Imagining a Post-structural Curriculum for Palliative Care: Reflections on Rural Healthcare Workers' Experiences in KwaZulu-Natal

Nyna Amin
Laura Campbell

Abstract

This paper, based on the experiences of healthcare workers in rural parts of South Africa, offers an imagined curriculum for palliative care and its impact on patient care. Palliative care is a medical intervention for a patient facing death due to an incurable disease, or poor health prognosis. In this study, many of the patients receiving palliative care live in impoverished homes and have had minimal access to healthcare. Thus there is uncertainty about whether they will die because of a life-limiting illness, or because sophisticated medical care is not available. An additional anxiety is the tensions between their spiritual beliefs and cultural practices and the palliative care approach. Six healthcare workers, four qualified and two unqualified volunteers cared for patients in their homes. Photo-elicitation techniques were used to generate data during interviews. The caregivers' experiences of home-based care made apparent the limitations and ineffectiveness of a curriculum that excluded patients' spiritual beliefs and cultural values in respect of healthcare, dying and death. A curriculum, reconceptualised through a post-structural lens, we argue, will not only respond to the needs of patients and caregivers, it is also a more resilient means to capture the simultaneous, yet different realities within the same context or across multiple contexts.

Introduction

What kind of a curriculum is suitable to prepare healthcare workers to care for persons who, presumably, are facing death due to an incurable disease, or poor health prognoses in South Africa? This is an important question considering the high rates of mortality linked to HIV and AIDS and drug resistant tuberculosis in recent years (Avert 2009). There are many persons with a life-limiting illness who, despite the poor prognoses, are still in need of physical and psycho-emotional care. This paper, based on findings from a study about a small group of palliative care workers' experiences in patients' homes (Campbell 2012), offers ways to imagine a palliative care curriculum framed by three questions: who should be cared for, who should provide palliative care and what should be the roles of palliative care providers?

The principles that underpin the imagined curriculum emerged from gaps between the prescribed and the enacted curriculum experienced by palliative caregivers in rural parts of KwaZulu-Natal. For instance, the prescribed curriculum was silent about care in conditions of abject poverty, profound neglect and absence of medical facilities. It is not surprising, therefore, that caregivers discovered that they were ill-prepared for the socio-cultural practices and the spiritual beliefs of their patients which challenged the prescribed approach to palliative care. The healthcare workers, some of whom were semi-skilled volunteers, were seen as bearers of death. Many patients refused to discuss impending death and sought pain-relief medication from the healthcare workers who were not qualified to dispense medicinal drugs. The curriculum, it appeared, did not factor in the peculiarities of a developing context to provide appropriate care (Campbell 2012). Consequently, we propose the use of post-structuralism as a lens for curriculum designers to acknowledge and to take into account the uncertainties, challenges, insecurities and dilemmas which caregivers are likely to encounter in rural spaces.

The focus on curriculum is crucial because a curriculum constitutes and prescribes the totality of actions of a practice. The contents of a curriculum are captured through language with words constructing, as in this

case, the realities of palliative care practice. Language, from a post-structural perspective, is open to multiple interpretations, creating ambiguity. Post-structuralism is often associated with the 'linguistic turn', a term coined by Bergmann (1964:177), due to an inherent interest in language and its deployment to represent reality. Meaning that is constructed through language, an order of symbols arranged in predictable patterns, gets subverted by cultural, spiritual and social influences resulting in discursive, elusive and obfuscated interpretations because words do not represent common understanding. Expressed differently, language constructs multiple realities that are peculiar and particular to the interpreter as she is influenced by history, culture and locale (Anderson 2003; Williams 2005). Language, therefore, is not about capturing the certainty of reality; it is instead, a disrupter, and an interlocutor introducing multiple paths, each representing a different meaning. For example, the notion, 'rural' is open to interpretation. For some individuals it means sparseness, for others, remoteness, or a combination of sparseness, remoteness and lack of resources. So it could be geographic, demographic, under-development or a combination of one or more of these factors. Under these circumstances, only rich description can reveal the reality. Without description, the term 'rural' is characterised by undecidability, leaving it open to multiple interpretations. From a post-structural perspective, multiple interpretations are not regarded as disruptive, but as vital fragments that reflect complexity (Campbell & Amin 2012). We argue for reconstructing the curriculum by exploring how the language of the prescribed palliative care curriculum constructed a reality of care that was inconsistent with and contradicted the realities of palliative care in practice, because it assumed that all contexts are alike.

