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## **Title Page**

**Title:** “Because it’s the wife who has to look after the man”: A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life

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### **Keywords**

Palliative care, end-of-life care, family caregiving, informal care, gender, women, older adults

### **What is already known about the topic?**

- Women are central to the provision of palliative and end of life care for family members.
- As populations age, older women's responsibility to provide unpaid family care will increase.
- Female gender norms position women to provide care.
- Women experience greater degrees of caregiver burden than men.

### **What this paper adds**

- Evidence particular to palliative care that female gender norms construct older women's expectations about end of life care.
- Evidence that older women have internalized gender normative beliefs that they are expected to care for others at the end of life and that it is their duty to care, while not having similar expectations of men.
- Evidence that older women hold to these beliefs despite being cognisant of the significant effect of caregiving on their health and wellbeing.

### **Implications for practice, theory or policy**

- Palliative care policymakers and practitioners need to consider the impact on older women when relocating palliative care initiatives into the community.
- Palliative care researchers need to pay greater attention to the gendered nature of palliative care in general and to caregiving within an end of life context in particular.
- The discipline of palliative care needs to encourage the development of an explicitly feminist perspective that critiques the biomedical paradigm which minimizes attention to the role gender plays in determining individual experience.

## **Abstract**

**Background:** Research indicates women are the primary family caregivers for others at life's end and, because of ageing populations, will keep fulfilling this role as they age. Yet little is known about how the gendered nature of caregiving contributes to older women's understandings of providing care.

**Aim:** To explore how gender norms constructed older women's views about the appropriate roles of women and men in providing palliative and end of life care for family members.

**Design:** Six focus groups were conducted with 39 community dwelling older adults (36 women and 3 men) using two vignettes to prompt discussion about experience of end of life caring and attitudes towards Advance Care Planning. This paper reports on data gathered from female participants' reactions to Vignette 1 which prompted significant discussion regarding the intersection of gender and older women's caregiving experience.

**Setting/participants:** 36 women in the age ranges of '50-59' through to '90 to 99' from New Zealand.

**Results:** Three themes regarding gender and caregiving were identified: the expectation women will care, women's duty to care and women's construction of men in relation to caregiving and illness. The women adhered to stereotypical gender norms that regard women as primary caregivers. There was little connection between the burden they associated with caregiving and this gender construction.

**Conclusion:** The expectation that older women will provide end of life care even when experiencing considerable burden is an unacknowledged outcome of gender norms that construct women as caregivers.

## **Introduction**

Women are central to the provision of palliative and end of life care for family members. Indeed, few would challenge the assertion that women are primarily responsible for taking care of family members who are sick, chronically ill or dying.<sup>(1-5)</sup> They are the cornerstone of care, although their role is often obscured by the euphemism 'family care'.<sup>(6)</sup> Furthermore, because populations are living longer, women can expect to continue to care for others, even into their 80s.<sup>(7)</sup> Like their counterparts, women of retirement age and older undertake such tasks as accompanying those they are caring for to medical appointments, assisting with feeding, bathing and toileting<sup>(1)</sup> and administering medication.<sup>(7)</sup> They also offer social and emotional support,<sup>(8)</sup> which may be conceptualised as companionship or providing comfort such as through listening or physical touch.<sup>(9)</sup>

The rapid rise in ageing populations means there is an increased demand on family care as well as formal health services.<sup>(3)</sup> Moreover, governments have responded to this demand with policies and programmes that promote community care. Among other initiatives, the drive for shortened hospital stays has moved care from institutions to communities, prompting Read and Wuest to assert that "the rather slippery notion of community care tends to mean unpaid care sustained by families."<sup>(3)</sup> (p. 932) Such an observation has been recorded in the popular press: "the hospital of the future will start in people's home".<sup>(10)</sup> Such trends are particularly apparent in relation to palliative and end of life care.

