

## Working in paid employment and caring for elderly relatives

ELIZABETH A. WATSON  
AND JANE MEARS

report on a recent study which yielded insights into the lives of women committed to two major responsibilities – their position in the workforce and the care of their frail elderly kin.

**T**his paper is based on a study, conducted between 1992 and 1995, of forty women who were working full-time and carrying a major responsibility of care for an elderly relative. The study is confined to women carers primarily because it is women who comprise the majority (67 per cent) of unpaid carers (ABS 1993) – especially of the group involved in inter-generational care, as distinct from the care of a partner or spouse.

Participants were recruited predominantly from the human services and health fields. We focused on this sector of the workforce for three reasons. First, women predominate in this field; in the community service sector, for example, women comprise 64.2 per cent of the workforce (Baxter et al. 1990: 64). Second, we were interested to examine how people who had chosen jobs characterised as caring, people-oriented work, perceived a situation of dual caring responsibilities and made decisions about both paid and unpaid work. Third, because a main focus of the research was

on actual workplace environments, we were also interested in how these particular 'caring' workplaces responded to the 'outside-of-work' caring responsibilities of their employees.

In general, contact was made with participants by advertising through the central bodies of agencies such as Homecare (a state-wide agency in New South Wales providing general housework services, personal care, and in-home respite care), church-based aged care services, and the hospital system.

The study is an in-depth qualitative study, with the detailed accounts provided by participants forming the basis for the analysis. The definition of a major responsibility of care was a self-definition and included every caring circumstance from co-resident caring to the care of a relative in a hostel or nursing home.

The project was conducted in the context of increasing concern about that range of issues which fall within the policy arena labelled, 'workers with family responsibilities'. Important assumptions underpinning the research are that increasing numbers of workers in paid employment will find themselves with some level of responsibility for the care of elderly relatives, that such caring is an important and significant part of family responsibilities, and that this needs to be recognised and supported by governments and in the workplace.

### Being Stretched

'Stretched lives' captures the tension, the sense of being absolutely fully extended, in attempting to juggle the demands of paid work and caring responsibilities. In the accounts of the women themselves, this was a particularly apt image.

*'I think having said to you that I don't acknowledge stress, I acknowledge "stretch". I'm stretched! . . . I don't think modern woman says what is enough. We just keep doing a little bit more and a little bit more.'*

'Juggling' was another term used by participants to convey the competing demands of fulfilling both responsibilities.

*'Juggling is the right word. I sort of have this mental picture of about five different things up in the air. Your family, your friends, your job, the person you are caring for, your social life – you've got all these things up in the air and you can only hold on to one at a time, not two, one. You throw them all up and you (don't always know) which one is going to come down next. So it is literally a juggling act . . . It's tiring and it's one of those things that you look at and think, one of these days I'm going to miss, and all those balls that are up in the air are going to fall on top of my head, and all I'm going to be able to do is go "help!" and cover my head.'*

It is clear in this research, as in earlier research (Watson and Mears 1989), that while the physical demands are stressful for carers, it is the emotional demands that are the most stressful of all. The impact of both on the health of the carer can be considerable, with those participants claiming to be in good physical health being quick to emphasise the emotional toll. None claimed to have survived without some or considerable cost to their health or wellbeing.



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It is difficult to separate physical manifestations of stress from emotional outcomes. Fatigue tends to be accompanied by tears and short temper; headaches and migraine are common; sleep patterns are affected. There may be problems with eating and digestion, with gaining or losing weight, with back problems and hernias as a result of lifting and other straining activity, and a vulnerability to any infection that is going around. Existing health conditions such as asthma may be exacerbated.

The emotional or psychological manifestations of stress tend to be the ones that people are most aware of and which they find the most distressing. Depression and anxiety are not uncommon, and some spoke of being 'up-tight' or 'on a short fuse'.

*I had reached the point where I did need to take some kind of action because I was like a short fuse about to be lit. Like a volcano. And I was capping the top of the volcano all the time. And as I said to my boss, sometimes I feel like a volcano is inside me and every time I get stressed, I'm putting a plug in the top of the volcano to stop it exploding.'*

Stress was experienced as uncertainty – or even dread – about the future, as a sense of poignancy, or as distress.

