

Views on death and dying among health care workers in an Indian cancer care hospice: Balancing individual and collective perspectives

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Abstract

In providing palliative and end-of-life care, professional and lay hospice workers alike attend to patient and family needs to encourage a dignified death. However, there are few comparative inquiries documenting how differential workplace preparation affects the processes and outcomes related to being confronted to death and dying. This qualitative study explores and compares these experiences among a diverse sample of health workers ($N = 25$) in a grassroots cancer care hospice in Bangalore, India. Our findings underscore how personal views, socio-economic status, beliefs and values, occupational experience, and workplace interventions interact to shape ‘worldviews’ about death and dying. Whereas health workers report conflicting feelings of relief and sadness when confronted with the death of their patients, these mixed emotions are often lessened through open dialogue among newly trained and more experienced health workers. Moreover, experienced hospice workers wished to ensure that less experienced ones are provided with the necessary workplace support to lessen psychological ‘hardening’ that may occur with repeated exposure to death. In dealing with the diverse needs of hospice workers, both individual and collective needs must be considered to ensure an optimal workplace climate. Future work should study how hospice workers’ views on death and dying evolve with time and experience.

Keywords

Death and dying, health assistants, hospice workers, India, individual and collective perspectives, palliative care

Introduction

Institution-based palliative care was established in India in the 1980s.¹ Prior to this movement, most individuals in terminal stages of illness were treated in homecare settings by family caregivers according to traditional spiritual, religious customs, and rituals.^{2,3} Lately, India’s health managers, clinicians, and policy makers have been actively involved in setting benchmarks for palliative care practices, creating innovative models of care, developing trainers and training programs, and providing evidence-based clinical guidelines for the care of the dying.¹ These imperatives are

necessary considering that India’s large population (surpassing one billion) and the significant rise of late-stage illnesses diagnoses (e.g. cancer) are presenting staggering demands on palliative care. Moreover, India’s vast geographical area and multiplicity of religious affiliations compound the need for decentralized, more easily accessible, and culturally sensitive palliative care institutions. In addition to a growing demand for end-of-life care, India must also contend with limited health care resources, yielding the need to put forward creative and cost-effective supportive care modalities. The paucity of trained and experienced health care

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providers, such as oncologists, nurses, and other health care professionals, adds to the challenge of providing accessible end-of-life care to those in need.^{2,4}

Regardless of the diversity of religious traditions, contexts, and resources in India, they all aim to achieve an optimal end-of-life experience that includes a peaceful and dignified dying process.⁵ Amidst India's diversity, common themes pertaining to death and dying are present.⁵ For instance, tension between body and soul, in terms of behaviors of previous lives and a need for further suffering to 'burn' away the *karma* accumulated over multiple lifetimes, often means that providers must be sensitive to the notion of pain relief at end of life. In addition, the collective duty of the family is often to ensure that the family member dies an auspicious death;⁵ thus palliative care settings should provide the necessary context and care for the family and larger community to be integrated into the dying process.

Health care providers and administrators in India have been looking for innovative ways to provide professional and lay support to individuals at end of life.¹ One such innovative 'win-win' initiative involves the recruitment of young women from small villages to be trained as health assistants. Typically, women from the ages of 18 to 23, primarily from low-income families, are provided with classroom and clinical training for a six-month period.³ During this training period, the women are fully integrated within palliative care hospices and are provided with free room and board in addition to a stipend of 500 rupees per month. As a social movement, this successful initiative has contributed both to expanding the scope of palliative care interventions and securing earning for the young women and their families.³

This approach has been implemented in Bangalore, India, at a cancer care hospice, where a 'Health Assistants Training Program' has been established. This hospice opened in 1999 and has admitted nearly 7000 patients to date. Within the hospice, physicians, nurses, counselors, and additional staff are dedicated to relieving psychological distress, managing symptoms, and contributing to an overall 'good death'.³ The program's main goals are two-fold: (1) to provide skill training and education in palliative care to these young women; and (2) to provide ongoing psychosocial support to the hospice personnel. These goals are in line with the World Health Organization (WHO) Cancer Unit's expanded definition of palliative care, which includes considering the impact that death and dying may have on the well-being of patients and family members, as well as health workers.⁶

Literature suggests that young women, as caregivers, are particularly vulnerable to symptoms of distress⁷ and that this vulnerability is increased for the less educated

caregivers.⁸ The rationale of this study was to explore the experiences of hospice workers as they relate to death and dying, with a particular focus on young health assistants. This inquiry was primarily motivated by the managing trustee, who communicated concerns that young women with lower resources may be particularly vulnerable to repeated exposure to dying individuals (an average of 30 individuals died at the hospice every month) with the potential outcomes of being 'hardened' and becoming insensitive to this important life event. The perspectives of other health workers (i.e. registered nurses, social workers, nuns, and physicians) as well as administrative staff (a managing trustee) were also obtained to compare and contrast unique and shared experiences of these hospice workers. As such, the overarching research question guiding the inquiry was: 'What is it like to work in an institution where death and dying are a part of everyday life?' The importance of this study is two-fold: (1) to assess the well-being of hospice workers at this particular institution; and (2) to foster future avenues of research related to cross-cultural comparisons and the evolving worldviews of hospice workers as they gain additional experience.