Caregiving comes with emotional and physical costs which are experienced differently by women and men. For example, Suigura et al<sup>(11)</sup> found depression amongst women caring for husbands to be significantly higher than for men caring for their wives. Similarly, Brazil et al<sup>(1)</sup> found women reported significantly higher levels of caregiving strain than men when caring for a spouse at the end of life. Exploring the intersections of sex and relationship, Chappell, Dujela and Smith<sup>(12)</sup> concluded wives, in comparison to husbands, daughters and sons, were most vulnerable in regards to both burden and self-esteem. The caregiving role is also physically taxing for older women, especially when experiencing their own chronic conditions which have often not been addressed.<sup>(13)</sup> Indeed, a Canadian study found 23.9 % of women over 65

reported chronic pain that interferes with their activities compared to 16.7 percent of men.<sup>(14)</sup>

While the caregiving tasks older women perform and the toll caregiving takes upon them is known, within a palliative care context very little research attention has been paid to examining the intersection between gender and family caregiving for elders. Indeed, a recent systematic review identified only 19 previous studies that concern gender and family caregiving for people over the age of 65 years with a life-limiting illness.<sup>(15)</sup> Such a gap in knowledge is significant given the rapidly growing need for palliative care internationally.<sup>(16)</sup> In addition, policy directives adopted in many developed countries are shifting palliative care provision into community settings, for example by increasing the proportion of deaths at home.<sup>(17, 18)</sup> These factors are combining to place significant, but unacknowledged, demands on female family caregivers.

It is important to note that within this paper we understand 'gender' not as biological sex, with which the term is often confused, but in relation to how societies construct notions of femininity and masculinity.<sup>(19)</sup> While context and culture contribute to differences in gender performance, hegemonic norms exist that influence how women and men are expected to express gender. For Western women, such norms include acting compassionately and sympathetically, being sensitive to others' needs and willing to put others before self.<sup>(20, 21)</sup> Gender norms prime women to be caregivers, yet it is this gendered nature of caregiving which is not acknowledged in the palliative care literature.<sup>(15)</sup>

## **Aim**

To explore how gender norms constructed older women's views about the appropriate roles of men and women in providing palliative and end of life care for family members.

## **Methods**

### *Sampling and recruitment procedure*

The study from which these data were generated adopted an interpretivist, qualitative, design to explore community dwelling older adults' knowledge and understanding of Advance Care Planning. Onwuegbuzie and Leech<sup>(22)</sup> argue that one of the strengths of an interpretative approach is that it 'lends itself to

unexpected findings, some of which may be very surprising to the analysts'.<sup>(p. 243)</sup> Referring to Miles and Huberman,<sup>(23)</sup> they stress that such findings should not be ignored or dismissed, but followed up on as they have the potential to significantly shift accepted understandings and theories about how certain phenomena operate. Within the context of the present study, an unexpected finding was identified during analyses which surprised the research team, namely the ways in which older female participants used normative understandings of gender to frame their responses to Vignette 1 (described in detail below). A decision was therefore made to analyse the older women's accounts by themselves in order to contribute new knowledge regarding the intersection of gender and caregiving within a palliative care context. Therefore, the views of the three men who participated in the focus groups are only included in the findings section when their remarks are offered within the context of the women's discussion.

### *Sample*

The sample comprised 36 women. Their ages were recorded in ten-year age increments from '50-59' through to '90-99'. Participant socio-demographic characteristics are listed in Table 1. Participants were recruited through community organisations that lobby for, or are organized by, older people. The coordinators of each organization were asked if they would be willing to extend invitations to participate to community dwelling older adults interested in participating in a focus group exploring older people's attitudes to Advance Care Planning. They also distributed participant information sheets and consent forms for participant review. Whilst having end of life caregiving experience was not a condition of study participation, it is perhaps unsurprising, given the trends outlined above, that the participants had either their own and/or female relatives' experiences to draw upon. On the day of the focus groups, the researchers reviewed the information sheets with participants and obtained their written consent. The focus groups were held either in private homes, community group rooms or in one instance, a private conference room at a local restaurant. Each focus group was audio-recorded and then transcribed by a transcriptionist who signed a confidentiality agreement. The study received

ethics approval from the University of Auckland Human Participants Ethics Committee (UAHPEC). Focus groups were moderated by GB and LW.

