

An ethnography of managing emotions when talking about life-threatening illness

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Aim: This ethnographic study was concerned with how dying patients, palliative care staff and family caregivers communicate about life-threatening illness in a palliative care setting in Ethiopia.

Background: Ethiopia, as a developing country, had few resources for caring for those requiring end-of-life care. However, palliative care was supported by local champions in Ethiopia and by the Federal Ministry of Health.

Introduction: The disclosure of bad news was discouraged because it was believed that such disclosure may lead to unnecessary distress and to loss of hope.

Methods: Non-participant observation amounting to 276 h of observation and ethnographic interviews with four patients, six family caregivers and five palliative care staff during two periods of data collection (November 2011–January 2012 and May 2012–August 2012) in Addis Ababa, Ethiopia.

Findings: Although palliative care staff create openness in communication with patients and family caregivers about terminal illness and dying, ultimately palliative care staff deferred to family wishes about significant news disclosures, in order to avoid upset. Family caregivers were found to avoid disclosing news of a terminal illness to their family member and wished to keep the patient in closed awareness. In contrast, an open awareness context existed between palliative care staff and family caregivers.

Discussion: In managing truth telling in different cultural settings, medical and nursing staff as well as health policy makers need to take into account the various awareness contexts highlighted in this study. Palliative care staff should consider how actions such as protecting patients from upset may inadvertently deny the patient the right to exercise control.

Conclusion and implications for policy: Health policy makers should ensure that the design and implementation of palliative care services should not be a wholesale adoption of Western style services but ensure that such services are adapted to reflect the religious, cultural and social needs of the community. Foreign workers and volunteers who deliver palliative care services and education in Ethiopia should reflect local religious and cultural sensitivities.

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Introduction

The importance given to truth telling varies from culture to culture and across countries in Europe and further afield (Kazdaglis et al. 2010). However, open communication with patients is the preferred context for communication in the United Kingdom (UK), reflecting the ethical principle of patient autonomy, accompanied by open awareness and open communication about dying and end-of-life care (Goldstein et al. 2006). A common criticism of palliative care in Western society has been the lack of attention to cultural understandings and practices in truth telling and breaking significant news (Clark 2007). This study reports on how palliative care staff communicated with dying patients and their family members and how they handled sensitive communication with patients and family members in a palliative care service in Addis Ababa, Ethiopia.

Background

At present, national planned health services for palliative care are at an early stage of development in Ethiopia (Federal Ministry of Health 2016; Kassa et al. 2014). Consequently, those seeking hospice and palliative care services normally have advanced cancer or acquired immune deficiency syndrome (Federal Ministry of Health 2016). Services for people with HIV and AIDS are more developed than services for those with cancer as a result of foreign aid (Balcha et al. 2011; World Health Organisation (WHO) 2014). Cancer as an emerging public health issue has received little service provision with most people diagnosed at an advanced stage of the disease (Balcha et al. 2011; Onyeka et al. 2013), with many unmet needs reported such as poor access to pain relieving drugs and symptom management (Sepulveda et al. 2003).

Ethiopia, as a collectivist society, prioritises the collective responsibility where the family is at the centre of decision-making. The term collective responsibility describes how members of a collectivist society are accountable to each other and to the community when caring for the sick and dying (Conway 2011). Ethiopians expect their family members to help them cope during a crisis, and this plays a large part in the care provided for a sick relative (Beyene 1992). Caring for a sick family member with advanced cancer or other life-threatening illness places enormous emotional,

social and financial burdens on the family (Sepulveda et al. 2003). In the next section, the role of the family related to truth telling across different cultures is discussed.

Truth telling and the role of the family

Some cultures consider delivering bad news to those with cancer or other life-threatening illnesses as unacceptable as this could lead to loss of hope. Healthcare practitioners may withhold information about serious diagnoses and prognoses, and decisions may be made about treatment with family members in the absence of the patient (Broom & Doron 2009). Furthermore, being diagnosed with a terminal illness may lead to isolation and avoidance in the community although community health programmes addressing palliative care needs are becoming more available in Ethiopia (Onyeka et al. 2013). McGrath et al. (2009) found that oncologists in the East Indian healthcare setting were unlikely to tell patients of their terminal diagnosis; consequently, patients ended their lives in curative healthcare settings.