In South Africa, the care curriculum has been influenced by a European model for home-based care. Palliative care, a specialized form of nursing of persons whose health prognoses are poor, and for whom death is imminent, emerged in the early 1970s as a response to perceptions that patients who faced death were being neglected by healthcare professionals and, therefore, had unrecognized, unmanaged, severe and frequent symptoms related to the silence surrounding dying and death (Doyle, Hanks & McDonald 1998). It was also a response to a pervasive assumption that the 'death denying' culture was symptomatic of a failure to care for end-of-life patients (Ariès 1974; Zimmermann 2007). Thus palliative care emerged with three inter-connected aims. The first was to ensure that specialized and

holistic care was provided to individuals, for whom every curative attempt had been made to no avail, the second, to enable patients and caregivers to access and participate in the discourses of dying and death as preparation for the inevitable for patients and their families, and three, to manage pain. Palliative care would, presumably, remove the shroud of uncertainty and reconcile the divide between patient and healthcare workers.

One can infer that the European model, which takes these three principles of palliative care into consideration, is based on the principle of certainty. In Europe, qualified medical doctors take all appropriate measures to provide holistic care, to manage pain and to make attempts to cure patients before making end-of-life prognoses. Only when there is no hope of prolonging life, is palliative care recommended. In essence it means that the physical, psychosocial and spiritual domains of patients' lives are the foci for palliative care (see e.g. the WHO 2012 definition).

In South Africa the situation is different. In the next section we discuss, in particular, the complexities and dilemmas emerging for caregivers because there is an assumption that physical, psychosocial and spirituals needs are common to all communities and individuals.

The Palliative Care Curriculum in South Africa

Palliative care is a fairly recent medical intervention in South Africa (Gwyther & Rawlinson 2007) with a course for professionally-trained palliative nurses developed by the Hospice and Palliative Care Association of South Africa (HPCA) in collaboration with the Foundation for Professional Development (FDP)[1]. The contents of the curriculum are discussed in this section and have been organized around three questions: what does the curriculum say about which patients should be cared for; who should do the caring; and, what are the purported roles of the caregivers?

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[1] This curriculum is not available on-line. It is only made available to nurses who attend palliative care training run as a collaboration between HPCA and FDP. The course is run as a 'distance', part-time course and lasts for two years. This paper focuses on four written manuals designed to accompany the course. It is noteworthy that the course includes lectures and practical, experiential learning at palliative care sites, such as hospices.

Firstly, regarding who should be cared for, the curriculum identifies the following individuals:

> Patients with a life-limiting or life threatening illness (Vol. 1:19, 2009) or
> Patients and their families for who care is no longer an option (Assessment guide:12, 2009).

The curriculum implies some knowing on the part of palliative caregivers about those they care for. The patients, from the impoverished socio-economic strata, have minimal access to healthcare and resultantly, do not have the benefits of technologically advanced medical scans and tests or treatments like chemotherapy and radiotherapy. Poor prognosis is not based on the certainty of diagnosis; instead palliative care is sometimes the first and only healthcare option. The diagnosis of 'incurable', it can be assumed, is arbitrary. Consequently, a patient can make a 'miraculous' recovery, or shun the care offered by healthcare providers or the rural community expects that anyone who is ill be attended to by the palliative caregiver irrespective of whether the illness is fatal or not. As a result, healthcare workers often face dilemmas not anticipated in the curriculum (Campbell 2012). In rural and remote areas of South Africa, the assumption that a patient has access to a skilled diagnostician, tests or scans or potentially curative therapy has already been established as a probability, which is often not available. This means that those identified for palliative care may not be threatened by a life-limiting illness. They could, for instance, be in poor health because of inappropriate nutrition or a curable condition (Campbell & Amin 2012). Palliative care workers are, therefore, not in a position to know whether those they care for are dying or what is causing the illness. They do not know if the illness is potentially curable or how long the patient will live.

Secondly, regarding who should be the caregiver, the curriculum prescribes well-trained, 'specialist' healthcare providers:

> Curing for patients and their families, for whom cure is no longer an option, is a rapidly developing area of medicine and nursing which requires specialist skills and knowledge (Assessment guide:12, 2009).

