

Constructions Of Dignity In End-of-Life Care

ANNETTE F. STREET, End of Life Care Program, School of Nursing, La Trobe University, Victoria, DAVID W. KISSANE, Centre for Palliative Care, Department of Medicine, University of Melbourne, Melbourne, Australia

Abstract / The meaning of dignity is commonly assumed but rarely examined in palliative care. Dying with dignity often forms the basis of clinical decision making at the end of life, but is constructed differently depending upon setting and context. A discourse analysis of patient and family case studies found that relationships and embodiment were important aspects of dignity that have been neglected in the literature, although these constructions of dignity matter to dying people and their families. An understanding of these constructions can assist clinicians in providing sensitive palliative care across a range of community and medical settings.

Résumé / On accepte couramment la notion de la dignité dans les soins palliatifs mais rarement ne s'attarde-t-on à en comprendre le sens. Le concept de la mort avec dignité est à la base de toute prise de décision de nature clinique, mais il n'en demeure pas moins qu'on le conçoit différemment, selon le contexte et selon le milieu. Dans des études de cas, où l'on fait l'analyse du discours des patients et de leurs familles, nous nous sommes rendus compte que les relations personnelles et l'image du corps étaient deux aspects importants de la dignité qui étaient peu abordés dans la littérature alors que ces interprétations de la dignité importent au mourant et à leurs familles. Une plus grande compréhension de ces interprétations pourra aider les cliniciens à dispenser des soins palliatifs avec plus de sensibilité tant dans le milieu clinique que dans la communauté.

INTRODUCTION

Dignity is a central concern in discussions about care and decision making at the end of life, yet it is rarely defined in clinical contexts or the literature, nor is there substantive published empirical work on the topic in the medical literature (1). A tacit assumption is often made in clinical papers that dignity has an agreed upon, unproblematic, and consensual meaning (2). Yet Coope (3) found the conceptual work was so mystifying that he advised that "the phrase 'death with dignity', which was never very clear in the first place, should be given up" (3, p.38). Similarly, Wear (4) argues that "the sanctity of life" and "human dignity" are anachro-

nistic terms that are inadequate tools to apply to decisions about the end of life (4, p.57-58).

Yet, an exploration of the psychological and social implications of an understanding of dignity is necessary for palliative care. Euthanasia or physician-assisted suicide has been practised in the Netherlands; Switzerland; Oregon, U.S.A.; and the Northern Territory, Australia, on the basis of providing a dignified death. Loss of dignity was posited as the main reason for requesting aid in dying in the Dutch Rimmelink Report, according to 57% of patients surveyed (5). Interestingly, in this study, 46% of people did not want to experience what they termed "unworthy dying". Clearly, loss of dignity and an unworthy death are intimately related, with this study demonstrating that the public perceive these areas to be of substantial concern in making decisions around the end of life.

Despite fear of intolerable pain being a concern raised in most studies on the desire for death, Emanuel (6) found that "no study has ever shown that pain plays a major role in motivating patient requests for physician-assisted suicide or euthanasia" (6, p.75). Likewise, the review of the first year of the State of Oregon's Dying with Dignity legislation found that patients who chose physician-assisted suicide were seven times more likely to be concerned about loss of autonomy and nine times more likely to be concerned about loss of bodily functions than control patients (7). People who chose to die under the Northern Territory's Rights of the Terminally Ill Act were much more concerned with being dignified, exercising autonomy and control, maintaining an intact self and a sense of worth, than with being pain free (8).

This paper is derived from a study in progress titled Dying with Dignity (9), a discourse analysis of the qualitative findings on dignity from a number of related studies on end-of-life care (10-15), along with an analysis of the diverse professional and lay literature. In this article we want to open up the debate on

dignity at end of life by exploring areas rarely discussed—the silenced discourses of dignity as relational and embodied. These aspects of dignity have been described as “being human...the capacity to communicate, recognise close family and friends and to maintain continence” (16). In this paper, we extend this description further and argue that dignity is relational and constructed through relationships with others. We contend that dignity is also embodied, as it involves aspects of how people experience the disintegration and decay of their bodies. Although there is a range of clinical implications that flow from such an expanded understanding of dignity in palliative care, this will be addressed in another article. The intention here is to situate these aspects of dignity alongside other important interests of palliative care, such as symptom control and attending to psychological, social, and spiritual needs.