The disclosure of bad news runs the risk of shattering hope and has been found to be problematic for family members, especially when family members have an important part to play in speaking for the sick person, giving care and taking on the burden of the illness (Kazdaglis et al. 2010). However, relationships between healthcare professionals and patients rest on trust, strongly associated with the ethic of truth telling and honest and open communication (Kazdaglis et al. 2010). Disclosure practices in the Mediterranean, Middle Eastern and African countries are unquestionably influenced by the presence of close family members and close local communities. Regarding palliative care, a complex picture emerges where communication practices in end-of-life settings take place in a cultural context and where the emotional and social preferences of the patient, family and medical staff are negotiated (Broom et al. 2014). Families in Ethiopia expect to be present with patients during life-threatening illness and within the Ethiopian culture; this may extend to other key people beyond the family, including local community elders and religious communities (Crowley et al. 2002). Furthermore, the World Health Organisation emphasises the situating of palliative care services within the social and cultural setting in which it develops (WHO 2005).

The rise of non-communicable diseases (NCDs) such as cancer challenges emerging economies and nurses are expected to play a large part in developing and leading preventative as well as palliative care services across the lifespan for those with NCDs (De Cola et al. 2012). A lack of knowledge of palliative care may be a barrier to the development and uptake of palliative care services (Sneesby et al. 2011). At the time of this study in Addis Ababa, the palliative care service received patients through referrals from hospitals and health centres in the community as well as through patient or family self-referral. Self-referral occurred through word of mouth from those who had previously used services or by information from the palliative care website (Ayers 2014). The aim of this study was to investigate how palliative care staff communicated with dying patients and their family members.

Methods

Research design

The study was designed as a focused ethnography, which enabled a context-specific examination of end-of-life care as it is practised in one palliative care setting in Addis Ababa, Ethiopia. One of the underpinning concepts of focused ethnography concerns how it allows the in-depth study of communication (Knoblauch 2005), and the management of emotions which are central to the study.

Sample and setting

A palliative care setting was approached within the capital city of Ethiopia after an initial scoping visit was carried out. The palliative care setting offered a range of services including home care and in-patient care. The principal investigator (PI) a citizen of the UK, had experience of working in the Middle East and Africa and was able to speak Amharic, the main language spoken in Ethiopia. A purposive sampling approach was utilised to access the participants.

Ethical considerations

Researching vulnerable patients such as those receiving palliative care requires a rigorous ethical process (Broom & Cavenagh 2010). A favourable ethical approval for the study was gained from the Ethiopian Health and Nutrition Institute in Addis Ababa (EHNRI 643/830) after consultation with the Federal Ministry of Health, as well as from the University Ethics Committee. Ethical considerations were deliberated throughout, ensuring participants were not observed nor interviewed whilst actively in discomfort. Anonymity and autonomy were maintained for all participants in the study

by the use of pseudonyms for confidentiality. All participants voluntarily shared their experiences to the PI. Written informed consent was provided from research participants prior to interviews and observations.

Data collection

Data were collected through 276 h of participant observation, with the researcher taking on the role of 'observer as participant' (Silverman 2013). In addition, field notes were recorded during 21 home visits. Interviews with five palliative care staff, four patients, six family caregivers and three spiritual leaders were transcribed and translated into English before the process of analysis.

