

ORIGINAL RESEARCH

A poststructural glimpse at the World Health Organization's palliative care discourse in rural South Africa

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ABSTRACT

Introduction: The World Health Organization (WHO) defines palliative care in terms of three constructs of care, namely, physical, psychosocial and spiritual, for a person who has a life-limiting illness. Life-limiting illness from WHO's perspective signifies and qualifies a patient for palliative care. Poststructuralism offers insights into how language constructs reality and sets up the limitations and possibilities of palliative care when it is practiced in a rural and remote area of the developing world, such as in South Africa.

Methods: The study employed the qualitative method of photo-elicitation, which was used as a launching point for one-on-one discussion around photographs taken by participants. The participants, four palliative care nurses and two home-based care workers who work in rural homes in KwaZulu-Natal, South Africa, were purposively selected to provide rich information based on their personal experiences.

Results: Defining palliative care in terms of a life-limiting illness may present challenges in rural areas where there is limited access to the diagnosis and prognosis of an illness. Limiting care to those with a life-limiting illness may not be culturally appropriate. Physical care did not prove to be a common care requirement and cultural care, which is not included in the WHO palliative care discourse, was common and necessary.

Conclusion: The WHO palliative care discourse can be thought of as not presenting a neutral way of looking at care and an irresolvable dichotomy may be set up in traditional rural, isolated areas. The question emerging is whether palliative care can be



offered if it is not known whether an illness is life-limiting or not? Further poststructural work, in conjunction with exploration of palliative care practice, is required in this context.

Key words: discourse, palliative care, poststructural, South Africa, World Health Organization.

Introduction

This article is premised on the idea that language, as a medium of communication, whether oral or written, is fuzzy, arbitrary and confounding¹. What is said and what is written is often interpreted in unexpected ways, independent of the communicator's intentions and meanings. It is assumed that the ability to structure and use language sets human beings apart from other life forms. A post-structuralist thinker claims that the 'self' (or a person's reality) is structured and defined in a context of language and hence language reflects a certain way of thinking and of looking at the world².

For persons working with patients requiring end-of-life care, communication is not only necessary, it is a sensitive and vital means of caring. Talking and practices of care are ways in which palliative care is both constituted and enacted. Through the spoken word, caregivers are informed of patients' health needs, desires and complaints, and in turn caregivers can convey information and empathy to the patient and their family. Using a poststructuralist lens, speech, policies, definitions and curricula are referred to as discourses. The notion of discourse can be viewed as a general idea that languages are structured according to predictable patterns that people's utterances follow when they take part in different domains of social life, familiar examples being 'medical' and 'political' discourses³. Framed differently, discourse can be viewed as a particular way of talking about and understanding the world.

The importance of language in palliative care is illustrated in literature and Carol Tishelman believes that while many people may feel palliative care providers focus unduly on semantics, the terminology used does have implications for

how palliative care is conceptualized, organized and provided⁴.

This article draws on findings from a larger study on palliative caregivers' experiences⁵. The findings from the study are used to review the World Health Organization's (WHO) definition of palliative care against participants' experiences in remote, isolated and rural areas of South Africa. Furthermore, it provides an opportunity to read the experiences from a poststructural perspective. Poststructuralism has an inherent interest in language and in its deployment to represent reality and offers a way to gain insight into a phenomenon that is shaped by a variety of factors⁶. The value of poststructuralism is that it allows for multiple interpretations of a situation and allows for contradictions, incoherencies and inconsistencies to be factored into explanations. A poststructuralist perspective acknowledges that language and words can confound, and allow unanticipated surplus meanings⁷.

What follows is a brief review of palliative care and a review of the WHO definition of palliative care. It illustrates that while the WHO definition may be meaningful in well-resourced contexts in the developed world, it can cause challenges in rural developing-world contexts, such as in South Africa, where diagnosis and prognosis of illness are not readily available and where people follow traditional ways of caring that are unrelated to modern medicine.

Palliative care discourses

Palliative care is a concept which developed in the UK in the 1970s and largely grew from the work of Dame Cecily Saunders⁸. She and many of her colleagues felt that patients in hospitals, who faced end-of-life due to an incurable illness,



were relatively neglected by healthcare workers – not because they did not care, but because nurses and doctors were uncomfortable in dealing with death and dying. Beyond the walls of a hospital and clinic, society's discomfort with death was an anxiety that took the form of avoidance, described as 'death-denying'⁹. Palliative care was initiated to remove the veil around dying and death. It allowed for communication of information around patients' prognosis, and enabled patients' and families' involvement in decisions related to on-going care. More importantly, it advocated that that death would not be regarded as a failure of care. The principles of palliative care are based on holistic care which implies that care providers aim to see the patient beyond a patient-identity and provide and/or coordinate caring which is humane, sensitive and necessary. Due to the positive outcomes and successes of early programs, palliative care services have grown throughout the world, and palliative care training is available in undergraduate and postgraduate medical and nursing training institutions¹⁰.