The relationship between the carer and the cared-for can itself be a source of stress, with a new relationship usually having to be worked out. Often carers experience a role reversal – for example, a daughter may feel that in a sense she has become the mother. But, of course, it is never that straightforward – one's mother remains one's mother, even if her behaviour has become childlike due to dementia.

Sometimes the relationships were particularly difficult. In three cases the relationship between mother and daughter had always been strained. In other instances, for a range of reasons, the quality of the relationship was also stressful – a mother used to getting her own way, a father becoming increasingly dependent and demanding after the mother's death, one parent refusing to accept the extent of decline in her spouse and thus to allow the daughter to provide the necessary care. Some parents constantly criticised the way their grandchildren were being raised, or did not understand why their daughter wanted and needed to continue to work.

Then there is the impact on the carer's relationships with children, with a partner and with other relatives. It may also be difficult for carers to sustain friendships. In particular, for women who had never married or who were divorced, the possibility of developing and sustaining a relationship was immensely difficult; some described a string of relationships and engagements that had been 'broken off'.

It is perhaps inevitable that having both work and caring responsibilities will increase the stress of each experience. But in addition to this, participants in this study were drawn predominantly from

sectors of the workforce which might be characterised as 'caring' or 'people oriented' – nurses, teachers, Homecare staff, human resource managers, academics, and social workers – occupations that are typically stressful.

Additional tension had been created by cut-backs in funding to services such as Homecare. Not only was there the general pressure to do more with less, but also the curtailment of services to people in circumstances similar to those of the participants themselves. Agencies were having to make difficult decisions about who was 'most in need' of the service, with those in paid work being typically perceived as 'less needy'.

A number of women working in local agencies had decided to continue to provide services to individual clients after that service had been officially cut because in her view the recipient still needed the service and because she had an ongoing relationship with the client which she felt unable to put to one side. Such decisions created extra work – and some guilt, as these actions did not have the approval of their agency.

### Costs to Carers

The cost of caring work is both personal and financial, both immediate and long-term. In personal terms, working carers find themselves with little time to themselves, few holidays, and little or no regular leisure. They spoke of the lack of opportunity to reflect, to do something spontaneous, to be frivolous. Their accounts set out the degree of fragmentation of time and, at times, the difficulty in concentrating on any one task.

*'Fragmentation of time, the fact that I'm never guaranteed of carrying through and completing anything I start in any type of career . . . I'm too fragmented . . . my concentration is fragmented.'*

*'Sometimes it just overwhelms you. You can feel yourself start to slip backwards. You say, "Oh, another bill to pay – when am I going to find the time to do this?" I'm far too preoccupied. I'm thinking of too many things. I even find when I'm talking to people I'm saying two words together because I'm trying to get it all out in a rush. So there is too much going on and I don't have time to concentrate to get it all done properly to my satisfaction, and they're all demanding things, all demanding.'*

Other writers have examined this aspect of the 'stretched' lives of carers. Their attempt to spend quality time with the person, means that the carer 'must be present or readily available', and not 'too preoccupied with their own activities'. It 'fragments time': it 'imposes a severe restriction on the carer's thoughts, let alone their activities' (Land 1991:12).

Activities such as study, something for one's self, but especially an investment in

one's future, are particularly problematic. The consequences in the longer term of this 'putting self last' (and the lost opportunities that are not easily taken up later when caring is over) are again both personal and financial. While for the most part they were ready to emphasise the gains, the feelings of satisfaction, the belief that there was no other course of action open to them, the women were also conscious of time passing and the impossibility of going back and making up for what could not be contemplated while caring continued.

The financial costs that carers sustain are also considerable. As well as the actual costs involved in providing care, there are the costs in income foregone, and opportunities for career advancement and promotion not taken up – of career progression being 'put on hold'.

*'My career comes at the bottom of the list. It's something that I dearly want to do, but I can't because of all the dependants I've got around me.'*

Some had chosen to change jobs in order to secure the flexibility that would enable them to continue in the paid workforce while continuing to carry fairly onerous caring responsibilities. Others, feeling they already had enough stress in their unpaid caring work, declined promotions, or did not seek such opportunities, preferring instead to stay in work involving fewer responsibilities.

For many it meant shelving further education and training, and upgrading their qualifications.

