

Dilemmas of telling bad news: Paediatric palliative care providers' experiences in rural KwaZulu-Natal, South Africa

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Background. In general, the principles of palliative care suggest that, at some stage, patients should be given 'bad news' about poor illness prognosis. The information is often important for care planning, especially when it involves disclosure to children. Although there are ongoing debates about whether to tell or not to tell children bad news, these debates have largely been informed by patients who live in a developed-world context. In contrast, this paper focuses on telling bad news to children and their families from a rural, developing-world context.

Objective. To analyse the experiences of providers of palliative care to children when they attempted to fulfil one of their roles as palliative caregivers, i.e. to prepare patients and families for a child's poor illness prognosis.

Method. This was an exploratory study that was approached qualitatively. Five nurses and eight home-based care workers who provided palliative care for children in rural areas of South Africa formed a purposive, information-rich, self-selected sample. Data were produced through discussions with participants, using photographs taken by the caregivers to stimulate and contextualise the discussions.

Results. Participants experienced four dilemmas with regard to telling bad news: when families did not want to be told any bad news; when participants felt uncomfortable about telling bad news; when participants and patients shared dissimilar values about telling bad news; and when participants were unsure about when to tell bad news.

Conclusion. In the rural areas where the study was conducted, children are not usually given bad news about their illness. Disclosing poor prognosis led to the dilemmas faced by caregivers. The result was that the emotionally charged work of caring for children reaching the end of their lives became more challenging for the caregivers because they were not prepared for cultural complexities. In view of the findings of this study, there is a need for ongoing research into paediatric palliative caregiving in context.

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The concept of palliative care for people who face an illness that may shorten or limit their life developed in the UK in the 1970s.^[1] Palliative care is offered from the diagnosis of such an illness, and ongoing care is provided to the family after the death of the patient. It has recently been introduced to South Africa.^[2] In South Africa, home-based palliative care (including paediatric palliative care) is available to patients in rural areas. In KwaZulu-Natal, the study site, rural people speak isiZulu as a first language and traditional customs influence the ways in which illness, dying and bereavement are approached. A study carried out in rural KwaZulu-Natal in 2011 concluded that palliative care providers could benefit from taking account of unique rural South African contexts and local cultural practices.^[3]

Palliative care providers carry out varied caregiving roles, one of which can involve telling a patient and their family about the incurability of an illness (telling bad news). In some cultures throughout the world, it is an acceptable practice for palliative caregivers to tell patients (including children who are old enough to understand) bad news about the incurability of a disease.^[4,5] Although the literature implies that telling bad news to children can be difficult for caregivers, there is recognition that it is crucial for preparation and planning for all concerned.^[4] A study in the UK reported that one of the most distressing tasks a nurse has to carry out is telling any patient, including a child, that they have a lethal illness.^[6] Findings in the literature suggest that doctors are neither comfortable with nor skilled in telling bad news to their patients.^[7]

Studies in the developed world have revealed too that the issue of whether, how and how much to tell children about a

poor prognosis is approached in different ways, depending on national culture. For example, in Italy, oncologists prefer not to tell patients, including children, that death is inevitable.^[8] In China, families object to nurses conveying bad news to patients because it is felt that such news will result in the patient giving up hope and becoming depressed.^[9] Interestingly, opinions of patients about whether they want to be told bad news have not been widely studied.

In rural South Africa, people have many and varied customs related to dying, death and bereavement. These customs differ from those in other parts of the world, and it is recognised that culture and indigenous knowledge systems are important considerations for providing healthcare.^[10]

In a situation where palliative care has recently been offered, some unanticipated complexities arose for paediatric caregivers when they attempted to inform children and parents that the child's illness may lead to death. The resistance from children and their families created dilemmas for the caregivers, which will be elaborated on in the discussion section of the paper.

Methods

The approach to this study was a qualitative one, premised on the idea that people's experiences are unique.^[11] An important strength of qualitative research is the potential for generativity, i.e. an agenda to construct new ways of understanding a phenomenon or event, with the reader deciding to what extent the findings are applicable to their own contexts.^[12] Consequently, this paper makes no claims that findings are replicable or generalisable. Qualitative

validity criteria, such as exemplarity, transparency, authenticity and trustworthiness, underpinned data production and analysis.^[11]

The study took place in a rural area of KwaZulu-Natal, a province of South Africa. The site was selected because it was an area where home-based care of Zulu children with poor illness prognosis was provided. Potential participants were 5 Zulu nurses and 8 Zulu home-based care workers who had been trained in and practised paediatric home-based palliative care. Participants were affiliated to a hospice or home-based care organisation. Those who were invited to participate were considered to be information-rich sources of data.^[11] The selection of participants was based on the principle of non-coercion. The researcher explained the aims of the study to managers of the hospice and home-based care organisations, who in turn informed potential participants of the study. Those who eventually participated in the study contacted the researcher of their own volition.

