

Caring 'from duty and the heart': Gendered work and Alzheimer's disease

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Abstract

Caring for people with dementia remains gendered with women still expected to undertake much of the paid and unpaid caring work in the community. This study draws on survey and interview data collected from 48 women community workers in Alzheimers Societies throughout New Zealand. Through the lens of the women community workers the gendered expectations about paid and unpaid work are revealed. The paper argues that cultural ideas about gender differences in caring abilities have implications for women and men as the population ages and the dementia 'epidemic' impacts in New Zealand.

Keywords

Alzheimer's disease, gender, caring, paid and unpaid work

Introduction

Dementia is in the news. There are now regular media reports which predict a coming 'dementia epidemic' as the 'baby boomers' age (Laugesen, 2011; Moyes, 2011). There are also compelling fictional accounts of people with dementia, such as Lisa Genova's (2009) *Still Alice*, in bookshops, and films such as *Away from Her* (2006) with mainstream actors Julie Christie and Gordon Pinsent playing the lead roles. Many of these reports and accounts deal with the issue of caring for people with dementia as well as the experiences of people with dementia themselves (Catherall, 2010). Caring work has long been women's work (Kirkman, 2002; Poole, 1997) and the feminist analysis underpinning this paper illustrates the continued relevance of feminist theorising when considering the caring work undertaken with people with dementia. This analysis reveals that caring work is still done largely by women and because caring is seen as 'women's work' it is undervalued. However, as the population ages it is apparent that there will be fewer women to do this work and many of those who will be caring are ageing themselves (Gee et al., 2001). This raises critical questions generally about who will do the caring for the 'baby boomer' generation as they age, and more specifically who will do the caring for people with dementia - a condition which has a higher prevalence amongst women (Access Economics, 2008).

The coming dementia 'epidemic'

Alzheimer's disease is the most common form of dementia. Between 50 to 70% of people with dementia have Alzheimer's disease, a condition characterised by progressive loss of brain function. In New Zealand, in 2008, it was estimated that 1.0% of the population or 40,746 people had a diagnosis of dementia, 39.8% of this number were men and 60.2% were women, the greater number of women being a reflection of women's longer life expectancy. In terms of ethnicity 1,483 (3.6%) were Maori, 1,227 (3.0%) were Asian; 683 (1.7%) were Pacific and 37,790 (92.7%) were European. The overall figure is expected to exceed 70,000 by 2026 and by 2050 2.7% of the New Zealand population or 146,699 people are predicted to have demen-

tia and new cases will comprise 0.8% of the population (44,375 people) each year (Access Economics, 2008). Until recently the numbers of people with dementia were likely to be underestimated because there was no specific diagnostic test for Alzheimer's disease; however neuroimaging technologies and increased skills in diagnosis have led to more accurate prevalence predictions (Access Economics, 2008). In addition to the increasing numbers of people with dementia there also appears to be a rising incidence of people with early-onset or younger-onset dementia. In New Zealand, in 2011, there are estimated to be at least 2000 people with a dementia diagnosis before the age of 65, with some in their forties and fifties (Catherall, 2010). This earlier onset has a major social impact on the individual, their families and the wider community particularly with the disruption to employment. The person with dementia may no longer be able to participate in paid work and members of their family, most frequently their spouse, may encounter disruption to their paid work due to the unpredictable nature of caring for a person with dementia (Perkins, 2005).

Much of what is known about the current situation for people with dementia and their families is because of the work of Alzheimers advocacy organisations worldwide. In New Zealand there are 22 Alzheimers Societies. These have been established since 1986 under the umbrella of the national organisation, Alzheimers New Zealand (<http://www.alzheimers.org.nz/>). The Societies' roles include education and awareness campaigns, provision of support for people with dementia and their carers, and advocacy. Media coverage of dementia usually includes comment from Alzheimers New Zealand and the increase in media coverage in countries similar to New Zealand is paralleled by the growth of advocacy organisations such as Alzheimers New Zealand (Kirkman, 2006).

The focus of Alzheimers New Zealand on support within the community means that it fits well with current government policy, that of ageing-in-place. In New Zealand, like other similar societies, there have been policy shifts away from residential and institutional care towards informal care provided by families or formal care by paid care providers within the community. This government emphasis is reflected in the *Health of Older People Strategy* that lists one of its objectives as 'supporting people to age in place in the community' (Ministry of Health, 2002: 46). This emphasis is also present in numerous other policy documents (Ministry of Social Development, 2001; Ministry of Social Policy, 2001). Home care (such as help with personal care, household tasks, and social problems) includes a wide range of health and social services that could assist a person with dementia to live at home. In New Zealand, home care services vary in availability and quality in different parts of the country (Access Economics, 2008; Dew and Kirkman, 2002). So while ageing-in-place is a policy goal, it may be much more difficult to achieve in reality.