*'I couldn't continue tertiary education. When degrees were being offered and we could take credits for being a RN (registered nurse), I was only 40 and I worked out where a lot of the girls around my age were starting it. I knew that I couldn't cope. It was too much of a burden for me to cope, because I've also got an 82-year-old mother-in-law living beside me. So my responsibilities were just too high.'*

*'I've remained in my current position because I know the hours that I work and where I am with holidays. So I felt that it was better that I keep that side of my life stable while I had the demands of my father going in and out of hospital, and so on. So I've kept to that and I've also postponed my study because I felt that, again, it was taking away from time that I could be spending with him.'*

*'I probably should say that the prospect of finishing my PhD is at risk. And, if it is, my future employment is at risk – either casual teaching or, at the best, hanging in as a tutor.'*

It is important to make clear that participants downplayed the consequences of their career decisions and were philosophical about the future. As those who had children argued, caring for young

children had been a stage in their lives when they had to make choices and compromises regarding work and family responsibilities. The same applied to this stage of their lives, only now it was caring for elderly relatives that was a priority.

## Separation of Work and Caring Roles

A recurring theme in this research was the notion that a 'good worker' was one who left her family troubles and preoccupations at home and, while at work, focused exclusively on work concerns. This perceived need to keep separate paid work and family responsibilities created additional stress and guilt for many participants, because in apparent contradiction to this notion, the separate nature of paid work was often experienced as a relief, as an escape from the strain of caring. In reality, it was not possible to achieve such com-



partmentalisation. This was all the more likely in those times during a crisis in the caring situation which would rebound on the work situation, and, conversely, when the pressure at work escalated and rebound on the caring situation.

The supposed requirement that work and caring be kept separate has negative repercussions for carers in paid employment. One of these is a general assumption that major caring responsibilities signal a less committed worker, and that a good worker will be 'one hundred per cent' dedicated to his or her work, with this dedication being evidenced both in terms of the availability to work when needed and in a lack of domestic distractions. Women in particular are regarded by many employers and managers as likely to require time off to fulfil caring responsibilities.

All the participants regarded themselves as conscientious workers who took pride in their work. It is one thing to embrace as a survival strategy the construction of paid work as a separate domain. It is quite another, when such a powerful notion is an entrenched part of a workplace culture that compels employees to act as though they had no home and family – a destructive mythology indeed.

## Importance of Paid Work

One of the consequences of such a mythology is that workers with family caring responsibilities are likely themselves to accept the notion that if caring grows so onerous it becomes difficult for them to continue in both roles, they may have to accept the 'inevitability' of cutting back on their hours of paid work or dropping out of the workforce altogether. Assumptions about women's employment have long depicted part-time or casual work as the best means of accommodating their

family's needs. However, very few of the women were in a position to take up the option of part-time work.

*'I'm too frightened to even think about it. I depend on my job because that's the only source of living, and I've got three dependents. My 20-year-old is still out of work. She got her degree this year, but she's still unemployed and it's really hard. All three of them aren't working, so I really need the money. I couldn't give up my job.'*

*'I couldn't give up work to care full-time. Financially there's no way I could even consider it.'*

Some women had husbands or partners who were unemployed or retired, or had low incomes or irregular employment. Others were sole breadwinners. A number spoke of the cost of caring for their elderly parent and the need to stay in the workforce to meet those expenses.

Work was valued for other reasons. Many women mentioned the enjoyment and satisfaction they gained from their jobs; they liked working, felt they were good at their jobs and were making an important contribution through their work.

*'I find my working life, basically, almost is me. Because I become very involved with the folk I work for. We had a questionnaire last week asking, "Do you think you could do better in the future?", and I really don't know that I could do anything better than I'm doing at the moment. I really feel I try and give one hundred per cent.'*

Some commented on the different nature of their paid and unpaid work and the different needs their paid work fulfilled. Their jobs provided some women with a fulfilment not generally present in their role as carers.

*'In a funny sense it helps keep you sane, because it is something you are doing for yourself. You are not just doing it just for the money.'*

Most were unable or unwilling to give up paid work, even if their circumstances changed. They would consider other options first, and hoped they would not have to make this decision. The ambivalence they felt was clearly expressed. They would like to continue to work; they would have to continue to work; if their elderly parent needed more care, they might withdraw from the workforce, but it would be a difficult decision to make.