In the developed-world, in an effort to increase access to palliative care, models of palliative care include home-based care. Home-based care workers (HBCW) visit patients' at home. These HBCWs are generally trained, accredited and are supported by professional nurses and doctors (Delvin & McIlfatrick 2010). In South Africa, well-trained and well-supported home-based care workers may not be readily available in rural and remote areas. As a result palliative care in patients' homes has been offered by volunteer HBCWs who have unaccredited training and intermittent support from nurses or doctors (Uys & Cameron 2003; Defilippi 2005).

Thirdly, regarding the roles of caregivers, the curriculum describes the roles of caregivers as providers of physical, psychological, social and spiritual care:

> Palliative care is provided in order that that patient and their family receive optimal care at physical, psychological, social and spiritual care (sic) (Assessment guide:20).

The curriculum supports the World Health Organization's (WHO) definition of palliative care which signifies three specific constructs of care: physical, psychosocial and spiritual (WHO 2012). In a South African context, the community, family and patients' expectations of the roles of care-giving differ from those in a developed-world context. For example, rural African patients expect their caregiver to mediate the relationship between the dying patient and their ancestors, introducing an unanticipated cultural care role. Cultural care is briefly mentioned in the curriculum (six pages in total are allocated to cultural care and include brief, stereotypical descriptions of the cultural practices of Christian, Hindu, Jew, Muslim, Buddhist and Traditional African followers (Vol. 4:57-61).

The South African curriculum currently in use, if imagined (see Fig. 1), mirrors the model designed for developed contexts. It is a reproduction that ignores contextual specificities and complexities.

The application of a curriculum without due consideration to contextual peculiarities is problematic for the reasons discussed heretofore. The complexities of the South African context require translation into palliative care practice that is coherent with and works for the benefit of patients and caregivers. A curriculum for palliative care should include an element of uncertainty as some patients may have erroneously been offered

care in the absence of equitable, appropriate and sufficient healthcare provisioning.

Fig. 1 *Palliative care curriculum - a mirror image of the developed world curriculum*

When contrasted to their counterparts elsewhere, the varied experiences of the healthcare participants necessitate a curriculum that is informed by particularities which are unanticipated, ambiguous and uncertain.

As a post-structuralism view makes visible contradictions, variations, complexities, and uncertainties in practice and its experiences thereof, it would serve to influence curriculum design so that it is relevant for, and responsive to contextual differences, and makes it possible for uncertainty to be consciously integrated into design and enactment. The data elicited from palliative care workers will be used to imagine a responsive curriculum. In the next section we outline the methodology used to produce palliative caregivers' experiences in rural spaces of KwaZulu-Natal.

Research Methodology

The study was an exploratory, qualitative one with the aim of documenting and analysing experiences of caregivers who provided aspects of palliative care in rural patients' homes in relation to the curriculum which prepared

them for home-base care. The intention was to produce thick, descriptive data which is generally not feasible in large-scale studies. The data revealed details which would have been undetected in quantitative studies. Furthermore, because experiences are subjective, social methods that are commensurate with personal encounters between researcher and participants are relevant in a study like this one. The claims, resultantly, are not generalizable as findings apply to peculiar contexts and individuals. The notion of generativity (Vithal 2008), which leaves it to readers to decide to the extent to which the findings apply to their own context, may be more appropriate in this case.

Setting

The setting for the study was rural homes in KwaZulu-Natal, South Africa. Most of the patients attended to by participants presented with conditions associated with HIV and AIDS. Many of them had not travelled far from the area of their birth and had limited formal education. In this setting, poverty and starvation are rife, unemployment is high and many people live in makeshift, unstable dwellings. Electricity is not available and water is sourced from rivers and community taps shared by households. The prevalence of HIV is very high and many people do not have access to healthcare as the clinics and hospitals are situated far away from their homes, and transport costs are unaffordable. There is a strong affinity for traditional medicine and many people see a traditional healer before seeing a nurse at a clinic or a doctor at a hospital. For many patients, palliative care is the only medical intervention available.

Participants

The participants consisted of six palliative healthcare workers. Four, of the cohort of six, were trained nurses and two informally trained home-based care workers. The latter were volunteers from the local community, and were intermittently supervised by nurses with professional credentials in palliative care. The participants had all been trained in palliative care using the HPCA and FDP curriculum. Participants were deliberately chosen as they were rich sources of information. The participants were isiZulu speakers with insider knowledge and familiarity of the culture, beliefs and social mores of their patients. They were chosen because they were ideal candidates to explore

gaps between the curriculum that they were trained in and their experiences of palliative care in a rural context.

