

The meanings of gender and the home space for recipients of palliative care, and some implications for social workers in the field

// Catherine Rose Hughes // Helen Gremillion

Unitec Institute of Technology, Auckland, New Zealand

This article explores the occupation of gendered spaces on the part of four men and four women journeying through palliative care. Drawing on ethnographic and interview data focussing on participants' experiences with cancer, the authors analyse patients' engagement with gendered concepts and activities surrounding either the home space, or intentional efforts to be away from the home space. Participants were followed from referral to a community palliative care team until the point of death. This article reports on one part of a larger ethnographic study by Hughes (2009) that examines the context and culture of palliative care, and the important role of social work for such care, from the perspectives of these eight terminally ill people and their extended family/whanau. All participant names cited are pseudonyms.



Gender and the Occupation of Home Space

Berk (2004) suggests that men and women tend to occupy different spatial domains which they have been socialised into in early childhood. Within the home environment there are spaces that are conceptually regarded as male or female. In the early stages of data collection, on arrival at participants' homes, the researcher would often find women participants in the kitchen or living area and men outside, in the garage or in the garden. These patterns either deepened or changed over time, with a noticeable shift in the occupation of certain spaces as a direct result of participants'

illness. However, the gendered patterning of home spaces varied along with participants' background experiences.

Gender Role Shifts

One participant, Jack, had established clearly identified gendered roles in his marriage. His wife had worked part time and taken care of the home and their three children. Jack had always worked full time, played rugby and coached the local rugby team. Although Jack was initially found in the garden or in his workshop when the researcher first began visiting, he later talked often about housework. He said that taking over some of the household chores gave him a sense of purpose,

and helped him maintain a sense of dignity as he felt he was still contributing to the running of the home. Jack explained that stepping into a different gendered role also made him think critically about his wife's life and his own behaviour. As detailed in the researcher's field-notes

Jack explained that he had learnt how to cook and look after a home when he was very young as his mother became seriously ill. He said, "I either had to learn to cook and feed us kids or starve to death." He went on to explain that after he was married he was not involved in the daily running of the house and he had forgotten how time consuming it was.

A second participant, Helen, was still working part time when I met her and she tended to carry out most of the household tasks, such as the gardening and the cooking. Her husband Chris did the lawns and worked full time in their business. Helen had decided to teach Chris how to look after the house and how to cook before she died. She also had to teach him where to go shopping for clothes as she had always bought his and their children's clothes. After Helen's death, Chris kept up with her work in the garden and built a memorial garden for Helen. He kept cooking the traditional meals she had taught him to prepare and maintained their large home until he later downsized.

'Traditional' Gender Roles Deepening or Becoming More Visible

One of the younger female participants, Alice, was a primary school teacher prior to her illness and her husband was a labourer. After leaving work Alice spent more time baking and cooking meals, tasks that she and her husband Dennis had shared when they were both working. Alice had always done the housework though and often joked that Dennis was incapable of doing so. As her illness progressed, the meaning of carrying out these chores changed for Alice; these acts became symbolic of life itself. The following is from field-notes:

"It means so much to me to be here with Dennis and when he goes to work I just feel empty. But doing the housework and things around here makes me feel close to him and I like doing this. ... It may not seem like much to other people but I feel really good if I can get something as simple as the vacuuming done, it makes me feel like it's worth living".

It did become a lot more difficult for Alice to continue doing these things as her health deteriorated, and the house grew increasingly messy and



disorganised. Alice died in a bed with no sheets, surrounded by piles of washing that needed to be done; she had asked Dennis for help but his skills and abilities around the house were severely lacking.

Another participant, Daniel, had been a truck driver prior to his illness. He bought a car not long after I met him and he spent a lot of his time out driving, highlighting his tendency to be away from the home space. His wife preferred him to be out of the way so she could get her housework done. She did not drive or deal with money. They were very clear about the gendered nature of their roles and neither of them were interested in changing them.

Non-traditional Gender Roles

Joan had been widowed in her 50s and had taken over her husband's trucking business after raising her seven children. She maintained the gardens, the house and the business into her 70s. She then met Bill and as she got sicker she sold the trucking business. Bill, who had also been widowed for a number of years, carried out the household chores, the cooking and cared for Joan using all the skills he had developed in the years he had been on his own.