METHOD

This paper is derived from a discourse analysis concerning portrayals of dignity at the end of life. The study drew upon the published texts provided by the literature, Internet sites, media reports, legislative and policy statements on euthanasia and palliative care in a number of countries, along with the created texts of narratives and case studies from interviews with patients and family members. The interviews and literature were subjected to a qualitative content analysis to code the text into designated core concepts, chosen because of their faithfulness to the data and their relationship to the literature on dignity.

These concepts provided the basis for a discourse analysis that identified discourses pertaining to dying with dignity. A discourse is a useful tool for analysis, as it shows how particular forms of language, associated practices, and social institutions combine, not only to structure what it is possible for us to think or do, but also to limit our potential for thinking and acting differently (17). One of the most helpful ways of thinking about how discourses can be analyzed is captured in the words of Mills:

A discursive structure can be detected because of the synchronicity of the ideas, opinions, concepts, ways of thinking and behaving which are formed within a particular context, and because of the effects of those ways of thinking and behaving (18, p.17).

Discourse theorists are well aware of the differing constructions of such texts, and the way that certain texts and, by implication, certain voices,

ideologies, and relationships are silenced or privileged (19). The discourses of dignity that emerged from the wider study were the commonly discussed discourses of autonomy, sanctity of life, personhood, and psychological distress, along with the rarely documented discourses of social relationships and embodiment. It is these two latter discourses that we intend to explain in this paper.

Defining Dignity

Dignity is derived from the Latin noun *dignitas*, which means: (a) worthiness, merit; (b) greatness, authority; and (c) value, excellence (20). On this basis, it has been defined as an aristocratic term of distinction (21, p.133), a position of “social snobbery” (22), or an inherent right of every person without exception (20).

Dictionary definitions of dignity use terms such as pride, self-worth, self-regard, and self-respect. Such terms indicate the need to assist the patient to retain an intact self, to locate the care of the individual in relation to their value system, their own personality, and their social world. Dignity is the source from which human rights are derived, and it also refers to the way we feel about others and ourselves (20). Dignity is socially constructed through our belief systems, experiences, and culture, often being represented as autonomy, self-worth, sanctity of life (23), or physical capacity (3). Dignity is a subjective experience, perceived individually, such that each person has their own view about what is dignified for themselves and for others. For some writers, the manner by which a death with dignity is attained is a very private matter (24), whilst others are more concerned with the need to find socioculturally acceptable definitions that define social legislation and action (25). Theologians have explored dignity as a religious or transcendent experience inherent in human beings made in the likeness of their creator (26). Dignity is implicit in the writings of those concerned with spiritual aspects of death (27,28). It has been also linked to quality of life in much of the nursing literature (29), without further explanation. Similarly, there is a number of articles with “dying with dignity” in the title that ignore the issue of what this might mean (30).

An understanding of dignity is necessary to structure the concrete, everyday care tasks, relationships, and decision-making processes for dying people. Too often assumptions are made about what a dignified death would mean. Studies have shown that health professionals may be concerned about different indignities, in

terms of care situations, than those indignities that matter to patients (31–33).

The effect of this dissonance is evident when we consider requests for assisted suicide. The provision of excellent hospice care does not eliminate such inquiries, with the loss of dignity being posited as a reason in the literature (34–36). Differing views on a dignified death will affect the decisions made by doctors, the choices they offer, and their support for the choices made by dying people. Medical responses to such requests are influenced by moral and theoretical positions on medical roles in relation to patient autonomy (37).

Dignity as Autonomy and Self-Determination

Facilitating patient autonomy is a central concern of bioethicists, legislators, rights activists, and clinicians. The literature on end-of-life issues uses the word dignity continually in arguments supporting competing ethical positions (38,39). Although self-determination is the basis for some of these arguments (40), there is considerable slippage in usage. Readers are left to infer a definition on the basis of the context of the situation, through association with other terms or through comparison with alternative positions. In this way, the term dignity is socially constructed through the differing representations of various interest groups. An alliance with a particular group, such as a professional affiliation or a rights-based lobby group, might determine an understanding or usage of this term. Yet the meaning involved usually carries several subtle differences.

Emotive images of indignity are often used to delineate dignity by association. For example, in the following transcript from the court case of the voluntary euthanasia group Compassion in Dying versus the State of Washington, dignity is associated with adult humanity and is separated from childlike dependence.

A competent terminally ill adult...has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent (41).