Ethical clearance was obtained from the Social Sciences Research Ethics Committee at the University of KwaZulu-Natal (reference No. HSS/0079/10D). Consent was obtained from each participant, and information sheets were provided to them in both English and isiZulu (their first language). Before giving written consent, participants were assured of anonymity and confidentiality and the right to withdraw from the study at any stage. Participants also received feedback when the study was completed.

The primary method of data production was photo-elicitation. Participants were asked to take photographs that they felt would enable them to describe their experiences of their work.^[13] No photographs were taken of the patients they provided care for. The participants took photographs of items such as empty beds, weeds in gardens, torn posters, broken bridges and rural roads to assist them in describing their experiences. Photographs were not used directly as data; they were used as a stimulus for discussion in one-to-one English-language interviews. Group training sessions of the method, which included information on ethical issues (such as not taking photographs of children or patients), were held at a community hall before the photographs were taken.

Any data directly produced by or indirectly stimulated by photographs are often subjected to more rigorous evaluation by ethics boards than most other data.^[13] In this study, all photographs were presented to the Research Ethics Committee, who were the final arbitrators of which photographs could end up in the public domain. Discussions with participants about the photographs lasted for an hour on average, and were tape recorded. The recordings were transcribed to text. The role of the researcher was to prompt, encourage deep discussions and seek clarification when required.

When using qualitative methods, there is no quick and easy way to map out the interpretive processes involved with analysing data, and relevant literature was consulted for useful suggestions and guidelines.^[13] In this study, the analysis involved looking at themes that emerged from the data rather than matching data to predetermined categories. Analysis involved five steps: (i) familiarisation and immersion in the text; (ii) generating themes; (iii) coding; (iv) elaboration; and (v) interpretation and checking. These steps are fully explained in scholarly works.^[14]

Results

Five isiZulu-speaking nurses and eight home-based care workers agreed to participate. Four dilemmas faced by these participants were identified: children's families do not want to be told bad news; palliative care providers do not want to tell bad news; palliative care providers do want to tell bad news; and palliative care providers do not know when to tell bad news. Each of these dilemmas is discussed in turn and supported with direct quotations (pseudonyms are used).

Children's families do not want to be told bad news

Several participants indicated that dilemmas arose when the children's families did not want to be told bad news. They were reluctant to hear

bad news because telling bad news is not a traditional practice in Zulu culture. This point is illustrated by a participant who said:

It is very difficult to explain to our own African people that they will die because we always believe that there is a miracle that is going to happen. They don't want to be told. They believe that the inyanga [traditional healer] can do a miracle and get them cured. (Jabu, nurse)

In the presence of a belief system that promises delivery from impending death, it may appear inappropriate to inform the child or their family that the child will die. Telling bad news may nullify hope offered by traditional healers, who will not tell a patient that they will die, as a miracle (such as a cure) is presented as a possibility.

The dilemma for the palliative caregiver arises because the home-based care workers, who are native to Zulu culture, can be seen as transgressing cultural beliefs if they speak about impending death. Palliative care providers face a choice between their loyalty to their culture (which is also the culture of their patients) and their role as a palliative care worker.

Participants intimated that sometimes patients or their families suspected that the palliative care provider would tell them things they did not wish to hear, which could potentially place a palliative care provider in a challenging situation:

Traditionally in our culture if you talk about death it means that you have come to predict death that death will come soon to this family. I remember my first family; I went to introduce myself and I felt I was not accepted. I was chased away as one family members said to me, "You have come to predict that someone in this family is going to die. So please, we are not interested. We are no longer interested in listening to your stories. Now go away." (Themba, home-based care worker)

This participant describes the dilemma of wanting to provide care, while at the same time her presence at the patient's home indicated a lack of genuine care because the family assumed that she had come to convey bad news and thereby hasten death. The dilemma for the caregiver is whether or not to go to the patient's home. Either option is challenging. If she goes to the patient's home, her safety may be compromised. If she does not go to the patient's home, her role as palliative carer is compromised.