### *Data collection*

Two vignettes were used to guide group discussion on ACP. Vignettes may be comprised of text or pictures (or a combination of the two) to access responses to interview questions. They have been deemed useful for eliciting attitudes, perceptions and beliefs about sensitive subjects,<sup>(24)</sup> including end of life care,<sup>(25)</sup> and for use with older adults.<sup>(26, 27)</sup> Vignette 1, the focus of this paper, featured Hone, a seventy year-old man with heart failure who “lives at home with his wife who cares for him” (Table 2). Although not intentionally created by the researchers to do so, it placed Hone’s wife in the gender normative position of caregiver.

### *Data analysis*

The researchers undertook a thematic analysis to identify themes that would suggest a gendered perspective on providing family care. Braun and Clarke characterise thematic analysis as a useful method because it can delve beneath surface reality to interrogate ways in which discourses affect the research topic under scrutiny.<sup>(28)</sup> The analysis followed the National Centre for Social Research’s Framework that involved a structured process for evaluating material according to key issues.<sup>(29)</sup>

## **Findings**

In this section we present three themes that exemplify participants’ gender normative beliefs related to caregiving practices: the expectation women will care, women’s duty to provide care and the gendered construction of men in relationship to caregiving and illness. All speakers are women unless indicated in brackets.

### ***The expectation women will care***

Vignette 1 indicated that Hone “lives at home with his wife who cares for him”, a gender normative construction that reinforced the expectation that women act as caregivers. The statement was challenged only once (and is discussed at the



end of this section). Rather, participants took it for granted that his wife would care for him and responded by focusing on the support she would need:

A: And as he becomes more frail, well, she will expect to be able to get more help.

B: But are they getting more help?

A: Or he will have to go into hospital, wouldn't he?

[Group 1]

The women's familiarity with what Hone's wife might need was informed by their own experiences of providing care, including to those beyond the immediate family:

Yeah, well, I used to bed-bath my brother-in-law and when it came to the private parts I just used to soak the flannel and say to him, "here you are, do it yourself."

[Group 5]

Others had multiple experiences to draw upon. This participant framed her significant caregiving responsibilities as examples of her resilience:

I looked after my mother until she went, you know, and at the same time I had my father who wasn't very easy to look after (laugh). But I got through it and still going. I've never learnt the meaning of the words go slow.

[Group 6]

The following quote states plainly that the wife is expected to be the caregiver. Commenting on Hone's need for support, the participant remarked that ill health does not excuse the wife from providing care. The group laughter in response was a spontaneous recognition of the honesty in her statement:

It's sometimes very difficult for a couple who both have problems because it's the wife who has to look after the man, usually (laughter) not the other way around.

[Group 3]

Complying with gender norms, however, does not necessarily mean agreeing with them, and there was one challenge to the status quo. The discussion below demonstrates both the participants' awareness of the burden of caregiving and their desire to have a say in choosing the level of care they provided:

A: But, with all these cases that [the interviewer] is presenting here, we've all said that the wife would be looking after them.

B: Yes.

A: Maybe the wife doesn't want to.

...

C: Yeah, I agree. And she would like [to] put him somewhere.

A: Maybe they want to live their own sort of life. So, there has to be outside alternative care.

[Group 3]

### ***Women's duty to provide care***

The gender norm that requires women to put others before themselves promoted an adherence to duty, even when it had considerable detrimental effect on the female participants' health and time commitments. One participant's care for her husband extended to fifteen years, yet it was regarded by another participant as 'unremarkable': "Oh well, that's what it's all about."