Such an association immediately engenders an emotional response of agreement and distaste for many people. The use of words such as “helplessness, diapered, sedated, incontinent” preys on the fears of many, yet the court statement does not specify of what a dignified and humane death consists. This lack of definition is telling. Wachter (42), in a keynote address at the Eighth Biennial Conference of the World Federa-

tion of the Right to Die Societies, argued for care in the use of definitions:

Definitions are not neutral. They are not just the innocent tools that allow us to describe reality. Rather, they shape our perceptions of reality. They select. They emphasize. They embody a bias. Therefore, definitions constantly need redefinition (42, p.1).

It is a lesson that supporters of euthanasia and physician-assisted suicide have learnt as they have moved from using terms such as “mercy killing” to “right to die”, then “dying with dignity”, or euphemisms such as “gentle landing” and “deliverance”.

Similarly, palliative care practitioners have also refrained from defining dignity, despite their constant interest in preserving dignity for all. The key construct of “sustaining quality of life” through attention to all domains of patient-centred and family-centred care, including physical, psychological, spiritual, existential, social and cultural needs, has implied some preservation of dignity. But, again, dignity has been subsumed into quality-of-life domains, rather than having been explored for its complex and hidden meanings.

A notable exception was a study by Turner (16), which examined the final three days of life of 50 consecutive patients on a busy, integrated palliative care service, to ascertain if they died with dignity. As there was no agreement on a useable definition of dying with dignity, the researchers resorted to measuring a range of variables agreed upon by staff. These were the typical indicators of a quality palliative care program, and included the final cause of death, symptom control, drug prescription, retention of personal function, and other measures. There was no clear link between these variables and a dignified death. Staff reported considerable difficulty in assigning the death-with-dignity scores. Concerns raised by staff included: “not really being sure what we are actually measuring”, “uncertainty about whether the extrinsic factors really made any difference to the overall dignity of the death”, and awareness that the staff “did not really know what the patient thought about the whole issue” (16, p.11). The researchers went on to suggest that, if dying with dignity is “to be critically evaluated as a desired outcome of palliative care services, further conceptual development and appropriate studies are required” (16, p.12).

For patients in our studies, maintenance of their dignity lay in many things. Key needs were a sense of control and a capacity for autonomy. One woman described this as “being

able to define your own limits to suffering and not having other people define them for you". Such decisions sometimes violate the staff's opinions about what a dignified death can be. In the following case, medical and nursing staff struggled to come to terms with the decisions taken by a 30-year-old man and his young wife. His self-regard was aligned with his capacity to be faithful to natural therapies, even when they meant that he suffered great disfigurement, pain, and discomfort. Dignity as self-determination was important, and the nursing and medical staff had to negotiate through this process.

One particular chap—young man—who had a cancer on his tongue and was very alternatively oriented and refused all treatment right from the beginning, so had no excision or nothing and, of course, the tumour just eroded his tongue, eroded back to his jaw bone and right into his neck, so he had huge fungating tumour issues. So there was the smell, that was dreadful. He couldn't swallow. Pain issues were enormous. He was a poet and he was beautiful and he was 30, and his wife was an artist and she was 29 and beautiful, so their whole life was about beauty, and the irony was he had one of the most disgusting ugly tumours and cancers you could deal with. It was incredibly confronting for the service, and incredibly confronting for the GP...there were huge issues about trying to negotiate pain relief, huge issues around starting on a pump when the pain was out of control and the vomiting was out of control, awful stuff. That is one of the closest working relationships I've had with medical practice, because we all needed each other (43, NC1).

In other contexts the self-regard of dying people was tied up with their autonomy and capacity to maintain hope and courage to the end (44). In such instances, medical and nursing staff needed to find ways to support the integrity of the person without inappropriate use of expensive resources, yet with a sustained sense of battling the cancer.

Dignity as Personhood or Self-Worth

In contrast to the emphasis on autonomy, Cassell (45) focused attention on personhood, emphasizing the individual's past, their secrets, successes, lifelong work, together with their current strengths and interests, talents, vitality, and their context within a family and community. Inherent in this, he implied, was the need for respect and regard for all that this individual represents—their dignity as a human person. This interest in personhood typifies the relationship between dignity and personal worth. If "loss of dignity", in the Rimmelink study, can be equated to loss of autonomy, then fear of an

"unworthy dying" can be related to the concept of personhood or dignity as self-worth. Thus, palliative care draws upon concepts of dignity as both self-determination and self-worth.

Even in the best accounts of care, the struggle for the patient to be always regarded respectfully and not to become an objectified body part is evidenced in the following case of a wife speaking of her husband, an eminent doctor, dying from an unspecified brain tumour.