This article analyses the caring work that women do in paid and unpaid work with people with dementia within the community. Specifically the lens used is that of the experiences and insights of paid community workers in Alzheimers Societies, workers very close to the experience of people with dementia and their families. Underpinning the analysis is a gender relations approach (Connell, 2000) and therefore commentary is also made throughout the article about the situation of men in relation to women. A gender relations approach provides us with a way of understanding how gender is socially constructed through the different dimensions or structures of power relations, production relations, emotional relations and symbolism (Connell, 2000). In the field of Alzheimer's disease women do most of the caring work, whether this is the unpaid or paid work and this load is not likely to lessen as the Alzheimers 'epidemic' impacts on New Zealand, although more men are becoming involved as carers as people are diagnosed with Alzheimer's disease at a younger age. It is therefore useful to analyse this gendered patterning of care provision by women and men to identify the likely consequences for women.

Literature review: women as formal and informal carers

There is a substantial literature on the work of women as carers both in New Zealand (Kirkman, 2005) and in other similar countries (Fawcett and Hanlon, 2009). McLaughlin and Baker (2007) for example, showed how feminist analyses in the 1970s exposed the 'compulsory altruism' underpinning care in communities and recognised the previously unacknowledged labour by women in both formal and informal care. Morse and others (1991) defined caring as incorporating a number of dimensions: it can be viewed as a human trait, a moral imperative, an affect, interpersonal interaction, and therapeutic intervention. These dimensions can be identified in the formal (or professional) sector and in the informal (family or lay) sectors of care (Kirkman, 2005).

The professionalisation of care has a long history and nursing has been at the forefront of this process (Proctor, 2000). However, because nurses have often focused on activities of daily living (for example, eating, sleeping, hygiene, exercise, leisure and socialising) this serves to emphasise that the paid work that nurses do parallels the unpaid work that women as daughters, mothers and wives do. Increasingly, because of this connection, care work has become deskilled with untrained workers taking over paid care work. This deskilling occurs because care work is seen as an inherent female quality rather than a skill to be acquired through education as in the case of nursing. In 2011, it is possible that the person who is sent to undertake your house cleaning may also be the person who assists you with a shower, this latter care having been previously done by district nurses who were enrolled or registered nurses.

Since the 1990s there has been a division into what is termed 'bodily' care (Twigg, 2000) such as washing and hygiene care and more specialised technical care such as wound care and medications (Daykin and Clark, 2000). The former have increasingly been undertaken by untrained workers and this example alerts us to the changing boundaries between paid and unpaid work. Paradoxically for nursing emphasising the 'care' component of their work may in fact undermine their professionalisation goals when it is recognised by healthcare managers that some of this caring work is done elsewhere by unpaid workers (Kirkman, 2005). Added to this is the way that many of the attributes of the work are seen as 'women's work', and therefore work that is not highly valued (Waring 1988). In times of economic constraint it has become apparent to those managing the healthcare budget that this caring work could also be undertaken by lesser trained workers and even volunteers (Gower, Finlayson and Turnbull, 2003).

The main unpaid workers in the informal sector are family members and traditionally women have predominated here (Twigg, 2000). The caring role of women in the family places them at the interface between the family and the state (Gibson, 1998). They are frequently the link between the formal and informal system and are often well practised at caring through their family roles by the time they need to care for either a parent or a spouse. Ungerson (1997) has drawn attention to how women, especially, are 'negotiated' into caring by their relatives. The material aspects of caring can be seen as part of the ideology of familialism (Barrett and Phillips, 1992). This ideology underpins domestic relations and becomes a main organising principle upon which social relations outside the domestic sphere are based (Poole, 1997). This ideology affirms that it is natural and appropriate that caring for dependents takes place in the domestic sphere. As the de-institutionalisation of care continues in health and welfare policies, the family model of care is seen as an appropriate policy goal (Hale, 2003). The motivation of family members to respond to the needs of other family members is linked to the reciprocal and affectional bonds developed within families, and this applies to the caring for family members with ongoing needs such as Alzheimer's disease (Willoughby and Keating, 2002; Clare, 2002).

In New Zealand about 70 per cent of people with dementia are cared for in their own homes, usually by one person, often an older person (Gee et al., 2001). The 2006 New Zealand Disability Survey revealed that disabled adults aged 65 and over were most likely to get help with the activities of daily living, apart from heavy housework, from their wife or female partner or their daughter (New Zealand Disability Survey, 2009).