Emerging out of the foundations established in the UK, the WHO also appropriated and adopted palliative care as a viable intervention in the care of the terminally ill. From the WHO perspective¹¹:

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-limiting illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The WHO's palliative care discourse thus associates palliative care with a life-limiting illness and with three constructs of care (physical, psychosocial and spiritual). There is a clear sense that the quality of life of a patient with a life-limiting illness is important until death occurs. Quality of life, from this perspective is promoted through pain reduction, accurate diagnosis, and appropriate treatment of physical, psychological, social and spiritual needs. There are a number of assumptions that can be discerned from the WHO notion of palliative care. First, that those who are served by

palliative caregivers are indeed facing a life-limiting illness. Second, that every possible intervention, from prevention to possible cure, has been attempted and that the assessment was rigorously undertaken by trained healthcare professionals using sophisticated testing and remedial procedures. Third, it supposes that healthcare professionals have the knowledge, capacity, and inclination to deal with psychological, social and spiritual problems. Since the WHO is an influential body, its articulation can be regarded as influencing the way in which palliative care is conceptualized and practiced. But is it possible for the WHO definition of palliative care to be applied to and realized in every context? That is the question explored in this article by glimpsing palliative care practice as experienced by caregivers in rural areas of South Africa.

It is not surprising that in South Africa an approach to palliative care was influenced by the world body. As a country with the highest number of HIV infected persons in the world, serious levels of TB and malarial infections, palliative care was instituted to deal with the growing number of people facing death and in need of healthcare during the final stages of life. Many of the recipients of palliative care seek medical intervention when it is too late for remedial interventions, and due to poor infrastructure, an unequal distribution of healthcare services, and a shortage of qualified healthcare workers, the care of patients who face a life-limiting illness has been offered by organizations such as hospices which use a model of care delivery known as the 'integrated community-based homecare model'¹². In this model, healthcare givers, including professional nurses, semi-skilled and volunteer caregivers, work in remote, rural areas where there are no clinics or hospitals. The experiences of healthcare workers provide insight into the translation of the WHO notion of palliative care in a traditional rural space.

Methods

The study was qualitative and exploratory with the aim of documenting and analysing the experiences of palliative care providers. A qualitative approach, as in this case, is characterised by methods of observation, interview and



photo-elicitation techniques with a small sample of participants. A full review of the study method is available in another publication⁵.

Setting

The study site was rural homes in KwaZulu-Natal, South Africa. The prevalence of HIV disease in the study setting is the highest in the world. Many patients have never ventured into cities and make their living through subsistence farming. In some areas, no electricity is available and water is sourced from rivers or community taps shared by households. Literacy levels are low and there is a strong affinity to traditional medicine. For many patients, the care offered by palliative caregivers is the only intervention available.

Sample

The sample was four palliative care trained nurses and two home-based care workers (local community members, not professionally trained) who are supervised by nurses with professional credentials in palliative care. Those invited to partake were deliberately chosen as they were considered to be rich sources of information.

Data collection

The researcher explained to participants that the aim of the study was to find out more about their experiences of their daily work in providing palliative care in patients' homes. The study method employed photo-elicitation in which participants were asked to take photographs as reference points to illustrate their experiences in providing palliative care in rural homes. The participants then discussed these photographs in subsequent one-to-one interviews with the researcher, a technique known as auto-driving¹³. The photographs were not used as a direct source of data but rather as a form of 'production data', and the interviews were a primary data source¹⁴. The researcher looked at each photograph together with the participants and asked each one to explain why they had taken that photograph. The role of

the researcher was to prompt and encourage discussion around photographs and to ask for clarification.

Data analysis

In this study, an analysis involved looking at themes which 'naturally' arose from data rather than fitting data into predetermined categories. Analysis involved five steps: (i) familiarization and emersion; (ii) inducing themes; (iii) coding; (iv) elaboration; and (v) interpretation and checking¹⁵.

Ethical considerations

Ethical clearance was obtained from the Humanities and Social Science Research Ethics Committee of a higher education institution (HSS/0079/10D). Participants were volunteers and were assured of confidentiality and anonymity. This was achieved through the use of pseudonyms and by omitting specific details that may lead to accidental discovery of both patients and participants.

Results

Findings pertinent to this article are limited to discourses of 'life-limiting illness' and of 'care' (physical, psychosocial and spiritual) in a rural context.