He was extremely sensitive to whether the staff respected him or not. And they were really very good at that in the hospice...but there was one occasion, just a few days before he died, when we stood around his bed talking about something that was actually about him. We talked about his head. He made signs so that everyone's attention shifted, and we looked at him and he just rolled with his eyes, like this, and we all felt ashamed. We all felt that he was telling us, "Oh, now you are doing this again. You are talking about my head. Don't do that." And it was very striking. And if anybody—when he was not ill, when he was healthy—if anybody had treated him without respect, I guess he would have reacted very strongly (11, CS2).

In this and other cases, it was apparent that dignity meant maintenance of self-worth, self-respect, and personhood in their fullest meanings. The rhetoric of personhood, quality of life, and self-worth in palliative care creates a philosophy that guides the practice of its craft. Its use of language is equally critical in the transmission of its message to new practitioners (46,47), but also to the wider public, in enhancing their education about its purpose and intention. If dignity is not made explicit in this transmission, then practitioners may be bringing different interpretations to the encounter than are the people they care for.

Yet, there is a range of patients who come into care with problems in their sense of self, sometimes presenting with disorders of mood, at other times with developmental issues with their personality. Patients with such disturbances may appear vulnerable, indecisive, insecure, demoralized, or depressed (48,49). Poor self-esteem may engender in them long-held negative perceptions of themselves as people. Fears of lack of dignity may lead them to desire a hastened death as closure on an unhappy life. Their perception and beliefs may be dissonant to the perceptions of others, whose understandings of dignity are constructed differently.

Dignity is Embodied

Despite the emphasis on personhood in care for the dying, dying people know themselves and

are known by others through their bodies (50). It is their bodies that are changing, losing function, and decaying (51). It is their bodies that set limits to their experience and ultimately dictate that their lives must end (52). They communicate through their bodies; they experience the world through their bodies (53).

In working with the medically ill, Vamos (54) described four key components to the concept of body image: our sensory experience of the body or comfort; its functional ability or competence; its appearance, as evaluated emotionally and cognitively; its variability and our adjustment through this. Such conceptual work may provide useful analytical tools for psychiatrists but, as a by-product, it sanitizes and disguises the embodied experience of dying. To enhance our understanding of the experience of patients, we turn to the work on abjection (55).

Dignity and the Abject Body. Kristeva (55) argued that our sense of selfhood is connected with the separation and integrity of the body, but that this concept is limited; that the boundaries of our body are never completely drawn. By this she means that we know ourselves through relationships, and so we are never entirely separate and autonomous. Similarly, even when well, the perimeters of our bodies are routinely broken by "flows of urine, tears, shit, vomit, blood (especially menstrual blood), sweat and semen" (56). Abjection describes this state. It is an ambiguous state of ruptured boundaries of skin and orifices. It typifies the dissonance between clean and unclean, the proper and the improper, order and disarray. Abjection is a rejection of the body that cannot be known as a "clean and proper" thing (57, p.78).

In illness, the body is altered and suffers in myriad ways, through amputation, stomas, fistulas, bed sores, ulcers, and various impairments of limb and continence function. It becomes a source of disheartenment, a focus for shame, humiliation, and disgust.

Dignity and Shame. Shame is a psychovisceral response that is managed through processes of displacement, repression, or sublimation (55). Repression is part of the socialization of professional carers, who learn to suppress their instinctive horror at the abject body. Repression is learned through repeated encounters with abjection. Familiarity with the disintegration of bodies assists staff to cope with new encounters. Coping with the reality of the abject body is a much harder learning task for the dying person and their loved ones. Continuity of care enables some family members to accommodate to

gradual change and builds their capacity to accept bodily decay. However, for some patients, the shame and disgust with their body can cause overwhelming suffering (37).

Although routine to doctors and nurses, bladder and bowel incontinence are perhaps the commonest priority for patients and relatives in terms of the indignity and shame. Incontinence has a psychosocial relationship of horror to the abject body:

The personal disgust and various social taboos associated with *waste* also attest to a psychosocial horror at what transgresses border and boundaries. Bodily fluids, wastes, refuse-faeces, spit, blood, sperm, etc. are examples of corporeal by-products provoking horror at the subject's mortality (57, p.75).

The loss of capacity to affect these aspects of self-care, which are fundamental parts of early socialization, may be considered more of a loss of dignity than medical problems, which are considered the domain of the doctor or nurse.