The situation is also changing with a number of sociodemographic factors leading to decreased informal caregiver availability, such as increased labour force participation of women, later age of childbirth, smaller family size, and the tendency for family members to live farther apart from one another (Fox and Max, 2009). Consequently there are likely to be shortages in the supply of both female workers and informal carers in the future (Davey and Cornwell, 2003). One way forward would be to commodify informal care, as has happened in other countries, by putting it on a paid basis (Ungerson, 1999).

More recently, however, in contrast to the burden of caring identified in the earlier literature, the positive aspects of caring for a person with dementia have also been highlighted. Peacock and her colleagues (2009) illustrated how carers saw their experience as an opportunity to give back to the person they were caring for as well as an opportunity for personal growth. They also achieved a sense of competence in the role as well as discovering inner strengths through their connections with others involved in caring for a family member with dementia. Finally some spousal carers experienced caring as an opportunity for a closer relationship and commitment to the person with dementia.

Methodology and Methods

The data for this feminist analysis is qualitative and collected over a four-year period from 2006 to 2010. It included a postal questionnaire with open ended questions that gathered information about the work experience and the health of community workers, face-to-face interviews, and a wide range of documentary material including media articles and newsletters from Alzheimers New Zealand and the Wellington Alzheimers Society. The postal questionnaire was sent to community workers in all 22 Alzheimers Societies. Before this mail out I was able to speak about the proposed research at an Alzheimers New Zealand meeting in Wellington where there were representatives from all the Societies. I suspect that this contributed to the good response rate of 70 percent (48 returned questionnaires). I had also previously presented papers on the media coverage of dementia at an Alzheimers Conference (Kirkman, 2006) and written an item on this research for the Alzheimers newsletter so my work may have been familiar to some people within the Societies. Certainly a number of responses included comments on the importance of research on the situation of workers for Alzheimers Societies:

Every two years I attend the Alzheimer's disease International Conference and I have noticed quite a move towards recognising the importance of quality of life of the person with dementia and their carer. Much has been made of the issues faced by carers (family) in their role, and rightly so, but, to my knowledge those of us working in this sector who are so privy to these people's lives, often in a very intimate way and over many years, have been left in the shadows. Yes we do become hugely involved and affected by the traumas these families deal with – we are only human, and we have hundreds of families to walk beside on this journey and for whom we must be the strong one.

Following the initial analysis of the questionnaire individual in-depth taped interviews were carried out with 10 women who had responded to the questionnaire and volunteered for face-to-face interviews. These respondents were spread over four Societies in both the South and North Island and included one of the largest Societies, one medium sized and two small Societies. In these interviews I was able to follow up in more detail issues that arose in the questionnaires. I was interested in them talking me through the pattern of their working day and

therefore the interviews consisted mainly of their personal narratives (Riessman, 2008). I also conducted these interviews at offices of four Alzheimers Societies and this provided me with the opportunity to observe the working environment of these women workers. Approval for the questionnaire and the interviews was granted by the Victoria University Human Ethics Committee.

Field notes, questionnaires and interview transcripts were then analysed using a constant comparison method (Corbin and Strauss, 2008) until themes emerged and connections could be made across and among data. Following on from the example provided by Baines (2006) the data analysis involved linking the emerging themes to larger political, economic and managerial trends in the health care sector in order to develop themes beyond those found in individual narratives and observations. Sources for these larger political, economic and managerial trends included the news media, publications for health practitioners and publications from Alzheimers New Zealand.

Women working for Alzheimers Societies

There are a range of women workers who come into contact with people with dementia in the community as a part of their occupation, for example, nurses, doctors, social workers and other allied health practitioners in health centres and general practice. These health practitioners are not just dealing with people with dementia but people with a whole spectrum of diseases and other issues. Those whose entire role is concerned with people with dementia and their families are those workers employed by the Alzheimers Societies. There are a number of roles for workers employed by these Societies. Those with most direct contact with people with dementia and their families are the community workers (previously called field workers in some Societies). In some small Societies there may only be one or two community workers whereas in large Societies there may be a manager, office workers, education workers and fund raisers as well as the community workers.

The characteristics of voluntary organisations also differentiate the Societies from other public health care organisations in that they are usually dependent on fundraising for a large portion of their operation, the paid workers frequently work in part-time positions, and the numbers working in any one location are usually small. In addition, the work often involves supporting not just the person with dementia but also their carers.