Methods

Participant recruitment, sample, and procedures

Recruitment, data collection, and analysis took place between December 2008 and July 2009. Potential participants were sought who had diverse socio-economic and professional backgrounds, as well as those who had an interest in the study topic. Following approval from the hospice director and acceptance of the consent form, the second author (MS) approached potential participants in groups or individually to inform them of the nature of the inquiry. Participants were identified from all levels of the hospice staff to showcase a range of responses. Following this initial contact and informed consent, meetings were set up in a quiet room within the hospice with those who were interested in participating. Using a semi-structured interview guide, participants were either interviewed in small groups ($n = 2-5$) or individually. Semi-structured interviews with open-ended questions were developed and used to provide structure and focus on topics related to experiences at the hospice, while allowing participants the freedom to explain and expand upon their experiences.⁹ By alternating between semi-structured and open-ended questions, participants were given the space to tell their stories openly and occasionally deviate from the questionnaire.

The semi-structured interview questionnaire included the following: What do you like about

working here? How did you come to work here? Where are you from? Can you tell me one negative experience and one positive experience you've had since working here? How close to the patients do you feel after working here? How do you feel when a patient dies? If someone were to die in your family, how would you feel?

Continuation, elaboration, and clarification probes, such as 'Can you tell me more about that?', 'Go on...', and 'Can you describe that for me again?' were used to promote further explication of any issues raised. Non-verbal probes, such as pausing to allow the participant to speak longer, were used as well.¹⁰ To better understand participants' contexts, questions were asked regarding their backgrounds (e.g. socio-economic, age, education, and religion). Field notes were taken throughout the interview processes and thereafter. Each focus group ($n = 3$) was approximately 30 minutes and individual interviews ($n = 10$) ranged between 30 and 45 minutes. Participants did not receive financial compensation for their involvement in the study.

The study sample consisted of 25 health workers and administrative staff, that were interviewed on-site at a palliative care centre located in Bangalore, India. Interviews were audio tape-recorded and transcribed verbatim. The interviews were conducted in English with English-speaking participants. Non-English speaking participants' interviews were translated from Kanada or Tamil into English by a translator during the interview process.

Data analysis

Data were analyzed using the method of thematic content analysis¹¹ adapted from grounded theory. Analysis began during the data collection period and continued throughout the study. Two sources of textual data (transcripts and field notes) were read in their entirety for the purpose of data immersion. Next, line-by-line coding of the raw data was done. All text deemed to be relevant to the inquiry was highlighted and given a provisional label, remaining as close to the original data as possible. Data analysis steps were performed by both authors. Data were initially broken down into parts and subsequently conceptualized into categories, with the outcome being a description of factors pertaining to participants' experience at the hospice with a particular focus on death and dying.

Results

Participant description

Ten health assistants participated in this study and are identified with pseudonyms to ensure anonymity.

These health assistants had been recruited by hospice social workers and nuns from a number of small villages in the states of Kerala, Tamil Nadu, and Karnataka. These health assistants had no formal training in health care prior to arriving to the hospice. Their age range was between 18 and 22 and most had the equivalent of a high-school degree. All self-identified with a specific religion, primarily as Hindu and Christian, with one self-identifying as Muslim. All health assistants were single women.

In addition, five auxiliary nurses, four registered nurses, two social workers, two nuns, one doctor, and one managing trustee were recruited to explore their own perceptions on death and dying, as well as to share insights into the lived experience of the young female health assistants. The auxiliary nurses' ($n = 5$) age ranged from 19 to 23, self-identified as Christian or Hindu, and were all single women. The registered nurses' ($n = 4$) age ranged between 20 to 22, self-identified as Christian or Hindu, and were all single women. The social workers ($n = 2$) were married, Hindu women. The nuns ($n = 2$) were single, Christian women. The managing trustee ($n = 1$) was a married, Hindu man.