Palliative care providers not wanting to tell bad news

Several participants alluded to personal challenges they experienced when telling bad news. For example, a participant explained that she felt it was inappropriate:

I try to be positive because I can't tell straight. If I see this thing is wrong I can't tell the patient that you will die. I can't tell the patient I can't help you. I can always help. (Themba, home-based care worker)

This participant is a home-based care worker who may not be as skilled in palliative care as a nurse. She feels that it may be an error to tell a patient that they are facing death, as for her it would be tantamount to communicating a lack of care. Her view could be regarded as in contradiction with one of the roles of palliative care, which is to prepare a patient for impending death.

Caregivers and patients value telling bad news dissimilarly

Several participants saw value in telling patients bad news, but accepting this value also generated dilemmas in some instances. One participant described how being told helped her cope with the death of a close relative:

I can now talk to other people about the deaths that I have experienced and before I wasn't able to talk. It is time to grieve now because someone had explained to me about my father dying and everything. (Thandeka, nurse)

Telling patients about approaching death was useful to this caregiver, because she had experienced personally how talking about death helped her to accept her father's death and to grieve over this loss. The dilemma was created by contradictory experiences and

values: while talking about death worked for the caregiver, who experienced loss caused by a life-limiting illness and recognised the benefits of being prepared for the consequences, not all caregivers had been through this process, and they therefore did not approve of forewarning patients. Several participants also felt that not telling infringed on the right to access to information and joint decision making, even though doing so was culturally inappropriate. These points were illustrated by the following statements from participants:

'It is fair that people know that they will die soon. Sometimes we are hiding things that they have not been exposed to. ... We were just following in the elders' ways.' (Jabu, nurse)

'Everybody has the right to know what is happening in the world and they have to make decisions. Even the children have to make decisions in a family. When a person dies and they are in mourning they have to know why we are mourning today.' (Themba, home-based care worker)

These participants suggest that telling bad news differs from traditional 'elders' ways' of caring for the dying. While it could be interpreted as a 'conspiracy of silence' and withholding of information around dying and death, it could also be a tradition that has continued over time when elders felt that younger members of the family would not be able to cope with bad news. It therefore had a 'protective' function. The practice of not telling may also be interpreted as a reflection of a traditional patriarchal society, where elders make unilateral decisions on behalf of others. However, traditional practices are being challenged in more contemporary times, and the dilemmas faced by the caregivers are reflective of societies at the nexus of old and new ways of caring.

Not knowing when to break the bad news

A dilemma arises when a palliative care provider is unsure of when to tell a patient that they faced death:

'With cancer you can estimate the time period that is left for a person to die, but with HIV and AIDS it is hard. I've seen a number of people who we thought were dying but a week later the person is up and about. They continue up and down. One week he is on the bed and the next week he is up.' (Lungi, nurse)

This nurse participant draws a distinction between cancer and AIDS and suggests that predicting death is easier when a patient has a disease like cancer. In an area of high HIV prevalence where access to diagnostic and prognostic tools may be very limited, an isolated palliative care provider may simply not know when to tell the patient with AIDS that they are facing death. AIDS usually involves a fairly long period of illness interspersed with periods of good health. Consequently, a palliative care provider may be placed in a situation of uncertainty, and cannot judge when it would be an opportune moment to break bad news. A dilemma may also arise in this setting because of the nature of HIV and AIDS and the secrecy surrounding the disease. Patients may simply not want to discuss issues about AIDS.

Discussion

Findings from this study illustrate the dilemmas experienced by paediatric palliative care providers in the context of telling bad news. Examples were provided of when a child's family did not want to receive bad news. Some participants did not feel comfortable telling bad news, while others saw value in children and their families knowing about the inevitability of death. A particular dilemma arose around HIV and AIDS, where it appeared difficult to prognosticate accurately.