This is gendered work, and the 48 returned questionnaires had all been completed by women. In addition, almost all identified as pakeha or New Zealand European. Because of the small numbers of women identifying as Māori and the possibility of them being identifiable, I have not included the numbers here nor have I included any quotes that would specifically identify them as Māori. However the relative absence of Māori workers was of concern generally as the numbers of Māori being diagnosed with dementia is increasing as Māori life expectancy increases (Ministry of Social Development, 2007). A number of respondents were aware of the need to work in more inclusive ways and one respondent's comment illustrates this:

I have a large increase in Māori women with dementia – the men have died, women are living longer. Also, (in the past), Māori people looked after their own; but Māori people are required to work, so are not at home to care for family. I need to have some training in Māori protocol. In my job I am in and out of Māori health providers and this does help.

So while this woman acknowledges that her contact with Māori health providers provides her with some insight into working with Māori communities, she does not see that as sufficient for her work. Her quote also reveals changing demographic trends that influence working with Māori communities such as greater participation of older Māori women in the workforce and therefore not always being available as unpaid carers.

The age range of the respondents was between 35 to 65 years, with just over half of the women aged over 55 years. Most of the women were married with two-thirds of these with adult children living away from home. For the one-third with children at home these were all school age and ranging from 7 to 20 years, most of these were secondary school age.

Most of the respondents were part-time workers although most were working more than 20 hours per week with a quarter of the respondents working more than 37 hours per week. A small number of respondents mentioned lack of hours as a point of dissatisfaction with one stating that she 'would like an increase in paid hours as the job is developing into a more major role' and another saying that for her 'more hours were needed, for example, a full time position as the position available at the moment is 16 hours per week'. This is not to say that the other women thought there were sufficient work hours available in their organisations to cover what they thought needed to be done, and there were many comments about more hours in general being needed. A feature about the work is that it is not shift work, something that those who had worked in hospitals previously identified as a positive aspect of their present work.

While many of the community workers were registered nurses they were usually not required to have an annual practicing certificate and therefore were not paid on the scale that registered nurses within the public health sector are paid nor did they carry out the professional role of a registered nurse. Two of the larger Societies had made a decision to make a social work qualification and registration a requirement for applicants and consequently also paid salaries commensurate with social workers in the public health sector. The hourly rates of pay for field workers ranged from \$14 to \$20 per hour with just over 50% receiving between \$16 to \$18 per hour in 2006, whereas the qualified social workers salaries ranged from \$26 to \$28 per hour.

There was a tension evident in terms of what was seen as the appropriate qualification for working in this area, with one woman with a social work qualification commenting:

I'm interested in the great variation in background and qualifications of workers in the Alzheimers Society roles across the region – and concerned at the lack of clarity around roles and responsibilities. Many workers appear isolated and unsupervised (some by choice) professionally – this can leave workers and clients vulnerable.

Many of the women perceived their pay as insufficient and as one woman said 'I mainly do this job because I find it satisfying and only want part-time work. I would probably be unable to work in this sort of job if I needed to earn more money'.

However, if tenure of position can be taken as one measure of job satisfaction then many of these workers appeared satisfied, as 60% had been in their present positions more than two years with 25% being in their positions more than five years, with some ten years and more. However, part-time and low paid employment do not provide economic independence for women. Income from part-time work does not enable a woman to establish a separate household for herself and dependents if her relationship with her partner becomes unhappy or abusive. Thus, for many women, low pay and part-time work are a source of risk to health and well being (Briar, 2009). The importance of a good income to women should not be underestimated, since 'income from work outside the home can enhance women's autonomy and their mental well-being through reducing their economic and social dependence on a male partner' (Walters et al., 1998).

For this group of women, other more positive factors were also very important, and mitigated the effects of the low pay. It is not only the level of income from paid work that enhances well-being but also the conditions of work, the quality of interaction with other people that occurs in a workplace and whether the work is meaningful. The next section explores this by examining the reasons women entered this work.

Community worker narratives – ‘getting in community work’

Before commencing work within the community many of the women had been working within institutional care settings, either in the public hospital sector or in residential care settings. Seeking work in a community setting for one woman ‘seemed a “natural progression” from hands on care giving’. A number of women ‘wanted to get out of public healthcare system and work with families in the community’ and many liked ‘the autonomy of community setting’. This sense of autonomy was widespread amongst the community workers and was related to their ability to plan their own timetable and organise their workload. Research on ‘burnout’ in nurses indicates that lack of control over work process is a factor in this (Brotheridge & Grandey, 2002). Burnout has been identified as a situation where employees feel emotionally spent, where they feel detached from others and where they experience a low level of efficacy while at work .