Data analysis

Data analysis was spiral in nature, as further data were collected as the analytic process proceeded. Thematic analysis was used to analyse the data (Braun & Clarke 2006). The transcribed data, together with the field notes, were read and reread initially by the PI, as a way of engaging in the analytic thought processes to focus on the descriptions and meanings of the experiences of participants within the data. The data were then coded using open and focused coding, resulting in themes (Emerson et al. 2011). Mind maps and spider diagrams were also used to identify concepts which were then discussed with the research team. Themes continued to be defined and redefined and finally compared to existing literature. Existing theory helped 'place' or 'reject' the themes when compared with other research (Emerson et al. 2011). A key phenomenon of 'not wanting to upset' emerged from the data, followed by subcategories which considered how the patient's diagnosis is minimised by the family and life-threatening illness spoken about using non-specific terms to avoid upsetting the patient.

Rigour and trustworthiness

The trustworthiness and rigour of the study were established by the four principle criteria proposed by Lincoln & Guba (1985), to maintain rigour in qualitative studies. These criteria are credibility, transferability, dependability and confirmability. Credibility was enhanced by prolonged engagement in the setting with many hours of observation by the researcher and immersion in the field during two in-depth periods of data collection. Although participants' experiences are unique and not directly transferable to other settings, the subjective aspects of participant's experience are objectified in a way that reflects participant realities through their own words. Confirmability was achieved through data interpretations that were based on evidence from the field and

interpretation, by close academic supervision by two research supervisors, and were not figments of the researcher's imagination. An audit trail of all decisions and self-critical accounts of the research through the keeping of a research diary was essential to reflexivity. The audit trail also contributed to dependability through a process of establishing a transparent audit trail through keeping a research diary, field notes, digital recordings, letters, emails and close supervision of every step of the research process. Additionally, the findings were further strengthened by a process of forward and backward translation from Amharic to English and back, to ensure that the transcripts were a true reflection of the participants' experiences (Fetterman 2009).

Findings

The key phenomenon identified from the data was the processes involved in 'not wanting to upset'. The avoidance of upset was enacted to protect patients from threatening information that was thought to cause emotional harm. Family members protected the emotional equilibrium of their loved one by avoiding the disclosure of bad news. The palliative care workers in the community were requested by family members to hide the painful details of the illness and minimise the impact of distressing news on the patient. The findings will be presented through three main themes: This is a small problem, Deferring to the family and How much do you want to know?

This is a small problem

In the data extract below taken from field notes, Alex the son of a patient, called Saga, persuades Danny (the palliative care worker) to tell his mother that the problem she has was a small one which could be sorted out:

Saga lives with her husband, Fitzum, and two adult children, Alex and Frey. Saga has cancer of her colon and bladder, with lung and liver metastases. After showing Danny into the house, Fitzum, said to Danny 'Do you want to see the notes?' He presented Danny with a bag full of reports and scans for him to look at. Danny went through all the paperwork and found out the seriousness of Saga's condition by reading a scan report identifying advanced cancer. A young man came into the room and sat down. He introduced himself as Alex, Saga's son. After sometime, Alex turned to Danny and said: 'Danny, I want you to go in and see my mother and tell her that you have reviewed the paperwork and that it is a small problem and it can be sorted'... [HV: Sa-1]

In this data extract, Danny talks to the family before going to see Saga, which opens up the space for Saga's husband and

Alex, their son, to talk to him. Danny's approach demonstrated a delicately managed truth-telling situation. From this first visit, it became apparent that Alex wanted to withhold information about his mother's diagnosis and wished for his mother to remain in closed awareness.

In a subsequent visit to Saga's home, the family was observed to manage Saga's emotional expression by urging her not to cry:

Saga was lying on the bed. Fitzum was talking to Danny about his wife: 'my wife is a strong woman, she prays and she has faith... she is stronger than me'. Suddenly Saga started to cry. Her daughter, Frey told her mother in an urgent voice: 'you can't cry... You see this medicine [she showed her mother the Amitriptyline and Dexamethasone she had in her hand]... If you cry it will cause side effects'. After the visit, I asked Danny about this incident and he described what he thought was going on: 'it was strange... but I think that she (Frey) felt that, if her mother cried, it showed that she was hurt and there was nothing the family could do about it. She was trying to protect her mother'. [HV: Sa-3]

The data extracts provided insight into how modern medicine is believed to be powerful. Frey's behaviour identified the importance of her mother's stoicism and Frey's displeasure at the mother's expression of strong emotion. There was a fear expressed that strong emotions would interfere with the medicine and lead to side effects. Frey demonstrated to her mother how she should feel and urged her to control emotional expression. Therefore, not wanting to upset the person who was ill by urging the suppression of emotion was seen as an aspect of emotional regulation in serious illness.