Data Production

The participants were made aware of the aims of the study, namely, to find out more about their experiences of a curriculum and of providing palliative care in patients' homes. The dominant study method employed was photo-elicitation in which participants were asked to take photographs to serve as reference points for subsequent data production strategies. The participants then discussed these photographs in one-to-one interviews with the researcher, referred to as 'auto-driving' by Mitchell (2008). The photographs were used indirectly to stimulate the production data during interviews, which were the primary sources of data for the study. During the interviews, participants were asked to explain why they took the photographs. The role of the researcher was simply to prompt, ask for clarification and to encourage discussion about the photographs taken.

Ethical Considerations

Ethical clearance was obtained from the social sciences research ethics committee of a higher education institution (reference number HSS/0079/ 10D). Participants were volunteers and assured of confidentiality and anonymity. This was achieved through the use of pseudonyms and by omitting specific details that could lead to accidental or unintentional discovery of the identities of both patients and caregivers.

Palliative Care Workers' Experiences of the Curriculum

The experiences of the healthcare workers are presented in terms of their views linked to the same questions asked about the curriculum: who should be cared for, who should provide care and the roles of caregivers.

Who is Cared for?

The curriculum that the participants were exposed to identified patients as

those who have a life-threatening, life-limiting or incurable illness. Participants noted that in the rural context where they visited patients in their homes, it was not always possible to know whether the patient had a 'life-limiting illness',

> Even with all your experience as a nurse, you cannot identify the ones that are going to die because sometimes you find a very ill patient and they just miraculously recover when they get food.

The recovery of the patient implies that the patient could possibly not have had a life threatening disease or illness. In another interview, a participant related how patients were often very ill because they were starving and that once nutrition was offered they recovered. The recovery was seen as a 'miracle'. Another reason for not knowing the nature of the illness is because she offered care to patients who had never seen a doctor and had no accurate diagnoses or prognoses. The palliative care curriculum did not prepare the caregiver for this scenario because the possibility was not considered. Participants also discussed that 'rationing' care to specifically labelled patients (those with a life-limiting illness) was a new and foreign concept in terms of their worldview:

> 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.

This participant drew a distinction between white (western) people's approach (you guys) and Zulu (African) people's approach to who is cared for. In her opinion, white people offer palliative care to those who are dying, whereas Zulu people offer care to both dying and not dying individuals. The distinctions between the dying and the not dying are erased as both groups are cared for in the same way with the same expectation of getting well. Language, in this instance, does not clarify the distinctions, and the prescriptions of the curriculum are ignored to make care relevant in this community.

> 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.

The data illustrates that offering care to some patients and not to all patients may be culturally inappropriate. Here we have an insight into the constitutive force of language – a practice (specific to the care of the dying) is not a reality because they 'do not have a word that means to care for the dying'. The limitations of the curriculum contradicted the cultural mores of the care givers who, as Zulu insiders, realized that their training ignored cultural dimensions of care. In a sense, the curriculum was experienced as a restricted one, only concerned with narrowed needs identified by the medical fraternity as necessary basics of care and ignorant of the desires and needs of the patients. It means that home-based care restricts the kind of care that poor persons in rural communities can access, echoing a similar argument made by Wedin (2010), in an educational setting, that a restricted curriculum restricts success.

Who Offers the Caring?

The curriculum, which was designed for nurses, expected nurses (as specialists) to offer care for the very ill and dying and did not consider a context where a nurse or a doctor were unavailable. Care, in this study, was provided by non-specialists HBCWs who had little formal training and poor access to support and advice. They were placed in stressful situations when they did not know how to react:

> Hey, look at this one {she is discussing a photograph of a patient}. I am scared.
> Can you see what this is? It is a sore on someone arm. This lady is very sick and I have never seen this thing before. It is rotting. It smells. I see sick people but this one is different, she cries when we clean it.

Another volunteer HBCW also describes fear and lack of knowledge around caring for a patient.

> I am frightened even to help her. I am frightened but it is my job. I have to do it … I am frightened of her disease. I don't know how she got this.