Discourses of a life-limiting illness

The WHO palliative care discourse relies on a diagnosis (What is the cause of the illness and is this illness expected to limit life?) and also relies on a prognosis (How long is the patient expected to live?). In a rural area, without access to hospitals, clinics, doctors or equipment, a participant could encounter a situation where she was unsure of the diagnosis or prognosis of an illness, and this is illustrated in data:

We are giving them all the same care but you cannot identify the ones that are going to die because sometimes you find a



very ill patient and miraculously they just recover if they get food.

In this instance, the participant encountered a situation in which the patient unexpectedly recovered from a life-limiting illness. In the absence of a medical explanation, the recovery was interpreted as a miracle. One explanation is that the diagnosis was ambiguous and therefore an apparent cure was ascribed to a miracle. The situation becomes more complex as two possibilities exist: that the patient had a life-limiting illness (such as AIDS in this context) or a life-limiting condition (such as starvation). The question that arises is: Should the caregiver regard starvation as a life-limiting illness with recourse to palliative care? In another instance a participant appeared to be uncertain of prognosis:

We are not sure who will die and who will live. Even if you are a nurse, even with all your experience, you cannot say this one will die or this one will live.

The nurse or home-based care worker was confronted with a situation where she was unsure of when to offer aspects of palliative care (such as telling that death approaches) as she did not know which patient was expected to live and which one was expected to die. To complicate matters, cultural practices and mores also influenced the way they approached care. For example, it is not a cultural norm in Zulu society to limit care to a specific type of patient (the patient with a life-limiting illness):

We don't do it as you guys are doing it, you see? It's just we don't say, 'OK, because you are dying we have to let you die peacefully or alternatively we are not letting you die we are trying to save you'. It doesn't happen like that... We care for both the ones who are dying and the ones who are not dying.

White people must look after their dying as it is how they do it. But we must be available for whoever needs us — that is how we do it... White people have got their own ways to comfort their ill. White people have got words that they use to tell a person they are dying. We don't have a word that means to care for the dying... In Zulu you take care of the

living ones as well... We use a word Ukumakekela which means to care for all the ill.

Advocating care for a certain type of patient and not care for all seemed to be at odds with a Zulu caring ethos which offers care for all.

Discourses of care

The WHO discourse considers three types of care including physical care. In principle, participants agreed with the WHO notion of palliative care as pain reduction and symptom control:

Palliative care is about pain and symptom management. In palliative care we can be experts in pain and symptom management but in our daily practice we are mainly supporting care for all the patients on all levels because once they leave the hospital they will need somebody who will encourage them to take the medication.

This participant implies that her main role in palliative care is to support patients to adhere to medication (in this context probably antiretroviral therapy or anti-tuberculosis therapy) not to relieve pain and other symptoms. The conclusion to be drawn is that physical care and skills relating to provision of physical care were not of paramount importance when compared with other aspects of care, such as cultural care. Participants discussed the cultural needs of their patients at length:

Even in peoples' homes you will find to use a certain paintings to show that we are mourning. After one month we have to slaughter a goat to cleanse the family. The people then are allowed to attend the social gathering but you, as a woman you have to mourn the whole year. It used not to be the black clothes, the black clothes it came with the Western.

There are a great number of our African people who now go to Shembe religion [an African-initiated church founded by Isaiah Shembe in 1910 with approximately 4 million members where polygamy is permitted and animal sacrifice is



practiced in religious ceremonies] because it allows them to practice their own Africa cultures like slaughtering, like wearing traditional attire, like having polygamy and using traditional medicines.

The data indicates that practices appropriated from Western culture and adherence to Christianity could contradict the cultural beliefs, especially the rites and rituals that needed to be performed during the mourning period. From rural patients' perspectives the WHO's palliative care discourse can be interpreted as marginalizing particular articulations of cultural care because it assumes that its notion of care, exclusively informed by developed contexts, is universal and uncontested.

Discussion

A main objective of the WHO palliative care discourse is a reminder and an obligation to healthcare caregivers not to abandon or neglect the care of patients who face death. It is for this reason that 'life-limiting illness' is emphasised in its definition of palliative care. It also implies that patients require holistic care that can go way beyond care of their physical needs. It is the cloudy extension of care beyond the physical that opens its discourse to multiple interpretations and meaning making, and the reason that palliative care gets practiced in unanticipated ways.