Deferring to the family

Continuing with Saga's case, the family decided not to tell Saga about her terminal illness, despite the fact that palliative care staff encouraged them to be more open, as Saga's condition deteriorated. This was demonstrated in a conversation with Danny and Fitzum at the start of the second visit:

As Danny walked into the compound, Fitzum stopped him and said: 'I need to talk to you before you go in. We have decided as a family not to tell Saga that she is dying, we want to keep Saga happy' [HV: Sa-2]

Fitzum was adamant that Saga would not be informed about her dying. From Fitzum's perspective, it was important that Saga was kept happy and not upset by bad news but emotionally protected. Danny consented to the family wishes.

Danny was further observed trying to avoid upset using tactful and careful language with Merht, a young woman who had been working in Dubai as a maid, but had come back to

Ethiopia because she had been unwell. A data extract taken from field notes concerned Danny's tactful exploration of Merht's understanding of her illness:

Danny: *Tell me about what has been happening?*

Merht: *They took my womb out; the doctor said I had a lump. I was in hospital for weeks, but after that I felt a bit better for a while...*

Using an open-ended question 'tell me about', Danny learned that Merht thought she had a lump. This appeared to be her complete understanding of her condition, and this was confirmed by Merht's mother:

She thinks it is a lump... that is fine, she does not need to know any more, and I don't want her to get upset. [HV: Me-1]

The doctor was reported to have used the word 'lump' to describe the cancer, and Merht appeared to accept that. This concurs with Doumit & Abu-Saad's (2008) findings in Lebanon that euphemisms such as 'growth' or 'lump' are preferred to using the word cancer, and they describe this as 'tactful communication'. Merht's parents appeared content that she remained in closed awareness, a term used by Glaser & Strauss 1965. Similar to Saga's situation, Merht's parents had taken on the family responsibility of managing communication about serious illness and dying for their loved one.

In the next section, the palliative care doctor also described using a deference strategy by seeking clarification from the patient and the family member about what they would like to know.

How much do you want to know?

An example of the deference strategy used by palliative care staff was illustrated by Dr Benium, a 50-year-old man who did his medical training in Ethiopia with further training overseas. Dr Benium described how, as a young physician, he openly told a woman she had cancer, following which she became extremely distressed by the bad news disclosure, which made him change how he delivered such news. He described a strategy he now uses to avoid emotional upset and to avoid losing face with the patient:

After I did that, I didn't tell any patient right to his face what his problem is until he asks me. So I stopped that... What I do is, I tell patients to follow, to follow. So I show them I have done everything and that I am failing and finally you know they become frustrated and ask, 'What's going on?' Then I ask, 'How much do you want to know?' 'Do you really want me to tell you?' They are ready by then. After a lot of suffering, so you cannot tell at one go. It's catastrophic, you cannot do it. Its culture, it is fixed.

I am influenced just as much as society. So... it is a slow approach, ...patients need to see that things are failing... when you take time, examining them thoroughly, talk to them, give them this drug and then they become friends; they see you're trying your best. Sometimes they say 'I feel better' without anything. 'Are you sure you feel better, are you sure you're ok?' 'Well ok... it's a little bit better'... Then you know... Then they come to the stage that I am a friend and I am trying to help... so I will not be a monster. Some people need two or three visits; some people will need ten visits and so on. And I know of people who never ask this question... always avoided my eyes and finally died and then there are people like that. [Interview Dr B]

Dr Benium encouraged his patient to follow him; he took a slow approach and became 'a friend'. He described how he made sure that the relatives see that he has done everything. He described how he enabled patients and caregivers to ask about their situation; therefore, he had time for the patient and family. The 'to-follow' strategy enabled a tactful and culturally acceptable way to disclose distressing information, which allowed the patient and family control over how much information was delivered. In the 'to-follow' approach, the doctor bridges the gap between cultural behaviour, social expectations and understandings of sensitive care held by patients and family caregivers and the communication practices of medicine.