In the community worker role one woman said that ‘this particular role is more clear-cut than some of the others I have had and it takes the stress away of being all things to all people’, something that many respondents had found difficult in institutional settings. As one woman said:

I like having the autonomy of planning my diary. On the other hand it is nice to have a team of other employees that I can consult with over issues and vice versa.

Burnout is also connected to emotional labour (Hochschild, 2003) and both the quantity and the quality of people-to-people interactions involved in a work situation are important. In the above example the respondent values having a team to talk to as well as having the independence to plan her own work.

Past family experience of dementia was also a motivating factor for moving to work in this area. The narratives of two women illustrate an experience expressed more widely amongst the respondents:

There was nothing available when I looked after Mum 35 years ago. Interestingly, the help I needed was information, help with showering and time out for me. Someone to come in and look after Mum. These also, 35 years later, are still the biggest issues (for carers today). So I felt if I could help one person cope better then I was needed. Great now that there is help, I certainly had none then.

One of my parents died of a dementia and I wish I had been supported and educated regarding the disease. Therefore, I am passionate about this and love working with people.

Wilkinson and others (2005) have shown in their English study of homecare workers that usually when staff stated that they had experience of dementia, this was personal experience, and usually gained from caring for a member of their own family. This should not surprise us, as until recently dementia has been stigmatised and not readily talked about, and those people with dementia encountered a ‘social death’ (Sweeting and Gilhooly, 1997), that is they were (and sometimes still are) talked about as if they are already dead. Al Morrison, CEO of the Department of Conservation and former journalist illustrates this when he gives an account of being with his wife, Kate Clark and

‘Kate had just been diagnosed with Alzheimers and we were being talked to and this person turned to me with Kate right next to me and said, “And how is Kate?” I said, “Why don’t you ask her? It was like yesterday she was a normal person and today she’s a nutcase” (Sunday Star Times , 20 August 2008)

It is only with the disclosure of the diagnosis of dementia from people like Kate and Al that there has been more public awareness of the condition.

Narratives of 'making a difference'

The work these women undertook varied depending on the size and location of the organisation. However there were some activities common to all respondents. A central focus was regular contact with and support of people with dementia and their family members. The contact involved visits to people's homes and telephone calls. Most field workers facilitated regular support and educational group meetings for carers. Many workers also organised social groups for people with dementia. In addition to working with people with dementia and their families, community workers also played an educative role in the community, speaking about dementia at community functions and to other health professional organisations.

Indeed the referral of people with dementia to Alzheimers New Zealand organisations depends on Alzheimer Societies having a high profile within communities. Raising the profile is achieved, in part, through fundraising activities which promote awareness about Alzheimer's disease (the annual national awareness campaign) and the media coverage obtained through the advocacy and lobbying carried out by Alzheimers New Zealand. For example, when Mike Baldwin of the television programme, *Coronation Street*, developed dementia a phone number for how to gain information about Alzheimer's disease was screened at the end of each programme.

Respondents identified a number of key factors in their work that gave them job satisfaction within an overarching discourse of 'making a difference'.

The satisfaction the job provides. Everyone is very grateful for my help. It's a very flexible job and I feel very much my own boss. I have a fantastic committee who are there to support me all the way.

Good hours, working independently, an interest in the elderly, ability to grow and develop the service in my area.

Meeting people, not stuck in office, out and about, being able to help and advise people, and I like autonomy of community setting.

In general, the salient features of paid work include the demands of workload, hours of work and hazards as well as positive aspects such as control, challenge, the opportunity to help others and social support (Walters, 1998). All the above quotes highlight these positive aspects and illustrate examples of these.

The women workers were aware that their working conditions are in marked contrast to those of individuals who work in institutional settings or those who are unpaid family carers. In general, their observation of both of these other groups of women helped them appreciate their own job. For example, homecare workers in New Zealand (Burns, 1999), as in other countries, are mainly untrained and poorly paid. It is therefore a job option for women who are looking for employment that fits in with family responsibilities, who are re-entering the labour market, or who want to supplement a benefit or family income. These three reasons also probably pertain to many care workers in residential care, who are also often untrained and poorly paid, and are indications of why it might be difficult for these women to undergo training outside of their employment hours.

One support worker who participated in this study recognised the difference between unpaid carers and her own position when she says:

...for (unpaid family) carers, that 36 hour day 365 days a year is very stressful. Unfortunately paid care workers are often not trained in dementia management and for these care workers helping someone with dementia is stressful. But for us working with these people there should be no health problems. Shutting off is important and working with other professionals as a team is important so we are not alone.

The dominant discourse through all the responses was that of being able to make a difference. When asked the best aspects of the position almost all the women used the discourse of 'making a difference' either to the person with dementia or their families.