Three main themes emerged from the qualitative analysis of interview data. The first focuses on the paradox of death with mixed feelings of relief and sadness experienced by health assistants. Several health assistants also reported feelings of contentment and happiness with their work, despite the frequency of 'sad events' experienced (most witnessed about one death per day but some experienced up to seven deaths per day). The second theme relates to the multiple perspectives on death and dying that were reported and the mindfulness integration of personal and collective experiences. The third theme centers on how strategies and interventions to support health workers were seen as essential. Through several accounts, it became evident that these health workers' supportive strategies, such as open discussion amongst peers and supervisors, one-on-one counseling with social workers, daily meetings, and social excursions outside of the hospice, were implemented, monitored, and disseminated in the hospice as preventive measures. The psychosocial needs of all stakeholders in the hospice (e.g. health workers, registered nurses, social workers, and nuns) were equally attended to and were in line with the democratic philosophy of palliative care, where each actor is important and has a crucial and important role within the organization. Each theme is now reviewed, in turn, with relevant quotes from participants.

Paradox of death

The first theme relates to the paradox of death, specifically the mix of conflicting feelings (e.g. relief and

sadness) that health assistants felt while working with patients. Generally, these feelings were strongly linked to watching patients die, or 'expire', and the visceral experience of preparing a patient's body for the morgue in relation to the emotional experience of having had a personal relationship with them. As health assistants became familiarized with the hospice setting and with their role on the ward, the fear of death would begin to dissipate. As Ajita says:

Before I came here, I did not see death but, since I have come, I have seen death every day. I had a fear of the expired people, of touching the dead bodies. After one year the fear for this kind of work is gone. I was showing sympathy for the patient when the patient is in an advanced stage, when they are not in hope of cure. When I am taking care of this patient, that's when it's gone – the fear.

Ajita was able to overcome her fear of death by caring for patients up until end of life. The focus on caring instead of curing was consistent throughout the health workers' accounts of how they coped with 'touching' death on a daily basis. Yet, 'caring' and 'curing' would occasionally become intertwined, as in the case of Malika, who would provide some patients with false hope pertaining to curative therapies – a phenomenon referred to as collusion that is frequently observed particularly within non-western cultures:¹²

When the patient dies, I feel sad. But in that period I am saying 'Don't worry, you are not expired, you are not dead'. Then confidence is grown in dealing with these patients. In the period when I am sad, I say to the patients 'Don't worry, you are not expired'....When the patient is taken into care, I will get asked 'What is the condition of my health?' I will say, 'You have taken cure'. If they are to expire in the next day or the next month, I do not tell them that.

Although this approach was not frequently reported by the health assistants interviewed, it does suggest one facet of the paradox of death at the hospice: the false promise of 'curing' can be construed as a form of 'caring', as both a method of coping for the health assistant and as a way of giving hope to the patient. Often, the health assistants communicated fear, not for themselves, but on behalf of the patients, further underscoring the supportive emotional ties between the health worker and patient. By contrast, Vanitha was not scared of the patients' health condition, but instead felt a sense of empathy for their suffering:

No, I was not scared, but I'm very sad for the patients. I'm not scared, but they're suffering...we are feeding

from a tube, some people can't have their food, at that time I really feel for them.

All health assistants, auxiliary nurses, registered nurses, and nuns lived on the hospice grounds, thereby completely integrating their personal lives into everyday work routines. Although the health workers were given periodic leaves to visit their families in their villages outside of Bangalore, many expressed a reconfiguration of the definition of 'home'. For example, Vanitha relayed a personal narrative of how her parents had died when she was very young leaving her to live on the streets of Bangalore. Since starting to work at the hospice, she had only experienced a feeling of happiness and contentment with her life by working and serving patients in the terminal stages of illness:

When my parents died I didn't have any feeling for them and they looked after me very rudely, so I don't have any feeling for them. When my father died I was very small, so I didn't know. When my mother died I was twelve years old, I don't know how she died, but I don't have any feeling for that. I never felt bad. But when I came here, if I'm close with some patients and they die, I am very sad for them.

Vanitha's account of feeling 'sad' when patients died provides a more differentiated perspective on the literature's suggestion that young women with limited education are particularly vulnerable to symptoms of distress. Rather than a state of emotional vulnerability, Vanitha's account indicates a resilience and fortitude developed through her difficult past personal experiences that allowed her to be psychologically well-equipped to cope with palliative care issues. In this instance, a form of exchange occurs between the health worker and patient; the health worker provides emotional and medical support to the patient, while the patient provides the health worker with a sense of purpose. Occasionally, this health worker-patient connection was found to even supersede family bonds among health assistants. Deepa relayed an experience where she would not take her leave from the hospice:

One time the patient was crying on the deathbed and in that period I had to go home, but I said, 'I will not go home, I will stay with this patient'. If the patient is crying, I feel that I have to do service for the patient, nothing about myself.