[Group 5]

A participant in another focus group reported on her lengthy and burdensome experience of caring for her husband. Her story was met not so much with compassion, but with a reminder that she was carrying out her duty of care as a wife:

A: The Government doesn't give a stuff about me, but they want me to pay. And by law I have to pay \$3,459 every four weeks. And not only did I have to pay but I lost eleven years of my working life. I gave up a paid job to look after my husband and after ten or eleven years I have a heart condition now.

B: That's part of being married. I mean, we bring up kids, too.

A: Oh true, true.

C: But everybody's situation is so different.

A: It is, it is.

D: [man] You chose to look after him at home, eh, not put him in a rest home.

A: I did. I looked after him at home 24/7 for four years until I was on my knees.

[Group 2]

For another woman, transgression of the gender norm to put her mother's needs before her own produced feelings of guilt. The conversation below demonstrates the association women in the focus group made between care and fulfilling one's duty as a 'good daughter'. Furthermore, it was the hospital, rather than the participant herself, who limited her obligation due to its effect on her wellbeing:

A: [Her] mother was in [residential aged care]

B: Four and a half years.

A: Yeah, well, it was the best place for her.

B: Well, the hospital told me it was too much for me to keep –

C: And, you feel guilty and you shouldn't have, because she's, you know, you were a good daughter, you did the best you could. And then it was time to move on.

[Group 3]

### ***Gendered construction of men in relationship to caregiving and illness***

In the same way they concurred with female gender norms, the women viewed men through a gender normative lens, one that positions them as needing to be seen as strong, independent and self-sufficient, characteristics listed by Spence and Buckner as congruent with a masculine gender identity.<sup>(30)</sup> The women offered opinions on men and caregiving as well as men's attitudes toward illness.

The statement already discussed, “it’s the wife who has to look after the man, usually”, that was met with instant laughter, indicated they did not see caregiving as a primary role for a man. This attitude is supported by another participant’s opinion that women tended to be more ‘natural’ at caregiving, though she did qualify her statement, somewhat: “If they’re daughters they’re probably more caring than sons. I mean, not all sons are like that.” [Group 3]

Taken from a discussion about how a family meeting should be conducted regarding Hone’s need for more care, the following quote reflects the importance of him maintaining his status as ‘head of the house’, which his illness may jeopardise:

If he was the head of the house and now he’s being relegated – only makes him feel dreadful. His manliness is taken away from him, isn’t it? So, they’ve gotta be very tactful how they say these things, you know?

[Group 3]

Finally, for men, being sick meant being weak, a state that compromised their self-sufficiency:

Men don’t like to be sick. They like to be as strong as they feel, but it’s not always the way that they truly feel. And people, as I say, men do not like to be sick, so they can be difficult.

[Group 6]

## Discussion

This study's significance lies in its contextualisation of gender and older women's expectations and understandings of caregiving within a palliative care context. It provides new insights into how older women invoke the gendered framing of caregiving in their view that end of life caregiving is an expectation and duty for women, even into old age. Participants in this study believed that, because women are experienced at caring for others, it is 'natural' that they would assume the role. Indeed, they felt that deviating from these prescribed gender norms would produce guilt. They also viewed caring to the point of self-detriment as 'normal'. It was notable, however, that men, were not to be regarded in the same way.

The women in this study expected to care, and for the most part did not question the gender normative imperative that they do so. Of more concern to them was the need for support. In this way, they echoed the literature that recognised women were society's caregivers and called for more services to help support them in this role.<sup>(3, 20, 31)</sup> Even when gender construction was acknowledged, the solutions were similar: skills training and support.<sup>(1, 20)</sup> Missing from the discussion was whether the gendered nature of caregiving itself ought to be interrogated and challenged. This is an important oversight given that it is known older women may provide care while in poor health<sup>(13)</sup> and experience depression<sup>(11)</sup> and strain.<sup>(1)</sup>