Danny was also observed using cautious and tactful questioning techniques, to assess how Saga felt about treatment:

As Fitzum and Danny were talking, Saga gestured that she wanted to sit up. Frey came and helped her. Saga looked at Danny and said: 'the doctor says I should have chemotherapy and radiotherapy, what do you think?' Danny in turn asked Saga: 'how do you feel about that?' Saga replied: 'I really don't want any more... it is so hard and I felt so ill'. Danny gently nodded and said: 'I think that is a good idea'. Saga then talked about how God had been a blessing to her. [HV: Sa-2]

Chemotherapy and radiotherapy treatments are expensive in Addis Ababa and not always available. Danny, when asked his opinion about treatment, responded with an open question to find out Saga's thoughts. Danny was using tactful, culturally embedded communication to facilitate the conversation further which enabled insight into Saga's feelings about further treatment. It was noteworthy that Danny asked about emotions: 'how do you feel?' rather than 'what do you think?' This strategy of open questions with a focus on feelings and emotions encouraged Saga to express how she did not want further radiotherapy and chemotherapy due to how unwell she had felt previously.

Discussion

In this study, families were observed protecting their family members from distress by the 'not-to-tell' strategy that resulted in closed communication about the patient's dying. The 'not to tell' approach enabled the avoidance of upset and enabled the family to protect their loved one's emotional equilibrium. However, palliative care staff were observed creating spaces for openness in communication and employed tact and diplomacy when handling sensitive communication. Palliative care staff, patients and family members were observed to side step and avoid the direct disclosure of devastating news of a terminal illness to the patient, and in this sense, they enacted symbiotic niceness to avoid upset (Li 2004). Li (2004) found that symbiotic niceness was a core component of professional and patient interaction when caring for dying patients. Palliative care staff in this study were also observed to use niceness by respecting relatives' wishes, by deferring to those wishes about communication with the patient. It was the family members who were seen to be the ones who exercised control of information. This study demonstrated how worry and concern about emotional upset and the importance of nice, untroubled relationships were motivating factors for the avoidance of deeply upsetting communication concerned with the bad news of a terminal illness and dying. The emotional landscape around the dying patient was a priority for family members and for palliative care staff who worked with the family to maintain patient and family therapeutic relationships.

The seminal work in the USA, by Glaser & Strauss (1965), identified different awareness contexts from open to closed awareness as the two extreme contexts with suspicion and mutual pretence contexts in between. In the present study, families were observed to wish for closed awareness for their loved ones with a life-threatening illness. Palliative care staff and family members kept patients in unawareness and closed to information about the seriousness of the illness and impending death. The cultural dynamic of non-disclosure has also been found in Tanzania, where doctors were found to speak to the family about bad news rather than the patient, identifying an open awareness context by medical staff to the family and a closed awareness context with the seriously ill patient (Harris et al. 2003). A critique of Glaser and Strauss's theory is that it emphasised the management of information, rather than the management of emotions with a lack of attention to the emotional responses of having a serious illness (Timmermans 1994).

With the advent of palliative care in Addis Ababa, staff were observed to create space for openness with the patient by the use of open questions. One of the solutions to the

sensitive handling of open awareness was used by one of the doctors, when he demonstrated a way to communicate with the patient and family in closed awareness by facilitation of the patient to question the healthcare professional if they so desired. This process of encouragement and facilitation was an example of symbiotic niceness (Li 2004) when managing a sensitive boundary between patient/family wishes and medical obligations to inform patients about their illness without upsetting cultural expectations and conventions of caring behaviours. In Tanzania, physicians employed the 'mzunguko' counselling method, which used an extended process of dialogue to reduce the differences between individual cultural beliefs and modern medicine. Mzunguko was defined as the act of going around and around (Harris et al. 2003). The 'to-follow' strategy was similar to the mzunguko method by attempting to bridge the gap between family communication, patient communication and modern medicine using culturally appropriate ways of enabling dialogue and openness. By engaging in the 'to-follow' approach and using open questions to gauge the knowledge of the patient, the predominant non-disclosure ethic of the family and the potential open awareness ethic of the palliative care staff are bridged in a manner that avoids upset and supports the cultural context of an etiquette of niceness in communication.