This commitment to 'service' emerged as a significant theme among all participants interviewed.

Balancing individual with collective needs and well-being

The second theme relates to how the balance between individual and collective needs and perspectives contributed to ongoing dialogue amongst health workers and to the overall operations of the hospice. In particular, concerted efforts were made by the social workers and nuns to provide emotional and psychological support for all health workers involved. Yasmeen, a social worker who also acted as a recruiter for the Health Assistants Training Program, said:

Health assistants, according to me, they need as much as the patients. Health care, health givers, they also need psychological support. That's why these girls, the teenage girls especially, they're not very mature mentally. That's why we should speak with them and be friendly with them. Then they will be open. If they are feeling free, they'll tell everything: their fears about social stigma because they are from villages.

The hospice's openness on 'feeling free' to talking about experiences at the hospice, whether positive or negative, was emphasized by many of the health assistants as an integral process of functioning positively in their work life. The Health Assistants Training Program was designed to progressively introduce health assistants to the hospice wards and slowly increase their responsibilities towards patients before working more independently. The purpose of this gradual process (approximately six months) was to ensure that health assistants are provided with the necessary medical training to optimally support patients and to ensure that a tailored/personalized approach to psychosocial support is provided to this group of young women. Furthermore, once the health assistants begin to work on the wards, they joined daily meetings that were led by the social workers and nuns to provide emotional support through expression and sharing of feelings related to their experiences at the hospice. This sustained support from senior staff at the hospice acted as a preventive strategy to reduce the likelihood of health workers experiencing significant psychological distress and potential burnout. Yasmeen explained:

Very few [health assistants], but a few, and very senior girls [experienced symptoms of distress and burnout]. Maybe they finished five or six years. They are from this background, very standard family, very well-financed family. They expressed just one or two, that's it: 'I'm scared that if my father dies will I act like this? Here I do not cry, I am packing the body, I am seeing the body. I am scared'. And I tell her, 'This is

work and that is your family'. So that is why she took that break and went to see her family.

This example of distress in health assistants from 'very well-financed' families further complicates our understanding of the potential links between socio-economic status and emotional vulnerability, as suggested by some of the literature on the topic.

When asked if health assistants felt differently towards the death of a patient than the death of a family member, all replied that they felt sadness in both situations, but they had begun to lack feelings of fear related to patients' death. Both nuns, who had been working at the hospice and in a palliative care setting the longest of all health workers interviewed, expressed a similar perspective on death and dying. In particular, they described seeing many deaths as 'peaceful' and 'part of life'. Sister Nida explained:

Before I thought that death was something very bad, but now after seeing so many deaths, so many peacefully passing away, it is almost like going to my mother's house. I am not scared of dying now. I have seen so many of them go so peacefully. I don't feel sad or anything like that. Sometimes before death the patients struggle. That I mind more, and I pray that God take away their suffering.

In this instance, it is not the death of the patient that triggered a feeling of sadness or fear from the health worker, but the suffering and struggle of the patients in the face of pain. Encouraging the health workers to openly share their feelings about death and dying ultimately fosters a sense of camaraderie and support among them, thereby seemingly reducing symptoms of distress and burnout and contributing to the overall hospice operation and well-being of the collective.

Mindfulness of workplace initiatives as an exemplar of a thoughtfully designed grassroots initiative

The third theme centers on the hospice's mindfulness of how workplace initiatives supportive of health workers are implemented, monitored, and disseminated. Due to the unorthodox nature and recruitment structure of the Health Assistants Training Program, administrative staff members were particularly attentive to emotional, spiritual, and psychological repercussions that could arise by exposing these young health assistants to death at an especially vulnerable period in their lives. The hospice's managing trustee communicated this concern by stating:

The way I look at it is that these girls are coming from a background where it's more than likely that they

wouldn't have seen any death, not even at home...What I was talking about was not the fear element so much, but an element where once you begin to see deaths, which is quite likely because on average we have one or two deaths every day, once they're over the fear part of it, would they be taking death as something quite passé, something normal, and if they get that feeling would they, in later life, begin to regard death as something not really important?