HBCWs' discussions provide insight into the fears of caregivers and the intensity of problems faced by both caregivers and their patients. A HBCW was faced with providing care for a rotting, smelling wound and she could not be sure of the cause of the wound. She expressed fear of putting herself at risk of being infected, or of causing pain. This situation hints at a lack of support for a HBCW; no one is readily available for advice or assistance, and adequate analgesia is not available to ameliorate the patient's agony. The nurses' curriculum did not prepare nurses to offer advice to and support HBCWs who are not trained. The data, in this instance, is reflective of the unknowns that circulate on the margins of a curriculum, and not having been encountered in the developed world, was not built into the local version of the curriculum.

The experiences of the caregivers reveals that the curriculum is not only restricted in the way Wedin (2010) describes it; it can also be described as a hidden curriculum (Anyon 1980). Considering that the HBCWs are under-qualified, volunteer caregivers, the hidden message conveyed is that poor communities are not worthy of the best medical treatment available and that qualified personnel are reserved for the richer social classes.

The Roles of Palliative Care Providers

In keeping with the WHO definition of palliative care, the curriculum prescribed physical, psychosocial and spiritual care. Data reflected that the participants also viewed palliative care in this way:

> Palliative care is about pain and symptom management. In palliative care we can be pain experts but 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.

In a context of high HIV and TB prevalence rates, this participant viewed her primary function as providing care on all levels, meaning that they had to offer support beyond pain and symptom management, including a practice of 'drug policing', that is, to regulate and monitor drug-taking activity. She had to encourage patients to continue to take their medication as patients were relatively uninformed about medical treatment protocols; for example, patients believed that medicines were only needed when a person was sick. Data strongly indicated that roles undertaken by the caregivers were often well beyond the roles stated in the curriculum. For example, many participants alluded to the importance of cultural practices, which were only briefly mentioned in the official curriculum:

> I think that on the African side the family as such, no not the family - the clan - they used to acknowledge oh there is a death in that family and that there is a certain way that is expected for them to behave. For instance, especially if I have lost my man, my husband, I'm not allowed to go to the social gathering the family. The women should be quiet; there should be no fighting and no raising of the voice.
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> 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.

Data highlighted the need for caregivers to be aware of local cultural customs and traditions as patient silence and social isolation could be mistaken by outsiders as symptoms of a psychological problem such as severe depression. Additionally, practices, such as slaughtering a goat could be seen as cruel and primitive to an outsider who is unaware of the value of slaughtering animals in traditional beliefs. Participants noted the relative neglect of cultural care in their curriculum:

> It [the palliative care course] didn't involve people who are prac-

ticing traditional medicines. You never invited a Sangoma[2] there and you never invited an Inyanga[3] there to tell us what they think we need to do in order to ease the life of the person that is suffering from HIV and AIDS. I believe that it would have worked because they will come with their own understanding of the whole problem because some of the problems are not really physical.

The participant shared her worldview of how illness, death and mourning are practiced in a Zulu community. The involvement of elders and traditional healers are significant in the lives of patients and to help them to cope with illness.

The data is instructive of the absence of vital aspects of care in the curriculum, referred to as the null curriculum (Flinders, Noddings & Thornton 1986). The null curriculum can be inferred as the absence in the curriculum of practices, principles and policies of palliative care in relation to what is valued by the caregivers, patients and their communities. In particular, the curriculum excluded their spiritual beliefs and cultural practices.

Considering that the formal curriculum is restricted, conveys hidden messages that devalue those cared for, and excludes personal, spiritual and cultural care, means that the curriculum has to be reconceptualised.

Imagining a Post-structural Curriculum

In this section we explore how a curriculum can be culturally responsive by integrating uncertainty, contradiction and unpredictability. The possibility of a responsive palliative care curriculum, we argue, is feasible by drawing on a study in education about the importance of context and curriculum, and that has placed uncertainty of context at the centre of any learning and practice endeavour. Amin and Ramrathan (2009:69) foreground the multifaceted

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[2] A Sangoma is a practitioner of herbal medicine, divination and counselling in traditional Nguni (Zulu, Xhosa, Ndebele and Swazi) societies of Southern Africa. A Sangoma is called on to communicate with ancestral spirits.

[3] An Inyanga is an herbalist who is concerned with making medicines from plants and animals.

nature of school contexts in South Africa by way of the following description:

> The post-apartheid landscape in South Africa is characterized by multiculturalism and homogeneity, multiracialism and mono-racialism, co-education and gender-specificity, class distinctions and class elitism and a range of disparities, inequalities, similarities, and differences between the polarities presented, and beyond.