Getting those with common interests together for self-help, getting people to share their problems, I can seem such a small player in the field but can make such a difference.

Knowing I can make a difference in people's lives just by providing some emotional support and information.

Discussions about their job satisfaction is set within the context of this overarching discourse. Given the professional qualifications that many of the women had gained before working within the health and social services sector it is likely that this discourse also featured in these education programmes, including nursing and social work.

Obstacles to making a difference

Nevertheless there were issues that resulted in dissatisfaction. These included working for a not-for-profit organisation that depended on fundraising and working for a committee of volunteers. Fundraising was an issue that was especially acute given that most had previously worked in occupations that did not require this involvement.

One woman discussed the need for 'more financial stability from partnerships and contracts with DHBs (District Health Boards) as this would provide sustainability to planning' while another wanted it 'to be recognised amongst other health professionals that we are more than a voluntary organisation. Knowing that your employment depends on fundraising inevitably results in stress if that fundraising is not successful and your income is essential to your household. The work on fundraising also detracts from the main goal of assisting people with dementia and as one respondent exhorted 'reduce the fundraising so that more time can be spent on and with clients, carers and staff'.

Relationships with other health workers were also seen as potential areas of conflict or dissatisfaction. The boundary disputes between different health professionals are now well documented in the sociology literature (Dew and Kirkman, 2002) and while there has recently been a focus on the development of multidisciplinary teams the boundary defining still persists. This was illustrated earlier in terms of the defining that occurs between social work and nursing. The point being made here is that some of the field workers felt that their role and skills were also not recognised by other health practitioners such as general practitioners.

Sometimes there is less than satisfactory liaison with other health professionals.

I would like GPs to remember that our service is out there, they are improving with PR work from my organisation.

Reporting to a committee can also be difficult. Indeed in this research the committees were viewed as either excellent or not rated highly by respondents with problems with 'the attitudes of committee members, lack of support from committee at times, and no real understanding of work load or context'. Finally a number of women worked either on their own or with only one other person and, as one woman put it, 'more support (is needed) as I work in a very isolated role and there is a need for more people employed in the same role'. Some Societies had tried to ameliorate this isolation by arranging meetings between the workers of a number of Societies in one geographical region, however this is costly and time consuming to arrange on a regular basis. Another way of attempting to deal with isolation was the provision of professional supervision, although how it was provided varied from an external supervisor chosen by the individual through to a supervisor chosen by the Society Committee. Current legislative

requirements for quality assurance for the health professions have raised the profile of professional supervision generally and this is evident for those working in dementia care.

Gendered perceptions of unpaid carers – ‘caring from duty and the heart’

Caring for someone with dementia has been likened to a 36-hour day (Mace and Rabins, 1999). As Opie and her colleagues (1992) point out, family caregivers experience exhaustion, isolation, ill health and depression, and as a consequence are at risk of becoming abusive and requiring health care themselves due to the stress of their work. This is especially the case with carers of people with dementia because of the added complexity of caring in this situation. This is exacerbated by the fact that many of these carers are already older.

Because women have traditionally been carers within families it is not surprising that much care work falls to women (Twigg, 2006). What this research demonstrates is that women community workers also expect women family members to be more suited to caring than men. This has implications for when they are advising and supporting people with dementia and their families. Because of these gendered views their expectations may differ depending on whether the person who is caring is a woman or man.

For the older age group caring was seen as a ‘natural’ role for women with a number of community workers pointing this out. Workers suggested that women were more suited to caring because of their nurturing abilities. These abilities were seen to result both from their socialisation, for example, their mother’s caring roles, and their ‘natural’ tendencies:

Women are instinctive caregivers as they are brought up in this role. Learn from mother. [They] can multi task. Sometimes women struggle with financial responsibilities. Men struggle more with intimate care and also learning to cook and clean.

Women can usually naturally care for people. Men usually have to learn how to care for someone with dementia. Men make good carers but they sometimes take over everything and are afraid of being a failure. They generally relinquish the person with dementia to full care before a woman does.

One implication of women being perceived as natural carers is that they may be expected to care for a spouse or partner at home for longer than a male spouse or partner:

Women naturally good as carers which means there are higher expectations upon them. This means that they ‘may feel that they need to keep their spouse at home longer’ and ‘see caring as a duty’.

Duty was a word frequently used to describe how women become carers. This is a finding of other research as well with Bruce and others (2002) finding that a sense of duty was a ‘potent inhibitor’ that prevented carers, both women and men, from seeking professional help earlier and attempting to care for a spouse or partner in their home for as long as possible.

Female carers see it as a ‘duty’ and an extension of their nurturing life. Male carers are more likely to view it as a ‘job’ and devote all their time to it.