The managing trustee described constant exposure to death as potentially 'hardening' and leading to a reduced propensity among these young health assistants to distinguish, emotionally and psychologically, between death from a professional perspective and death from a personal perspective (i.e. a patient versus a family death). Whereas the present inquiry did not find evidence for this process of being 'hardened' in the face of death, a longitudinal study that would follow these young health assistants over time and after they leave the hospice would provide further insights into this potential outcome. Health workers at the senior level (i.e. social workers, nuns, and administrative staff) were particularly mindful of the potential effects that working in a palliative setting may have on the lives of health assistants. In particular, specific protocols were established, such as the progressive exposure to the workplace over a six-month period, daily meetings to share feelings and experiences, and an encouragement of openness and comradeship amongst health workers at all levels. The focus on 'team rapport and bonding' has been suggested elsewhere as a way to open up a dialogue on death and dying – a topic that is generally avoided – to open up channels of communication among all involved: health care providers, patients, and family.¹³

A certain workplace hierarchy did exist within the structure of the hospice in terms of the specific duties that each category of health workers was responsible for (e.g. only registered nurses and doctors could administer medicine to patients). Yet overall, all hospice health workers performed very similar approaches to caring for patients and they were treated with the same respect by the senior staff. In this sense, a democratic process of mindfulness was demonstrated that not only supported the philosophy of palliative care, but also acted as an exemplar of how a grassroots initiative can provide egalitarian support for all levels of health workers. Not only did each actor contribute a crucial and valued role to the overall operations of the hospice, their work added significant value to their own lives. Multiple health assistants described feeling 'confident' and 'happy' while working with terminal patients and expressed fulfillment for the overall experience of living in the hospice facilities. The program

was seen as a means to provide young women, many recruited from the surrounding slums, the opportunity to enhance their education while also providing financial support for themselves and their families. Furthermore, a sense of moral responsibility and gratitude seem to have been cultivated through the multiplicity of experiences at the hospice by virtue of their exposure to a very intimate and often meaningful process – that of dying. As Pratima, a social worker, pointed out:

The hospice name means 'what is the life'. This is a 'life university' and day to day I am studying here. I improve my life here. I think 'what is the use of my life? What is the preparation of my life? What is suffering? What is pain?' I do not have pain. I feel some pain, but I see the cancer patients and I cannot explain their pain. This is humanity and now I am doing good work to help these people. So I've changed my behaviour and lifestyle since I started working here...Five years back I would think I want to own a car and a big house, but here this is nothing. This helping has more satisfaction. I have no money in the bank account, but I think with God some account is there.

Pratima's reevaluation of the guiding principles in her life is indicative of a shared understanding amongst the health workers that bolstered their commitment to service.

Discussion

The implications of this study highlight the importance of mindfulness for multiple perspectives on death and dying that are brought about by multiple actors within the hospice setting. Based on the data from this study, attention to and support of these perspectives seemed to contribute to the success and overall operations of the Health Assistants Training Program, a much needed grassroots initiative. Our findings underscore the importance of integrating supportive interventions and strategies, such as regular open dialogue, within palliative clinical settings to allow health workers the opportunity to alleviate potential symptoms of distress and burnout. In addition, the significant role that young health assistants play within the hospice setting suggests a promising avenue to possibly increasing the critical mass of workers dedicated to the care of individuals at end of life, while offering education and employment to underserved groups of young women.

Although the relief of pain is still a cornerstone of the palliative care tradition, attention is increasingly paid to how the process of dying affects the physical, spiritual, psychosocial, and functional needs of all stakeholders involved.^{14,15} In particular, palliative

care programs in developing countries increasingly consider the multiplicity of cultural and social contexts to accommodate the needs of the populations they serve,⁶ as well as those who are providing care. A mindfulness of the similarities and dissimilarities in cultural, socio-economic, and religious backgrounds inform the manner in which steps can be taken to support, prevent, and alleviate symptoms related to health workers' psychological distress and burnout.¹⁶ The recounting of workplace narratives by health workers can shed light on shared workplace experiences, thereby contributing to a sense of openness, belonging, and support in health care settings.¹⁷

Future directions for research would be to gather data before, during, and upon completion of health assistants' work at the hospice to gain a longitudinal perspective on their experiences and views on death and dying. Collusion, the process of selectively disclosing or withholding health status information from patients and/or family members,¹² would be an area worthy of further investigation in terms of the nature of collusion, its prevalence, and impact within a hospice setting. For instance, future work would assess how health care workers navigate through the experience of collusion and how this affects their relationships with patients, family members, and hospice staff. Last, an international exploration of other palliative care centers, that include similar grassroots initiatives, would yield powerful cross-cultural comparisons while capturing the richness of various settings in terms of institutional philosophy, practices, supportive resources and interventions.

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Competing interests

The authors declare that they have no competing interests.

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