of the nurses who received palliative care training were able to define palliative care like the WHO definition (Kell & Walley, 2009). Similarly, Dekker *et al.* (2012) report that 9 of the 11 nurses in their study had no palliative care training and were unable to articulate what palliative care is; rather they made references to the care only of patients diagnosed with cancer.

Nurses Experiences of Care at the End of Life

Three studies (Bam & Naidoo, 2014; Gysels *et al.*, 2011; Van Rooyen *et al.*, 2009) show that some nurses experience positive feelings when caring for patients at the end of life. Bam and Naidoo (2014) reported that some nurses express feelings of joy whenever they help or care for the patients, while Van Rooyen *et al.* (2009) reported that nurses feel a sense of fulfilment when caring for terminally ill patients and supporting their families. Supporting the bereaved family to deal with loss and grief is a positive experience expressed by many nurses (Gysels *et al.*, 2011). However, some nurses felt concern over the pain and suffering of the patients and their family members (Van Rooyen *et al.*, 2009). Smit (2005) asserts that nurses experience a sense of futility while caring for patients, involving a sense of helplessness and a belief that they cannot change the situation. This is also evident in a study by Dekker *et al.* (2012) which shows that most patients (46%) experience severe pain in the last month of their life. However, Gysels *et al.* (2011) observe that the lack of effective pain management was largely due to a lack of standards in practice, knowledge, and resources. The following response shows how helpless nurses can feel when delivering care at the end of life:

“... there is nothing I can do to help this guy - he’s going to die. I think nurses are these days only nursing for the mortuary.” (Smith, 2005 p. 25)

The above statement clearly shows what nurses are experiencing when caring for patients at the end of life in a resource-constrained context. This experience of futility during the dying process is usually aggravated by the nature in which the patients are admitted, and their socio-economic status as suggested by Bester *et al.* (2006) that patients are re-admitted in a debilitating condition. And the pace of the dying process is more rapid in patients with lower socio-economic status than those with higher socio-

economic status because of their poor nutritional state, difficulty in paying fee-for-service and lack of access to treatment. However, nurses with experience and prolonged exposure to palliative and end-of-life care on hospital wards show more support and care to dying patients when compared with those with fewer years of experience (Bam & Naidoo, 2014).

Nurses Emotional Stress when Caring for the Dying Patients

Four studies (Bester *et al.*, 2006; Gysels *et al.*, 2011; Smit, 2005; Van Rooyen *et al.*, 2009) reported that death and dying are few of the hardest things that human beings face, while the emotional stress affects the dying patient and all those around him including healthcare professionals. A study conducted by Van Rooyen *et al.* (2009) in South Africa revealed that many nurses involved in the care of dying patients with AIDS report being emotionally drained due to the suffering imposed by the disease and the dying process. There are many instances where families are reported to abandon patients; this is due to a variety of factors including stigma that surrounds AIDS, costs of caring or inability to deal with suffering caused by the disease, inducing feelings of helplessness, anger, frustration, and depression (Van Rooyen *et al.*, 2009). The following nurse’s response clarifies that:

“I’ve experienced that sometimes you have to phone to remind them, hullo! One of your relatives is here; can you please come in and visit?” (Van Rooyen et al., 2009, p.6).

Another study in South Africa by Smit (2005) shows that providing care to terminally ill especially HIV patients is highly taxing mentally. The patients are helpless and demand more time-consuming care. In addition, some patients are not appreciative and are disrespectful toward the nurses caring for them, there is a negative perception of members of society towards nurses caring for HIV patients, and lack of seriousness in the approach of HIV/AIDS management by the

government (Smit, 2005). Emotional demands of caring resulted in loneliness, depression, and isolation (Gysels *et al.*, 2011). Other compounding factors that are occupationally related and found to increase nurses' emotional stress as explained by Smit (2005) include decay of hospital infrastructure, insufficient medical equipment and understaffing. He also added that there is an increased number of patient admissions in overcrowded wards with a nurse-patient ratio of 1:15 and a task shift – nurses working as doctors, pharmacists, and social workers.