Females usually care from duty and the heart. Males generally have a business like approach to caring.

What is seen here is the clear division between how community workers viewed women and men as carers. A consequence of these divisions is that men may gain more recognition when they take on a caring role. As the following community worker wrote:

More rigid gender roles in older couples. Male carers tend to get more praise and assistance. Women more likely to share trials with each other in social settings, friendship networks and find support for themselves.

Expectations about carers and caring are also generational with daughters expected to care as their mothers did with ‘sons of those with dementia readily allowing their sisters (daughters) to

carry the responsibility'. For men caring 'it is something new which they must learn', a point that was made time and time again.

I think for the majority of men it is more difficult. They have to develop their 'caring' and they don't empathise quite as well as females.

At the onset caring comes easier to the female carer – it is a continuation with more involved of the female role, in older people. Males do become adept at caring but as in older males, it is something new which they must learn. And they do.

While most of the community workers made clear distinctions between men and women one woman did question this distinction with her qualification of 'generally speaking only'. However after this she went on to identify some quite specific characteristics of male carers

Generally speaking only! Male carers often focus on the practical aspects/solutions/problem-solving. They can be more reluctant to address emotional issue/intimate issues 'head in the sand' stuff – often find it difficult to seek support, e.g. counselling.

Only three community workers didn't make a distinction between male and female carers with one stating that 'All carers are individuals and cope differently.'

Females, especially from the older generation, have traditionally taken the carer role i.e. cooking, cleaning so it is often that these roles come naturally. Men have to learn new roles as carers. However, it can work the other way too, with female carers having to take on new roles i.e. finances.

Nevertheless, this last quote still reflects traditional gender divisions in that it is not a case of women learning to care but rather taking on roles that may have been done by their husband or partner such as managing financial matters.

Discussion: gender, caring and people with dementia

In some recent academic writing on dementia care gender has ceased being mentioned as a significant factor (see, for example, Krishnamoorthy et al., 2010) but the feminist analysis undertaken in this paper demonstrates the continued importance of using a gender lens.

Connell (2000) claims that in societies like Australia and New Zealand there persists a dominance of men and a subordination of women. This is a structure that some feminist sociologists (Walby, 1990) called patriarchy. While the concept of patriarchy may not be nuanced enough to describe current gender relations in New Zealand, it is still the case that many women continue to occupy subordinate positions. In Alzheimers Societies the majority of community workers are female with men, when they are involved, at the management level of the Societies. Men also feature, along with women, in a voluntary capacity as members of Alzheimers Society committees. While committee members are volunteers they are influential in relation to the governance of individual Societies and have power in respect of this role. Although most Societies have a manager responsible for the day-to-day operation of the society, this manager usually reports to a committee composed of volunteers. Community workers were either very positive about the relationship between the committee and their manager, or alternatively not positive at all. The negative assessment usually related to the worker's perception that committee members did not understand the nature of the community work or the skills required by the community workers. When committees were evaluated positively by community workers it was usually because they believed that the committee members understood, often through the personal experience of family members with dementia, what the community work entailed and were supportive of the workers and their manager.

The women community workers for Alzheimers Societies represent a group of workers who provide a human service and who engage in emotional labour, something that has been tradi-

tionally seen as women's work and therefore it is possible that some committee members do not recognise the skills associated with caring work. Increasingly in the care of people with dementia the emphasis is on 'person-centred care' (Kitwood, 1997) and this approach increases the emotional labour expended by carers. Person-centred care is about recognising that the person with dementia is a human first and foremost rather than labelling them by their illness. This shift to person-centred care is also reflected in the language used in this paper where it is the 'person with dementia' who is the focus rather than the 'demented person'. The point about 'person-centred care' however is that it uses more emotional resources of the carers and as more care is required it becomes more expensive to provide. This has major implications for the management of residential care and dementia units where there is a shift from controlling a person's behaviour with medication to using behavioural strategies (Laugesen 2011), but it also has implications caring for people and their carers in the community.

