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

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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 participating 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 either had to learn to cook and feed us kids or starve to death.

A second participant, Helen, was still working part time when I met her and she wanted 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 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 caring 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.

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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 vary 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’ 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

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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, “I 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 (so 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 & Charteris-Black, 2008). They may reflect deep-seated cultural discourses locating home as a ‘woman’s domain’ and as a place that requires ‘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 the problematic masculinist 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 practised 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 Emmslie, 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 (Emmslie et al., 2008). 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. References


Gender still matters - I guess if you don’t think it matters, you probably won’t be taking part in this debate, so maybe this doesn’t need saying. But in the wider world of social work, beyond those who are interested enough to join in a debate on gender, there is perhaps a job to be done to remind people about the salience of gender. There are ongoing and deeply entrenched inequalities, despite the gains made in some aspects of women’s social status in recent decades. There are enduring fixed ideas about what is appropriate behaviour for men and women which become deeply embedded in people’s identities. So, for example, social workers in the child protection field will encounter some profound inequalities in families which are often linked to maltreatment of children. Domestic abuse, for example, which is so overwhelmingly perpetrated by men, can be found in perhaps the majority of child protection cases. And social work practice responses, whilst trying to help, can end up perversely deepening inequalities by making women (mothers) responsible for turning round grim family situations which are primarily caused by abusive men.

Gender doesn’t mean women (obviously) - Again, people taking part in this debate don’t need to be told that men too have gendered identities and men’s behaviour is shaped by gender. But as with the first point above, in the general world of social work, people do need reminding of this. Working with men is still a fringe, specialist and marginal area within social work. People like @bigrid39 and I have been banging on about it for some time but it remains a Cinderella topic. It would be a mistake to think that an interest in working with men need imply either (1) that you are a men’s rights advocate who thinks men are now the main victims of the gender order (or 2) that men should always be thought of as potential abusers. This kind of dualism is in fact very unhelpful, which leads to my next rather obvious point.

Gender’s complicated but femininity is still relevant - A crude feminism is no help to social work and neither is a crude men’s rights approach. Feminism is a broad church and includes a wide range of ideological positions. We need an approach to understanding gender relations which recognises that real life is more complicated than some simplistic sociological generalisations might imply. So, for example, we should recognise that there are several different kinds of domestic abuse, not all of which are about men terrorising women partners. But at the same time, we should not throw the baby out with the bathwater, so to speak, as the core concern of feminism with unequal social relations and a world stacked in favour of men’s interests is still relevant in 2012 and beyond. So, to use the same example, we need to recognise that most domestic abuse is indeed initiated by men and much of it is linked to the desire to control a woman partner.

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We need a better balance of evidence and ideology - Finally, I think that in relation to this issue of gender in social work, we need to spend a little less time on ideological assertions and a bit more time trying to find out what works. There is a tendency - for example in the domestic abuse field - for differences between approaches to practice to be based on what people believe rather than on evidence of effectiveness. But ideological debates are really interesting, I think, but we’ve had plenty of those and perhaps we’ve not had enough debate about which approaches to intervention actually help men and women – improve quality of life and material circumstances, change behaviour where necessary, make people happier. This is a complex issue of course, because there may be interventions which do well for men, but not women or vice versa. And that’s where we need some of the ideology to help us make sense of the evidence. So I’m not arguing the politics are not important, but just that evidence of effectiveness should play a greater role in academic and practice attention to gender in social work.