Bester *et al.* (2006) conducted a qualitative research study using in-depth interviews to explore and describe nurses' experience of the dying process of terminally ill AIDS patients in South Africa where ten nurses expressed powerlessness because nursing care can only support and not cure the terminally ill AIDS patient. The following response is an example: *“And your objective at that stage is to do everything we can do. It is as if it just doesn't help. So, it's very difficult”* (Bester *et al.*, 2006, p. 47)

Barriers to Palliative and End-of-Life Care Provision

Several challenges to palliative and end-of-life care provision were highlighted in five studies (Bam & Naidoo, 2014; Bester *et al.*, 2006; Gysels *et al.*, 2011; Smit, 2005; van Gurp *et al.*, 2015) these include: socio-economic burden, restricted access to adequate medical-technical palliative care and poor or non-implementation of palliative care policies. However, families are also facing hard times over the fee-for-service delivery system and mutual dependency on the family's resources. There is a lack of palliative and end-of-life care knowledge and communication skills from the nurses which are complicated by the unavailability of and lack of accessibility of opioids to treat patients' pain. Nigeria and most SSA countries have three levels of healthcare system, namely primary, secondary and tertiary levels, but the systems suffer a lack of funding by the government. Consequently,

palliative and end-of-life care resources are only found in some tertiary hospitals (van Gurp *et al.*, 2015).

Evidence shows that some nurses are reluctant to identify their religious faith in care settings; instead, they remain neutral in exploring patients' beliefs even though religious beliefs strongly influence people's perceptions of dying in SSA (van Gurp *et al.*, 2015). There is a barrier to meeting the spiritual needs of dying patients in hospitals, so dying at home was preferred by most patients and their families. As a result of that, they put pressure on nurses requesting discharge (Bester *et al.*, 2006). Therefore, education for patients and their families is essential in order to accept the serious situation and prepare for it. Smit (2005) stated that some nurses' families or significant others are also barriers to palliative and end-of-life care provision particularly to terminally ill HIV/AIDS patients because of their overwhelming concerns about their being exposed to HIV while providing care. One of the nurses gave the following account of her husband's concern:

“He would constantly ask me, are you making sure that you are protected when you work with patients? How many AIDS-people are in your ward? And so on. He's sometimes so paranoid about my safety - I know it is because he loves me, but sometimes he shows so much anxiety that I become stressed out”. (Smit, 2005, p. 25-26)

In another qualitative study on the experiences of nurses of palliative care patients, Bam & Naidoo, (2014) explore and describe the lived experiences of nurses caring for patients with terminal HIV illness in a level one district hospital of South Africa. The results show that the cost of care and overwhelming demand for nurses due to care workload and staff shortages hinder the outcomes of palliative care provision. This is similar to a study by Gysels *et al.* (2011) that end-of-life care is a significant physical and socio-economic burden on caregivers. These include physical

consequences of caring for someone with end-of-life care needs in the form of exhaustion and pains after patients care and role reversals, where elderly parents care for their adult children, as well as catering for the needs of their grandchildren. Low levels of support from other community members result in a social burden of end-of-life care for caregivers. Funeral costs were also mentioned as a large economic burden on caregivers. While emotional stress, lack of hospital resources such as beds, medicines and staff shortages affect healthcare professionals.

Nurses' Perceptions about Dying

The perception of what is referred to as good death when an adult died as compared to a child's death was reported by Van Rooyen *et al.* (2009), that it is more natural and better for adults to die than children. Although some of the respondents were uncomfortable with the death of children, they still viewed death as God's will because nothing could be done to prevent its occurrence. In a qualitative study on telemedicine's potential to support good dying in Nigeria by van Gurp *et al.* (2015), the results show that dying with one's dream accomplished and being reconciled with God and people is perceived to be a good death by some of the participants. While others said that good death is the consequence of brief illness that leads to death without wasting family resources.

According to Bester *et al.* (2006), some nurses, on the one hand, believe that medical treatment is futile and prolongs or complicates the dying process. While some of the nurses, on the other hand, have a contrasting opinion and said that medical treatment should receive attention as it increases hope and reduces suffering, thus leading to a good death. They suggested that investigating the nurse's experience of meaning and purpose while nursing dying patients and understanding their roles within the multidisciplinary team during this process will help to improve the quality of care at the end of life (Bester *et al.*, 2006).