They suggest that context is multifaceted and extraordinarily complicated. Their work is based on a premise that a curriculum cannot prepare a teachers-to-be for all teaching contexts and that a curriculum should aim to deliberately encounter, factor in and confront uncertainty associated within a school context or a diversity of school contexts. In assuming that some exposure to a diversity of context is important, they provide a 'context-driven learning approach' (Amin & Ramrathan 2009:72). This approach considers memory, experience, and learning as interconnected processes of the mind. Although their work applied to training of teachers, it is appropriated here to structure a curriculum for the training of palliative caregivers. The four-phase framework, reworked for palliative care training is described in the next section.

Phase One: Reframing Memory of Care

This phase is a theoretical orientation to palliative care. Potential palliative caregivers have previously learnt about some aspects of caring in various contexts, including hospitals and clinics. Their training may have been relevant to these contexts and may have led to a 'circular closure of memory'[4]. This view suggests that as a result of prior experiences of care-giving, palliative care may not be transferable to another context, such as home care. This 'circular closure of memory' suggests linearity and perhaps

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[4] By circular closure of memory, we mean that a person's memories around practice may be so deeply engrained that they are unable to be open to new ways of thinking and learning about practice. The term is taken from Dooley and Kavanagh (2007:67).

that a curriculum cannot arise or transform in a context other than the context in which the curriculum was experienced.

A major focus of this phase of reframing memory would be to reposition caregivers who are learning about palliative care by moving their thinking from decontextualized to context-sensitive care, in which they consider shaping their practice for the patients' benefit (e.g. beliefs, culture, needs, language use and socio-economic conditions).

Phase Two: Disrupting Experience of Care

This phase involves supervised visits to a number of patients' homes to which they have previously not been exposed during the training phase. The aim is to disrupt their frame of reference by exposure to a diversity of contexts. The contexts have to be carefully chosen so that the caregivers experience a range of issues that may emerge when they have to work as caregivers without supervision. For example, caregivers could be exposed to a context where they do not know what is causing an illness or how long it is expected that the patient will live. They could also be exposed to a context where analgesia is unavailable. Discussions that follow could assist in anticipating problems and sharing of solutions. The possibility that trainees could be more knowledgeable than trainers (for example, about culture) could raise the level of confidence for volunteer HBCWs.

Phase Three: Destabilizing Learning to Care

In this phase caregivers are given an opportunity to rethink palliative care practice. They would be required to design palliative care plans[5]. By now caregivers may have thought about differing ways of looking at palliative care, will have had been exposed to unfamiliar contexts, and will be given opportunities to develop palliative care plans for each context visited, which can then be discussed in groups. The plans, based on home-based visits, could include travelling to the homes of patients, introducing themselves to

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[5] A care plan outlines the care to be provided to an individual/ family/ community. It is a set of actions the caregiver intends to implement. It guides an ongoing provision of care and assists in the evaluation of that care.

patients and their families, responding to sores and wounds, explaining what they can offer and not offer, bathing patients and so on. They will come to realize that each context requires a different strategy or approach.

Phase Four: Reconstructing the Uncertainty of Care

In this phase, palliative care trainees practice care in an arranged context (of their peers). In groups they role-play patient and caregiver. It is an uncertain space which does not resemble the actual site of care work, but it does give opportunities to practice palliative care. Practicing palliative care skills at an arranged site (as opposed to an authentic setting) is an uncertain reconstruction of context. Amin and Ramrathan (2009:75) believe that an important part of this phase is a realization that:

> … the nature of teaching is unpredictable and that the most important aspect of learning for future teachers is to be prepared for unpredictability and uncertainty.

The thinking around teaching and teachers could in some ways be applied to thinking about caregivers who are finding out about palliative care. In this final phase, caregivers could present their understanding of palliative care to a larger group of caregivers who hail from differing contexts, and this phase is the most important as it brings together caregivers' understanding of context and contextual forces in deep, perhaps previously unexplored ways. This phase provides caregivers with a way of looking at and, if possible, dealing with challenges. Caregivers could jointly decide on topics necessary for learning further about palliative care. In this approach to curriculum and training, palliative caregivers could thus expect uncertainty in context, their memories could be reframed, and they could look at new ways of facing challenging issues when practicing in context. Uncertainty could be welcomed as a potential area for growth, and a curriculum for care would not be expected to provide answers for the problems peculiar to each context.