Participants understood that a woman's duty to provide care should be put before their own health, a finding which is also consistent with the literature.<sup>(13)</sup> For example, in a study exploring older women's transition from caregiving to widowhood, older women caring for husbands were reluctant address their own chronic conditions.<sup>(13)</sup> DiGiacomo et al attributed their 'suffering in silence' to life course factors; these were 'historical events and social changes in individuals' formative years' that 'impact on a person's inclinations and cognitive styles over time.'<sup>(p. 823)</sup> To this explanation, our study indicates that the impact of female gender norms might be added, as they have been in other disciplines. For example, Kramer found that gender identity shaped women's experience of caring for cognitively impaired adults. It encouraged them to endure hardship,

which contributed to their reluctance to call upon services designed to alleviate caregiver burden.<sup>(20)</sup> Similarly Eriksson et al found that older women's downplaying of the need for day-to-day support as they provided long-term care for their partners with Alzheimer's could be attributed to aspects of gender identity.<sup>(32)</sup>

The finding that participants did not hold men to the same imperative to care may seem at odds with current research that indicates more men are indeed providing care.<sup>(33)</sup> Three-quarters of the women in this study became adults prior to 1960 and thereby belonged to cohorts in which the gendered division of family tasks was more taken for granted.<sup>(34)</sup> This may, in part, explain their beliefs. Yet to dismiss their views completely as generational artefacts is to overlook how gender norms continue to be obscured when considering female and male caregiving roles. Indeed, del Rio-Lozano et al found that female and male family caregivers regarded women as having a 'greater natural ability for looking after others' due to emotional resilience.<sup>(35)(p. 4)</sup> Consequently, as one female participant in that study stated, even older women who were 'tired or weak' (p. 5) could still care for their spouses and others.

In palliative care, foregrounding gender is important because it extends the existing research literature beyond the simple association of women with the negative consequences of caregiving for others at the end of life or recommendations for interventions to improve their health.<sup>(15)</sup> By acknowledging how gender interacts with caregiving, gendered assumptions underpinning palliative care programmes and services may be explored. For example, policy directives to increase the proportion of deaths at home is one way in which older women are being counted upon in their gendered role as caregivers. Similarly, the current focus on reducing acute hospital admissions, seen as win-win because it aligns with people's preferences and reduces costs to the health system,<sup>(18)</sup> renders women's contributions invisible, particularly as they have not been adequately understood or quantified empirically.<sup>(36)</sup> Overall, it is imperative that the drive to improve end of life care, which is often operationalized as helping people spend their final days at home, should not come at the (often hidden) cost of older women's physical, emotional and mental health.<sup>(12, 20, 37, 38)</sup>

Within gerontology, a 'critical feminist gerontology' has emerged which "questions, challenges, contests, and resists the status quo". (p. 172) We would argue that a similar movement is urgently needed within the context of palliative care research. Such a move would not only encourage greater representation of women's issues, but also promote the use of research methods which interrogate the gendered production and dissemination of knowledge. Furthermore, ultimately, a greater understanding of the gendered nature of palliative care giving would also have very tangible implications for policy and practice.

### **Limitations**

This study is important in that it opens up a new area of investigation for palliative care research. However, certain limitations must be acknowledged. The participants in this research were predominantly white, heterosexual women. To a degree, the findings might be transferred to other female cohorts, as a woman's role as caregiver has been shown to persist across cultures.<sup>(39)</sup> However, further research that explores the intersection of gender with the end of life family caregiving experiences of older women from other social classes, cultures, ethnicities and sexual preferences is needed. For example, future studies could incorporate vignettes that transgress male and female gender norms, which would create space for looking at end of life caregiving within same-sex relationships. Finally, having established that gender norms are key to framing older women's expectations of caregiving, future research should also explore how they structure their day-to-day end of life caregiving experience.

### **Conclusion**

The expectation that older women will be the providers of end of life care, even in the face of considerable burden, is an unacknowledged outcome of gender norms that construct women as caregivers. Palliative care policymakers and practitioners needs to interrogate their policies and programmes to ensure they take into consideration how women, who are providing the bulk of family care, are affected.

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