Patients in the studies demonstrated heroic attempts to maintain bowel and bladder functioning, at the expense of comfort, in order to preserve dignity. For example, a dying 27-year-old man described his shame and humiliation around his struggle to continue to use a commode:

The other day I was sitting out of bed, on the toilet chair, and I knew dinner was coming soon, but I had the door shut, so I thought that would be enough. This woman knocked on the door and I said "No!", and she said "I've got dinner." I said "No!" again, and she repeated "I've got dinner" and just came in anyway. Then, while I was still trying to use the pan, two more people just came in without even knocking. I had the door shut and the blind down, but the blind is on the outside of the door, so they could have looked in and seen that I was on the toilet, and given me some space. But they have no brains, they don't care...It's not just lack of personal space, though. It's more than that—it's lack of respect, lack of humanity. That's humiliating. To have no rights. And I can't even get up and shut the door myself (11, CS3).

The difference in priorities for patients and family members, concerning what was socially desirable and what belonged to the domain of medicine or nursing care, was apparent in Roy's wife's account.

With Roy, managing to go to the toilet was terribly important right up until he died. He would undergo agony just to go there and not need a nappy. He thought that being assisted at the toilet was most humiliating. He was always a very fastidious man. He didn't want any nurse to be touching him "down there." He did not want nurses dealing

with his private parts. And some of that was about dignity for him....Roy was happy with them (nurses) managing his awful wound...that's their business. But he wanted to deal with his own...thing (points to groin) (11, CS1).

When incontinence or smelly discharges are part of life for the patient, then the maintenance of a semblance of control and normality is essential for self-regard.

Dignity and the Smells of Death. The problem of managing body odours is another psychovisceral horror that challenges the notion of a dignified dying. For one woman, the heroic efforts by nursing and medical staff to repress their reactions to the smell of her fungating wound confused her. During her interview, she spoke about her feelings of being "so smelly" at length. She said that she had felt so strange and isolated when everyone behaved as if they couldn't smell anything. She had ideas about how to "make the room smell better", but didn't know how to raise the topic with the seemingly oblivious staff. Yet these same staff had been intentionally devising specific strategies to manage her care without gagging.

Keeping any reminders of the post-mortem body at bay through ritual practices becomes important, as is evident in one woman's description of a hospice:

All the time in the hospice, it was so clean. They used soap that was very, very lightly perfumed. They always changed sheets and pillows and everything, just if there was a small, small stain they changed it. So you could really sit in the bed...I could lie close to him in his bed without feeling that there are smells that I don't like, or it's urine, or anything. It was always that clean (11, CS2).

However, other family members were concerned at the lack of attention to the environment surrounding their loved ones, citing "cracked flaking walls" and "fluff in the corners" as creating undignified places for people to die. Economic constraints had affected the level of cleanliness and maintenance in some facilities, and this was regarded as humiliating.

My son likes me to clean because he knows that staph lives in dust, and so he likes it if there's no dust, and the only way there's no dust is if his mother sometimes cleans. Cleaners don't clean...I once asked a cleaner who cares a lot if she could mop the floor. She was pleased, but she brought in the most foul-smelling mop you can imagine, and she had just filled the bucket up, I watched her fill it, but the mop smelt like a large men's urinal (11, CS5).

Attention to cleanliness and odours enabled a nurse to cope with the smell of death in a digni-

fied way, and to understand the power of hygiene to nourish communication with her dying husband.

And even when he smelt from his mouth the last days, I felt that I could embrace him, and give him a big hug, and sniff the back of his neck, and it was a good smell. And I thought a lot about that, as a nurse, because you are taught that hygiene is very important, more to control the bugs and bacteria, but I hadn't thought of all hygiene as communication before. And that's probably the most important time, especially when, as a relative, you are their only link to the real world. You are the only hope. I mean, it's so important to maintain the physical links, to hold, and be very touchy and close. And it's only as a relative that you can give all that, you can't as a nurse. You can't be that close as a nurse. It's nothing that staff can compensate (11, CS2).

The ritual practices of nursing hygiene can assist relatives to repress the abjection associated with decay, and enhance the dignified facade of an intact body. This account also demonstrated the way that dignity is not an isolated concept, but a relational one. In this instance, dignity was facilitated by the staff's attention to hygiene, and by the wife's ability to give her husband the love and touch that affirmed his worth as he was dying.