The literature indicates that breaking bad news is an essential skill for anyone working in children's palliative care.^[4] Our study does not dispute this, and the findings illustrate that knowing whether to tell or not may present dilemmas that have previously been unexplored in a rural African context. The study raises some

general issues around telling bad news in the context of a traditional Zulu community where it may be culturally appropriate not to tell. Other studies support the notion that Zulu patients may prefer to be ignorant about the inevitability of death, as denial appears to be a coping mechanism.^[15] However, the view that it is a cultural practice not to tell can be contrasted with other studies, which report that in Zulu societies the traditional healer tells patients when death approaches.^[16] Other literature highlights the complexities of telling bad news in a Zulu society, as some relatives prefer to tell their children about a poor prognosis while other relatives prefer a child not to know.^[17] Telling or not telling a child therefore presents a complex challenge. Challenges are compounded in a community where there is a high prevalence of HIV and AIDS and associated stigma; it may be challenging for a palliative care provider to discuss information about illness and poor prognosis if the family does not want to discuss the nature of the disease with the child.

The caregivers in this study who were not nurses experienced dilemmas when they were not comfortable with telling bad news. This speaks of a need for continuing training and support for home-based care workers, so that they are able to determine and respect the wishes of the patient with regard to sharing information. The literature also provides useful steps for finding out whether children and their family wish to receive bad news or not.^[4] If a home-based care worker does not feel comfortable about disclosing bad news, there may be a need for support from a more experienced palliative care provider, such as a nurse.

A dilemma may also arise when the palliative care provider sees value in telling bad news and the patient does not want to hear it. This requires further research, as palliative care providers may experience a sense of frustration when they cannot practise aspects of palliative care that they believe to be useful. More importantly, further research could aim to reduce the frustrating aspects of paediatric palliative care.

With regard to HIV and AIDS, a specific dilemma arises over when to tell bad news. In this context there is limited access to medical information, and palliative care providers often do not have access to diagnostic or prognostic modalities. In telling bad news, it is vital that the correct information is available regarding the prognosis, as potentially a patient could be told that they face imminent death when they do not. Prognostication is difficult even in the developed world; for example, caregivers note that children with AIDS ride a roller-coaster of repeated episodes of illness and recovery.^[18]

Other complexities that were not explored in this study may arise when caring for HIV patients. For example, telling bad news may place an emphasis on dying with HIV instead of living with HIV. The literature cautions palliative care providers against placing emphasis on dying from certain types of disease (such as cardiac disease) instead of promoting a positive message of living with such diseases.^[19]

In South Africa, the importance of involving traditional healers to deliver bad news when curative care has been unsuccessful has been reported.^[16] In view of this, consideration may be given to involving both elders and traditional healers when telling bad news.

Study limitations

The limitation of this study is a small sample size. The direct views of children and their families were not sought, and no discussion around telling bad news can be complete in the absence of this missing information. In addition, the views of elders and traditional healers were not considered.

Recommendations regarding changing the practices that concern whether to tell bad news or not cannot be made from this small, exploratory study, and we feel that that further research is required to explore the phenomenon. Further qualitative research juxtaposed with quantitative research may expand knowledge of when, whether and how to tell bad news.

Conclusion

Exploring the experiences of children's palliative care providers in rural areas, within societies still attached to traditional ways of caring, has yielded valuable insights about telling bad news. Peculiarities of context have created unanticipated challenges that may not have been factored into preparing palliative care providers for working in rural communities. As a result, they have encountered a number of dilemmas: having to choose between transgressing cultural beliefs or abrogating their role as palliative caregivers; choosing between compromising personal safety and compromising role functions; seeing value in not telling; seeing value in telling; and finally, not knowing when it would be appropriate to talk about impending death. There was no easy solution to any of these dilemmas.

Some dilemmas emerged because of competing beliefs and loyalties. The palliative care providers are insiders to both Zulu culture and palliative care practice. During training in palliative care, participants may have been introduced to perspectives that contradicted the beliefs they grew up with, and perhaps insufficient attention was paid to how to deal with contradictory belief systems. For some of the participants, telling bad news was therefore irreconcilable with their cultural ways of caring, and not telling contradicted their palliative caregiving roles. The disconnection between two views of the world, and a training programme that lacked a socio-cultural dimension, can be seen to be implicated in the complications that occurred.

Based on these insights, it is evident that those who train in and provide palliative care in some contexts make assumptions around telling bad news that have not been fully explored in a rural, home-based context. Although the disclosure of bad news about prognosis is a focus for debate in the developed world, with views ranging from children's rights to know to the possibility that telling will remove hope, the debates appear to be divorced from contextual particularities. In our study, children's families indicated that they preferred not to be told bad news. In an area of high HIV/AIDS prevalence there is a need for ongoing research into this complex issue. Attention may be given towards incorporating elders and traditional healers into a palliative care team.

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