Findings from this study indicate that there can be challenges around a palliative care discourse which stipulates 'life-limiting illness' to qualify for care as neither a diagnosis or prognosis of an illness may be available due to an inadequate health provisioning system. Additionally, in this context, the life-limiting discourse runs counter to Zulu cultural norms of caring as an inclusive one, and there cannot be a rationing or apportioning of care to some while others are excluded from the circle of care. In this rural setting, there is a wide distribution of individuals in need of care. Without access to healthcare facilities, it may seem unreasonable to inhabitants that care is only available to those with a life-limiting illness and those with an illness that can be cured are excluded. So,

home-based palliative caregivers have had to adapt and respond to the desired needs of their patients. They have had to include dimensions such as adherence counselling, culture, religion and spiritual beliefs to deliver a credible and acceptable service. Participants' experiences expose not only the way a context shapes practice, but also address a silence in the literature elsewhere in Africa which is widely supportive of the WHO palliative care discourse.

Interpreted purely from its definition, the WHO discourse restricts care to a subset of patients. Such a discourse may simultaneously discriminate against individual, idiosyncratic and perhaps indescribable needs of patients or may be challenged and adapted to context. One reason for these unusual outcomes is because the WHO palliative care discourse does not represent a 'neutral' reflection of the world. In this instance, the discourse favours doctors working in hospitals who will know, with a reasonable level of certainty, a patient's prognosis and diagnosis. It is therefore ideal for a smaller group of healthcare professionals, and problematic for semi-skilled home-based care workers. Any discourse, by its nature, causes a reduction of possibilities and all possibilities that a discourse excludes are termed by Laclau and Mouffe as 'the field of discursivity'¹⁶. For example the WHO palliative care discourse excludes many types of care, such the educational needs of a sick, young child.

The field of discursivity is understood as everything outside a discourse but because a discourse is constituted in relation to an outside it is always in danger of being undermined by things which are on the outside. The poststructuralist would pay attention to what types of care are not included in the WHO palliative care discourse with an aim of demonstrating contradictions and paradoxes. It would point out that there are perhaps tangential discourses, such as 'Zulus care for everyone and not just those with a life-limiting illness'. Other tangential discourses, which seem excluded by the WHO palliative care discourse in rural settings may include issues such as legal issues (a sick patient may wish to draw up a will).



Discourse around dying and death is not surrounded by a total societal consensus around the aims, objectives of palliative care⁹. For example, some argue that palliative care is required because society is death-denying while others dispute a 'death-denying theory'⁹. What palliative care is and why it is required continues to be debated. O'Connor and Payne propose that discourse analysis has the potential to contribute to new ways of seeing palliative care practices through deconstruction of meanings and advocate that discourse analysis may be useful when exploring how different versions of reality are produced negotiated and evoked in conversations and in texts¹⁷. They also believe that a disadvantage of discourse analysis is that because the analysis is focused on language and uses text and talk, the approach may be too remote from clinical practice¹⁷:

It may be difficult to infer issues around how to change behaviours because, arguably texts merely describe existing phenomena rather than offer transformative possibilities.

Perhaps, a more generous reading of poststructuralism is that it does offer solutions but not in the way of direct, predictable solutions by way of recipes. By exposing contradictions and vulnerabilities to multiple interpretations, it prepares to accept that the unexpected, the unconscious and the marginalized inhabit the same space as the expected, conscious and included. This realization can be the first step of problem solving. Thus, a poststructural glimpse at documents and discourse pertaining to palliative care in rural areas of South Africa (for example curriculum documents, clinical guidelines and patient-information sheets) may be valuable to ascertain how palliative care discourse and written texts could set up an unresolvable dichotomy in this context: who do we offer palliative care to or not to? More importantly, it obligates a dismantling of the dichotomy.

Limitations

The aim of this study was not to present validated, generalizable, reliable data. The study employed an idea of generativity where the reader is invited to apply findings to their own context¹⁵. The sample size was small and the

experiences illustrated may not represent the experiences of other caregivers in this context. The photographs used to elicit discussion and analysis in this study, are not neutral, and interpretations are generated by the researcher. The data produced was not used for its truth value but for its theoretical possibilities and to dialogue an important intervention deployed to provide quality of care of patients who face an illness which may threaten their life.

Conclusion

The article demonstrates that the idea of palliative care, as developed in the UK and the discourse around who needs it, is reasonable in a context where a doctor has access to a diagnosis and prognosis. In rural South Africa, such a discourse may set up a dilemma: can palliative care be offered if the caregiver cannot know what is wrong with the patient? The WHO discourse may depend on the availability of a doctor and as such discourse could potentially act to marginalize the isolated and vulnerable without access to doctors. The WHO palliative care discourse may inadvertently lead to a focus on physical care and types of care may be relatively neglected as they lie outside the definition. If it remains unchanged, the palliative care discourse may limit care to patients who have a life-limiting illness in contexts where this may not be appropriate.

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