Conclusion

The predominant cultural dynamic of families and healthcare professionals of 'not wanting to upset' was found to be the rationale for not talking openly about cancer and dying and keeping the patient in the closed awareness context. However, palliative care staff were found to use tactful and cautious communication strategies to avoid upset and allowed space for openness in communication, described as a slow approach for timely adjustment to the possibility of open awareness. Family members wished to avoid communication of devastating news about death and dying as they wished to protect their loved ones by minimisation of suffering and avoidance of the harsh news that their loved ones were dying. This study offers information surrounding cultural and emotional literacy in care behaviours and communication. The study offers insight into the priority given to emotional care by family members of those who are dying and also demonstrated the practical and sensitive engagement of palliative care health professionals with family members. The present study demonstrated how Ethiopian palliative care professionals dealt practically with the ethic of truth telling by the adoption of a friendly, slow approach using tact, deference and niceness. The study highlighted the potential tensions between cultural practices and the palliative care philosophy orientated

Table 1 Implications for nursing practice

Staff to be encouraged to use cultural and emotional literacy and to be aware of the various awareness contexts and the importance of 'not wanting to upset'
In dealing with truth telling, developing training to promote tactful and sensitive communication skills that allow for openness as well as deference to the unique needs of patients and family members
Senior staff should ascertain that all personnel, responsible for handling information and communication about death and dying in their care settings, respect religious and cultural contexts when dealing with patients and caregivers

to by Western healthcare professionals concerning open awareness and how in practice this was negotiated.

Limitations of the study

This was an ethnographic study, and the findings and implications have strong relevance for the setting in which the study was conducted. As a consequence, the findings cannot be generalised to the wider community. However, theoretically, the findings have resonance with similar care settings in the Middle East and African countries, and staff in such countries will be able to share similarities in their practice, recognise and appreciate the dilemmas associated with the management of truth telling and maintain culturally appropriate communication practices.

Implications for nursing and health policy

This study offers cultural information surrounding care behaviours. It offers insight into the priority given to the emotional well-being of the patient by family members within the emergent palliative care movement in Ethiopia. In the management of truth telling and the disclosure of bad news, practitioners and educators should take account of the various awareness contexts highlighted in the study. Palliative care staff should consider how actions such as 'not wanting to upset' or processes of patient protection may inadvertently deny some patients and caregivers the information needed for them to exercise control. Although the implications for practice principally target staff working in non-Western care settings, the findings and implications for practice have important relevance for staff in Western countries due to the increasing number of refugees and migrants from Middle Eastern and African countries settling in Europe and the west. Such refugees and migrants have similar beliefs, practices and expectations about healthcare staff. The nursing implications are further highlighted in Table 1.

Government departments responsible for healthcare policy in Ethiopia need to develop approaches to palliative care that incorporates religious, cultural and social contexts in care delivery. Policy makers should ensure that the design and implementation of palliative care services should not be a wholesale adoption of Western style services but to ascertain that such services are adapted to reflect the religious, cultural and social needs of the community. Statutory and voluntary organisations (for example, NGOs, UNHCR and WHO) responsible for sending foreign workers and volunteers engaged in developing palliative care services and education in Ethiopia should reflect local religious, social and cultural sensitivities in the training and preparation of staff.

Author contributions

Study conception and design: NA, AA and VV.

Data collection: NA.

Study supervision: AA and VV.

Manuscript writing: NA, AA and VV.

Critical revisions for important intellectual content: NA, AA and VV.

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