Tom and Michelle were in their 40s and had three children between them. Tom's first wife had died four years earlier and he had maintained the home until becoming ill. Michelle

and her son then moved in so she could care for Tom. Although Michelle carried out most of the daily tasks Tom helped where he could which, as for all participants, became increasingly difficult for him as his illness progressed.

Billy was in his 40s and his wife Rose was in her 30s; they had recently met and married prior to Billy's diagnosis. Billy had been a chef and he continued to cook as he was able, and he and Rose looked after their home together. They did not have clearly defined gender roles and shared most tasks.

Status Quo Gender Roles

Elizabeth, who was in her late 70s, was quite ill by the time I met her and although she had carried out every task associated with domestic life during her married life, her daughter Penny, with whom she now lived, provided all the care for Elizabeth and carried out all the tasks in their home. Penny's husband was a fisherman and away at sea for extended periods of time. When he was at home he carried out maintenance on the house and the yard but did little in the house.

Broader Gendered Discourses Surrounding Being at Home

This research project also queried whether participants felt marginalised after leaving employment and spending significant amounts of time at home. The findings suggest that responses here varied by gender. Women often experienced home as a type of life support, and a haven from the world (McDowell, as cited in Fincher, 2007). Men, on the other hand, expressed concern about being a burden at home.

The following from the researcher's field notes illustrate women's responses:

Alice - "people can't believe that I just want to stay at home during the day. All I want is for Dennis to come home from work, I just want to curl up on the couch with him and let

everything else stop.”

Joan was very clear that she wanted to go home when she was close to death. She characterised her home as a nurturing place and was especially looking forward to seeing her garden.

Men’s responses were quite different:

Jack said, “I suppose I’m better off here right now (in hospital), I don’t think I would be able to cope at home on my own. He also said, “it wouldn’t be fair on Betty if I went home right now.”

Daniel said, “I never told Emily or my family that I was sick, I kept it a secret for a long time ‘cause I didn’t want to burden the family”. ... He also said, “I thought about disappearing into the bush so no-one could find me, that would save Emily from having to look after me.”

Men’s responses to the idea or experience of being at home could be referred to as performances of masculinity (Seale and Charteris-Black, 2008). They may reflect deep-seated cultural discourses locating home as a ‘woman’s domain’ and as a place that requires the ‘protection’ of men. Perhaps in these contexts men are called into a concern that their very presence at home when ill or dying would become a burden (rather than a support) to their wives. These responses could be described as maintaining a stereotypical masculine identity (Seale and Charteris-Black, 2008) through which the man not only protects the family from outside influences but also from inside influences and threats such as terminal illness. Threats such as this may destabilise the home environment, the place that in traditionally gendered relationships has been provided by the man for the protection of the ‘more vulnerable’ woman and children.

Summary and Implications

As illness progressed, most participants found themselves spending more and more time at home, and many participants, as



well as their partners, began to associate being at home or being away from home with important gendered meanings that they linked with the process of death and dying. One key finding is that for all the cases in which significant meaning was associated with gendered activity, participants had practiced traditional gender roles prior to life-threatening illness becoming a major part of their lives. None of the participants, who had occupied more non-traditional roles in the past, attached significant meaning to shifting, or intensifying, their engagement with gendered activities during the course of palliative care. Another finding is that women patients often experienced home as increasingly important for comfort and meaning, whereas men often tried to stay away from home. We speculate that the latter is due to gendered discourses about male ‘weakness’ (in need of care at home) as a burden. Interestingly, no male participants died at home; one died in a hospice, two died in hospital, and one died in a rest home. The two who died in hospital experienced a higher level of medicalised death, which is not the preference in palliative care.

This project supports Seale and Charteris-Black’s (2008) finding that women do not perceive illness as a threat to traditional gender expectations, as well as Emslie, Ridge, Ziebland and Hunt’s (2006) research suggesting that the opposite is true of men. These

findings suggest particular directions for further research and/or palliative care practice. Special attention to gender, space and place for people – especially men – who have embraced more traditional gender role expectations might help to ensure that choices around death and dying are not blocked by gendered concepts that could potentially be minimised or shifted if attended to. Men and woman can consciously distance themselves from culturally dominant forms of gender identification and allow themselves to be

gendered in other ways (Emslie et al., 2006). The challenge for health professionals is to be critically aware of narratives that polarise masculinity and femininity in ways that might limit access to care.

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