There are two apparently conflicting demands and rights. On the one hand is the obligation to fulfil caring responsibilities and the belief in the right of those in your care to have the greatest quality of life it is in your power to provide. On the other

hand is the individual right to income security now and in the future and your entitlement to have rewarding work.

*'It is an extremely difficult question. By choice I'd rather continue working and cope with whatever I have to cope with. If it meant the quality of my mother's life is depleted, well, then I'd be forced into making a decision. Nothing is more important than family, and quality time with her is very important. But I'd be looking at all the options.'*

## Foregoing Degrees of Independence

Because participants were in full-time paid employment and had not relinquished paid work to care full-time, they would be characterised as part-time carers who have, as a result of their continued workforce participation, retained financial independence. However, as discussed above, they have foregone the possibility of advancement in their jobs and so of increase in their incomes.

The term 'degrees of independence' is used here to describe the loss of financial independence incurred compared with the salary they might otherwise have enjoyed. This can be described as the opportunity costs associated with caring even when the carer remains in full-time paid employment.

The point is that there are degrees of independence. In this sense – and this is an important re-conceptualisation of independence – the carers had given up a claim on a higher degree of independence and security both in the immediate future and, perhaps more importantly, into their retirement and old age. Given the increased emphasis on providing for one's own retirement, these women in their later years may see their financial resources more 'stretched' than might have been the case had they not had to curtail their earning capacity as a result of their caring responsibilities.

## Community Services for Working Carers

In examining the contribution made by formal services to the support of informal caring, this research provides a number of useful insights. Two particular features of the research design have been of significance.

The first was the decision to seek a large number of participants from the community sector and hospital system. This meant that many were well informed about the sector and the range of services available, something not so apparent in previous research on carers (Watson and Mears 1989).

The second was the adoption of the wide-ranging definition of a major caring responsibility. This enabled us to highlight the very different access to services of co-resident carers and their dependent relatives compared with carers whose elderly relatives lived in their own homes, hostels or nursing homes.

The most important of the findings is that the individuals who 'fell through the safety net' were the working co-resident carers.

*'I'm working and living in the same home, because I know Homecare's policies as far as that goes, which is, if you're working full-time then you turn to private help. I wouldn't qualify, I don't think. If my mother was living by herself, it's different. Obviously Homecare's resources are limited so I know the story there. Even mowing lawns. The fact that I'm living there, she could have someone mow the lawns – for example, from Homecare. But I wouldn't qualify.'*

*'There is absolutely nothing for working carers.'*

If the elderly were living in their own homes they were generally eligible for community services, but if living with their carers, the carer's status as 'employed' usually excluded both the carer and the cared-for from access to some support services. It would appear that a wider definition of 'need' should be employed. For instance, to provide services to one elderly person living in her own home with a working carer living separately, and to exclude another from access to services on the basis that she lives with her carer, a working woman, seems extremely unfair.

The research also highlighted the difficulties faced by carers whose relatives refused or were reluctant to accept available services. On the one hand, the carer saw herself as responsible for the elderly parent or grandparent, and felt that she knew her relative well and was in a good position to judge whether or not services were required; on the other hand, she had no control over whether or not the services were accepted. One explanation for the elderly person refusing such services was a reluctance to admit she or he was not coping.

*'No, she won't use them, she just won't. I've tried it. There are so many services. There's the day care service – she won't have anything to do with it.'*

*'There are a lot of good services out there, I just wish that she would use them, to give me a break . . . But she wouldn't use them. "I don't need them", she'd say. She doesn't think she has a problem.'*

A not uncommon situation was the refusal of the elderly person to accept any form of respite care, leaving the carer unable to take a break. Another was the refusal to accept assistance with personal care, sometimes insisting that the carer do this. While it is understandable that elderly people may resist an arrangement involving 'strangers' carrying out intimate tasks and witnessing situations regarded by the elderly person as embarrassing or humiliating, it does not make the job of caring any easier. Some of the elderly people had gradually withdrawn from social activities, depending

solely on the carer for social contact. Attempts by the carer to involve the elderly in social activities were often resisted.