A systematic review by Gysels *et al.* (2011) suggests that when a patient dies as a result of

HIV/AIDS, he or she is said to have lost ancestral status and is denied a befitting burial, thus leading to a private funeral. And the prospect of such burial affects their dignity and causes anxiety to the relatives, complicates grief and negatively influences bereavement. van Gurp *et al.* (2015) reported that providing adequate information on life-threatening illnesses such as HIV/AIDS to relatives is complicated by taboos because of the direct effect on the dying patient, grief process and bereavement. This is primarily due to people's awareness of the moral discourse and biomedical explanation of the mode of transmissions of the disease.

Family Carers Experiences of Care at the End of Life

Death among patients with terminal illness causes an existential crisis affecting emotions and perceptions for both patients and families. Family members often assume new roles and supportive responsibilities as caregivers; they become exhausted and thus need professional services and support (Iranmanesh, Abbaszadeh, Dargahi, & Cheraghi, 2009). It is evident that families of patients at the end of life always prefer to be with their family member, want to be informed about their patient's condition, be assured of his comfort, and receive support from healthcare professionals (Andershed, 2006; Reisetter & Thomas, 1986). Therefore, nurses need professional skills and attitudes to care for and preserve the dignity of dying patients and their families, as they need active informational and emotional support from nurses.

Patients and their caregivers in South African and Uganda reported several challenges at the end of life as identified by Gysels *et al.* (2011), these challenges include lack of information regarding symptoms, symptom management, and disease etiology, as well as lack of information on disease progression and treatment. Onyeka (2011) reported that healthcare professionals in many cases censor their information giving to patients and family carers in an attempt not to hurt them with sad or bad news. This practice of trying to shield

patients and their family members from the reality of the situation is common in most developing countries. The determinants of attitudes toward death and dying encompass cultural, societal, philosophical, and religious belief systems as well as a personal and cognitive framework (Stanislav, 2015).

Families are affected by the patients' illness, and it is important to involve them in the care (Wallerstedt & Andershed, 2007), but some nurses do not interact with the patient's family (Bloomer, Endacott, O'Connor, & Cross, 2013). When family members are not isolated from the dying family member, grief and mourning are more easily resolved (Reisetter & Thomas, 1986).

Conclusion

None of the studies primarily address nurses' experiences and understanding about nursing care of patients at the end of life. Only one study (Smit, 2005) focused on nursing care, but specifically, patients with HIV/AIDS, other patients with palliative and end-of-life care needs were excluded. Preserving the quality of life of a patient with a terminal illness is perceived to be the role of the nurse (Bam & Naidoo, 2014). There is a need to understand how nurses currently deliver their nursing care to patients at the end of life without pre- or post-registration education in palliative and end-of-life care in Nigeria, before appropriate ways of addressing the gap in knowledge can be devised.

The review reveals most of the studies were centred on HIV/AIDS, even though other conditions have similar needs for palliative care such as cancer, renal failure, heart failure, diabetes mellitus, liver diseases, and chronic respiratory diseases. However, most of the

studies were conducted in South Africa and based on the sample characteristics and other limitations such as sample size and study settings, and the results are not generalisable beyond the participants and the study settings.

One of the two studies conducted in Nigeria (Fadare *et al.*, 2014) uses a questionnaire to explore nurses' knowledge and attitudes towards palliative care in one of the tertiary hospitals. The study lacks the ability to seek a deeper understanding of the phenomena in question because it assessed only the knowledge and attitudes of nurses about palliative care. Therefore, exploring nurses' experiences of patients' care at the end of life in hospitals using qualitative methods will provide a better understanding of palliative and end-of-life care, and inform policy, practice and further research.

All the articles reviewed were congruent with the following: that findings of palliative and end-of-life care services are far from optimal. The majority of nurses in the studies had no prior palliative care education, indicating a lack of emphasis on palliative care at pre-registration level and within clinical practice. Information needs of patients during end-of-life care were commonly not met.

The studies recommend in-service training and education for caregivers. Enhancing communication skills of nurses when caring for patients at the end of life, appropriate skills development, education of student nurses on nursing care of patients at the end of life, update courses for registered nurses and more research on nurse's experiences of nursing care of the terminally ill patients. As well as research into palliative and end of life care.

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