Dignity as Relational

Dignity is reciprocal. It is about a process of inter-subjective relationships, because it is nurtured and supported in the interpersonal space that exists between people in relationship. Early development of personal dignity is derived through the mirroring affirmation that parents communicate to their child as they help that young person to grow in self-knowledge and confidence (58). The resultant self-esteem of the adult remains dependent on feedback from others to stay robust and empowering throughout life. Thus, early socialization is important in the values that dying people hold about themselves and in their understandings of what life means for them.

At the other end of life, relationships continue to critically influence dignity. Loving care for a sick member from a devoted family can be contrasted with messages of worthlessness and pointlessness sometimes delivered to alienated or isolated members of society. Health professionals can influence a patient's perception of his or her worth through their communication style about treatments, prognosis, and goals of care (37). Any sense of personal worth is nurtured or damaged, sometimes unwittingly, through the sensitivity and choice of words used

in communicating medical information (59). Doctors, nurses, and family members all develop strategies to sustain the patient's dignity and, in turn, their own self-esteem and dignity are enhanced.

Violations of dignity occur in relation to dissonances that develop between the picture we hold of ourselves and the experienced reality when our mortality confronts us (51). One man with a brain tumour feared loss of dignity as bodily functions failed. He was aware of his wife's horror at her mother's incapacity and neediness following a stroke. A premature death would save her confronting his disability.

She had a dreadful time with her mother. She appeared like a cripple, useless, not the person she'd been. It was pitiful to see her in that state. Watching her lifted with machinery from bed to the bath made my wife feel helpless. I wouldn't want to put her through that again. When I start to deteriorate, I'd prefer you give me the quick tablet (11, CP4).

Feeling helpless can influence our perception of a dignified death. Wanting to protect a loved one from the emotional burden of watching an undignified death can lead to requests for assisted suicide. Family members fear expressions of disgust or revulsion from relatives and avoid conversations that might give glimpses of such feelings (60). The nature of family relationships has a significant influence on the permutations of dignity as enacted within the family, especially in relationships shaped by sexual desire.

Dignity and Desire. One of the myths of the dignified death is that it is a sexless death. Desire, central to our being as people (61,62), supposedly disappears, and intimacy is reconstructed in such a way as to deny the sexual and sensual needs of the dying person. In order for one woman to maintain her relationship with her husband as that of a sensual lover, she chose to lie with him and stroke him until the end. She would not engage in care tasks that were negative.

I set my own boundaries...I helped, with joy, to feed him. But I never gave him the medication, because I know it tasted bad. So all of the negative things that were associated with negative experiences, I let the staff do. And I was never involved in changing any nappies or doing any of this. I didn't want to be in that kind of relationship with him. He had been my wonderful lover (11, CS3).

Freud's (63) original work on the body ego has been extended by Anzieu's (64) work on the skin ego, which argues for the sensory envelope of the skin that retains historical memory and

physical traces of experience. Madioni (51, p.162) argues that the end of life can tear the body-envelope reference points and reactivate "archaic sentiments related to maternal care." The "torn envelope" can allow a "nostalgic need for regression and the source of distress that is difficult to put into words as it brings up fragmented, forgotten sentiments" (51, p.162).

This need for the fragmented, forgotten sentiments of sensual intimacy was evident when another dying woman explained her need for sexual expression, but didn't know how to ask her husband, whom she assumed no longer wanted her sexually or who was inhibited by the hospital environment. She said:

It is so hard to put into words...it (sexual expression) seems undignified here (in hospital) somehow, yet I would find it so comforting (11, CP5).

The notion of what her husband considered dignified contrasted with her intimacy needs and dignity as a still-desirable woman.

CONCLUSION

Notions of the "good death", or even its less idealized form the "good-enough death" (65) as promoted by palliative care, bring romanticized ideas about a death with dignity. In palliative care environments, culturally sanctioned and prescribed behaviours are designed to make death meaningful. Maintaining dignity is central to end-of-life care. Yet the limited definitions of dignity that inform palliative care practice do not include discussion of those aspects of dignity that also affect how dying people feel about their bodies and their care at end of life.

Dignity is socially constructed, individually perceived, embodied, and relational. In contemporary society, where the authority concerning the "right" way to die has become increasingly vested in the dying individual (66), dignity becomes paramount to their mode of dying. Health practitioners need to become more aware of the hidden dimensions of the kinds of dignified death that matter to patients and their families, particularly in environments where resource constraints and staff cuts limit the possibility of providing the five-star palliative care death (12).

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