It is not just a matter of providing appropriate, needed and suitable services and supports, vital though that be. There is a strong belief that accepting services from strangers or the state is somehow not appropriate. The expectation that women in particular should provide care for family members is strong; 'family' are perceived as the appropriate carers (Finch 1989; Edgar 1995). This dilemma gives heightened significance to the responses of carers who found the most useful services were those that monitored the health and wellbeing of the elderly relative. Knowing that someone



was visiting the elderly and ensuring they were all right, contributed markedly to the carer's peace of mind.

Participants emphasised the need for the provision of good quality and flexible respite care, both in the form of day care (enormously valuable for working carers) and longer-term respite care which might enable a family to take a holiday together. However, it should be noted that respite care was not always acceptable, either to care recipients, who often resisted, or to carers, who sometimes felt guilty and regretful when they found a deterioration in the condition of their parent with dementia following a period in care.

As the provision of quality child care has come to be accepted as being crucially important in enabling the fuller participation of women in public life, so quality support services for the aged in our society are also critical. Wide-ranging services that are well run, well coordinated and well funded are vital both to the elderly who need this support and to those who care for them.

Provision of such services is also important to those who do not yet and/or may never have call upon these services. For all of us they represent a security, a protection, an important counter to that anxiety about our own and our parent's future that is felt, in some measure, by everyone.

### Workplaces and Change

As with the provision of quality services for the aged, the introduction of changes in the workplace beneficial to carers, are likely to advantage all of us whether or not we have major caring responsibilities at the moment. If caring responsibilities are acknowledged, given legitimacy and not depicted as an unfortunate feature of a worker's life signalling their status as a less serious worker, this is in the interests of all of us. Such a transformation of workplace cultures would be a recognition both of the interactions between the various spheres in the life of an individual and the complexity of contemporary family life.

The response of their workplaces to the caring responsibilities of participants was a major focus of this study. It should be noted that none of the workplaces included in this research had enacted formal policies addressing the caring responsibilities of their employees. Where work environments were supportive, it was as a result either of an understanding management, or of immediate colleagues, or both. This kind of support and understanding was of significance for the women concerned.

### Understanding in the workplace

Most participants said that what they really wanted was a recognition that those caring for elderly relatives had competing

obligations to their families as well as to their work. Allied with this recognition was the hope that there would also be an acknowledgment from employers and fellow workers that fulfilling family responsibilities was a legitimate activity.

*'I think they should listen to women who have had this experience – just listen.'*

*'In a general way it's understanding, being made aware of what the actual carer is carrying. They need to be made aware of actually what responsibilities you do have, other than your work.'*

*'Much the same, I suppose, as they are being forced to acknowledge the needs of child care. The government is not going to support people in nursing homes and those sort of institutions. Basically, it will be individuals that are going to have to support their elderly relatives and wanting and needing to be in the workforce.'*

### Changes needed

Responses to the question of what needed to change in the workplace so that caring responsibilities could be accommodated were of a modest nature, with no-one expecting major adjustments or provisions. There was a call for much greater flexibility in the ways managers organise work and schedule employees, and for a recognition that the requirement to vary arrangements and make allowances for the pressures on employees caring for an elderly relative are usually of a minor nature.

*'More flexible working hours are needed which reflect the reality of women's lives and their care responsibilities. Work is still constructed around a male nine-to-five worker with a wife at home. Most families don't operate like that. People don't have care needs which are pre-eight am and post-six pm. My mother-in-law's needs were from eight to eleven, and then from three to five. Which is precisely when I wasn't around, and we couldn't get services to come at those times.'*

*I'd certainly like to come to a more equitable arrangement, whether it be shorter working hours or whether I can work (all the hours I can) when I have the opportunity. "Can I work longer hours to work up a bank, like working flexitime?" . . . "Look, you've got all these hours out of me for when I take a morning off to take her to the doctor".'*

Where the variation needed is more far-reaching, then it is usually for a short period and to accommodate a temporary crisis. One woman recounted the way her own employer had behaved during the time she was burdened with particularly onerous caring responsibilities.

*I think that employers could do what my employer did. They knew the situation, they knew the problems and accepted that it was going to get better, not worse. He did improve from the stroke, so things have got easier for me and I'm coping better.'*

A number of women mentioned as a priority access to carers' leave to enable them legitimately to take time to attend doctor's appointments or to work from home for short periods.