In opposition to the mirror-like curriculum design (Fig. 1), we offer an imagined curriculum framework. This framework is inspired by the experiences of the curriculum by participants in the study and the uncertainty approach to training offered by Amin and Ramrathan (2009). The imagined curriculum is captured by the funnel metaphor in Fig. 2.

Imagine the current palliative care curriculum as manifesting three types of experiences: restricted, hidden, null. Each manifestation of the curriculum is represented by a circle which makes visible the borders that exclude, restrict and limit realities of contexts of care. The funnel represents the post-structural framework to influence the curriculum with contextual specificities and complexities. As the circles filter through the post-structural frame, they lose their borders at the narrow base and are release into a post-structural space making possible a curriculum without borders. A curriculum without borders is open to insertions of various kinds that characterize each context. It is flexible and makes space for the unexpected, the uncertain and the extraordinary. While we do not expect that every problem related to palliative care will be solved, a post-structural curriculum accepts complexities as integral components of its structure.
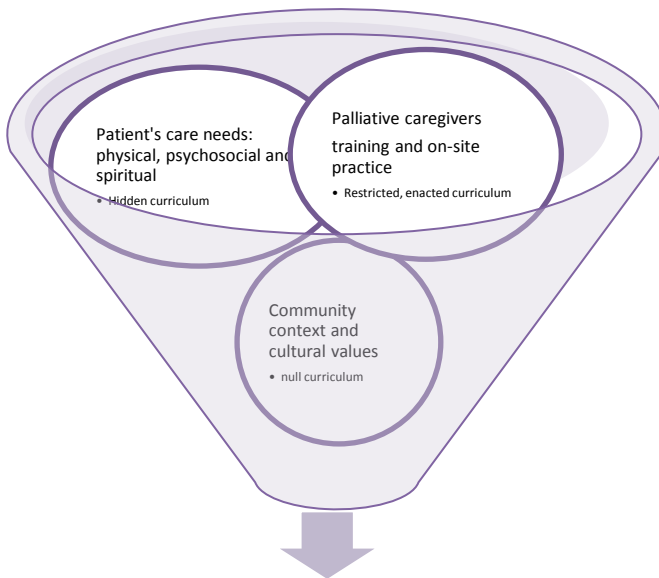

The space of unknowns - uncertainty, unpredictability and variation

Fig. 2 Imagining a post-structural palliative care curriculum

Conclusion

In this paper we explored the curriculum terrain of palliative care through the experiences of caregivers working in rural KwaZulu-Natal. Their experiences of home-based care have made apparent the limitations and ineffectiveness of an approach that excludes patients' spiritual and cultural beliefs in respect of healthcare, dying and death. The curriculum did not prepare them appropriately, ignored the needs of the community, and marginalized traditional worldviews. The curriculum, it transpires, was imported without adaptation to local needs. The differences in contexts where palliative care originated and its application in a rural part of South Africa are remarkably ineffective for both caregivers and their patients. We have demonstrated too, that a curriculum text constitutes the possibilities and limits of palliative practice, and, the complexities that emerged in practice were traumatic for patients and caregivers alike.

As curriculum design cannot escape language, it must, somehow, integrate a language of uncertainty, of contradiction, and unpredictability for successful outcomes. A post-structural curriculum has the potential to overcome the shortcomings of a simultaneously restricted, hidden and null curriculum. We, therefore, reconceptualised the palliative care curriculum through the lens of post-structuralism. Post-structuralism, we argue, is a more resilient means to capture the simultaneous, yet different realities within the same context or across multiple contexts.

For a country like South Africa, it is unfortunate that unequal healthcare provisioning for its citizens continues as we near the end of the second decade of the post-apartheid era. Those most affected are vulnerable communities like the sick and the dying in rural and remote areas. Considering the above-mentioned conditions, the curriculum shaping the approach to care of those who have a life-limiting illness should at least respond to the specific needs of patients. The model we offer is not more costly than the existing curriculum. It does not require material inputs or resources. It requires practitioners to make changes and to adapt the curriculum for local needs. It asks that we imagine palliative care as the means to make the final days of patients emotionally and psychosocially bearable. It means too, that those who have to implement the curriculum can do so with confidence and experience successful caregiving.

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Nyna Amin
University of KwaZulu-Natal
School of Education
Edgewood Campus
amin@ukzn.ac.za

Laura Campbell
University of KwaZulu-Natal
School of Clinical Medicine
Nelson Mandela Campus
campbella@ukzn.ac.za