'Person-centred care' is therefore labour intensive and is being promoted at a time when the population is ageing and there are likely to be fewer women available to care. However these workers themselves are also a part of this ageing population, with the age range of the community workers being between 35 – 65 years. This is the case with the nursing workforce more generally. In 2007 the average age of nurses in New Zealand was 44 years and in the future when more nurses are needed because of the growth of older people in the population there will be fewer nurses available (International Council of Nurses, 2007). While some Societies employ social workers it is likely that many will still employ women who are or have been nurses, in part, because of the 'making a difference' discourse relating to working for a voluntary organisation. This discourse is likely to resonate with women with a nursing education and experience. Despite their low pay, part-time work and the lack of recognition of their professional qualifications, many of the community workers were satisfied with their position because they felt they were 'making a difference' for people with Alzheimers and their family carers. They also valued the autonomy that their roles afforded them, something often not experienced by them in the public health system. By providing support and expertise rather than 'hands-on-care' they have also prevented their work being replaced by unpaid or voluntary workers. Indeed, as discussed earlier, in two of the larger Societies there has been an attempt to professionalise their work more by appointing women with social work qualifications to community worker positions. But there is a risk in making this move as it must be balanced against the Societies' need to fund raise to cover staff costs.

When talking with the community workers their narratives contained comparisons of their work situation with that of the unpaid carers, and the recognition that the unpaid carers' situations were much more difficult. Perhaps because of this comparison the community workers also spoke of the role of unpaid carers in very gender specific ways and as a result this may have influenced the expectations they had of both male and female carers. This group of workers saw women as more prepared and suited to caring for people with Alzheimer's disease. This is not to say that they thought men could not be carers, it was just that they need to learn how to do this, whereas women 'naturally' know how to care as a result of their socialisation and practice within families over a lifetime. Even those community workers who resisted the suggestion that women were more suited to caring gave detailed accounts of how men and women differed in their approach to caring. What was revealed in this research is how deeply entrenched and taken-for-granted cultural beliefs about gender are, and how this influences expectations placed upon unpaid family carers.

As we move into the future and the number of people with dementia continues to increase, challenging these cultural beliefs about gender will be essential if caring, both paid and unpaid, is going to be spread more equally across society. The ethos of 'caring from duty and the

heart' may also be a generational characteristic, given the age range of the community workers. Therefore we cannot necessarily expect that younger women will place the same value on doing this caring work. The neo-liberal reforms of the 1980s and 1990s in New Zealand have fostered an ideology in which individuals and families are required to take on responsibility for the provision of health care, education and welfare (Kelsey, 1997). With the emphasis on economic rationalism, and the belief that the market is the most appropriate way to allocate resources there have been cuts to government responsibilities and privatisation of services. For individuals and families, this means that they are free to make their own choices, and at the same time they are required to shoulder the blame if they make the 'wrong' choices. The young women who are to be the nurses, social workers and community workers of the future will have grown up with this neo-liberal ideology and therefore may not feel the same call of 'duty' that was experienced by their mothers and grandmothers. In light of this Alzheimers Societies may face difficulties in attracting women to community worker roles in the future. Furthermore it may mean in the future that young women are not prepared to undertake the unpaid care work that their mothers and grandmothers have undertaken. This means that who provides care and whether they are paid to do so will be an ongoing issue, with the commodification of care debate remaining on the policy agenda.

Conclusion

This study of women community workers for Alzheimers Societies in New Zealand illustrates the gendered patterning of paid and unpaid caring work in the field of dementia care. Women still undertake most of the paid community work within Alzheimers Societies and, in the main it is low paid and often part-time work. Because of the small workforce in many of the Alzheimers Societies there is the likelihood that the worker may also feel isolated. These negative features of the work are outweighed by the positive experience of being able to control their own work day, something they had not been able to do in the public health sector. The women also used the discourse of 'making a difference' as a strong motivator for undertaking the work. This discourse is gendered and reflects the traditional view that women are carers and nurturers both inside families and outside them as well. This discourse also influenced the community workers' expectations that women are the best placed to undertake the unpaid caring work. Because of this, and because of the predicted increase of people with dementia, it is likely that unpaid family carers will be expected to continue to play a pivotal role in the care of people with dementia. To ensure that this role can be achieved and that there are benefits as well as burdens to caring, requires support. The Alzheimers Society women workers' focus on 'making a difference' is an important component of this support. However these women workers also require support and recognition, especially as the emotional labour in their work increases with the focus on 'person-centred care' for the person with dementia.

To conclude, it is instructive to return to the title of the paper – caring from duty and the heart. Arguably this view of caring can reinforce traditional ideals of women as carers. Some of these ideals, however, have served to improve the care of people with dementia. What is needed as we plan for the dementia 'epidemic' is a recognition of the value of the work that women have done as paid and unpaid carers and the need to take gender into account when developing strategies for caring in the future.

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Acknowledgements

Thank you to all the women workers from Alzheimers Societies who contributed their thoughts, insights and time to making this research possible. Thanks also to the Faculty of Humanities and Social Sciences, Victoria University of Wellington for funding this research. Finally I appreciated the valuable suggestions for improving the article that came from the two anonymous reviewers for the journal.

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