*I would say that carers' leave is really essential. I needed carers' leave desperately during the stage when my mother-in-law was having her first stroke. Carers' leave would have made all the difference to me rather than doing what I did which was, when she was asleep, hopping onto the word processor, moving my office down to her flat, sitting by her bedside marking essays and so on. That was crazy. Carers' leave would have really made a difference.'*

*'Carers' leave. Knowing if I go there and ask her as a favour, I have to think about it ten times before I do it, and feel bad enough to have to say it. I feel I would get the support, but it's a favour.'*

Among other provisions suggested was the idea that more flexible pensions be made available for short periods of caring when a crisis arises.

## Conclusion

This research is an argument about how as a society we should respond to the fact that all individuals for some periods of their lives will be dependent: it is a significant element of the human condition. A major part of that argument is about how we support those who take on a major responsibility of care for dependent individuals, whether for a short time or for 'the long haul'. We have examined only one area of care by one particular group, but the argument is a general one even while it must take account of the diversity within the population of carers.

This is social policy research concerned with how we go about creating the 'good society', and so it must also be concerned with what 'good' means. The assumption

underpinning the research is that caring is not a peripheral activity for which only some have a responsibility. On the contrary, it is pivotal not only in analytical terms (Graham 1983) but also because the capacity to respond to another who is dependent and has some claim upon us is critical in achieving the 'good society'. Social policy research, in this sense, is always a moral discourse as well as a more practical exploration of ways of understanding an issue and of attempting to respond to it.

If we accept that critical to any debate about the 'good society' is the question of how we respond to those who are dependent, then there are two main issues to be emphasised in relation to care of the elderly.

First, to undertake a major responsibility for the care of a dependent elderly relative (or friend), the carer needs to be supported by well resourced, well managed, reliable, flexible community services. Critical among those services are those that, in the case of a lighter caring demand, provide a monitoring role and, in the case of more demanding care, provide the carer with both day and longer-term respite care.

Such support needs to be available for all carers whether or not they are in the workforce. It is unfair and inconsistent to provide services to an elderly relative living in her own home, which might be next door or very near her carer, but deny those services to an elderly person and her carer because they share the same dwelling and the carer has paid work. Many such carers are not in particularly well-paid jobs. They cannot afford to pay for many services, and some privately provided services would be completely out of their reach.

Further, it is unreasonable for policy makers to require that citizens take greater responsibility for funding their own retirement but base caring policies on an assumption that people (particularly women) will reduce their working hours or leave paid work to provide care or, if they are unwilling or unable to do that, place the elderly relative in a nursing home or hostel. Many people who cannot afford to leave work or even reduce their hours nevertheless want to provide care for their parents and grandparents but feel unable to place them in a nursing home (and may in any event have difficulty finding a suitable, affordable home near by).

If they have access to good services, working carers are enabled to maintain both the quality of care they want to provide and to be an effective and reliable worker not unduly distracted by anxiety about the welfare of their elderly relative. In addition and most importantly, their skills and experience are retained in the paid workforce

Second, workplaces must change. They cannot go on operating, as many still do, as though the typical worker is a male employee who has a wife at home taking full and sole responsibility for

looking after all the family (including children and elderly relatives) and running the home. Feminist researchers (Cox and Leonard 1991) have long been making the point that it is not appropriate or in the interests of workers or management to deny the valuable skills and experience workers have developed in the 'private sphere' – skills in communication, in negotiation and mediation, in management of both people and time, and in dealing with complex and stressful situations. Few would argue that Australian work environments would not benefit from such skills.

There is also the wider issue of what it is that really reduces productivity in the workplace. This research demonstrates how few demands working carers actually make on their places of work and of how responsibly they behave in relation to workplace obligations. They do so often at considerable cost to themselves.

What is clear in this research is that responding to the needs of carers can result in changes that are of advantage to all of us. Workplace reforms that acknowledge and legitimate caring responsibilities will serve us all, regardless of whether or not we are undertaking any caring responsibilities at the moment.

In the same way, adequate government funding of the community services sector not only supports present carers, it provides reassurance and security both to *potential* carers and the *potential* elderly – and that, after all, includes all of us.

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**Elizabeth A. Watson and Jane Mears** are Senior Lecturers at the Department of Social Policy and Human Services, University of Western Sydney, Macarthur.