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Primary carers: motivation to care and the impact of caring on personal and family life

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Abstract

For just on 5 years researchers have been mining data from the 1998 ABS Survey of Disability, Ageing and Carers to characterise the unpaid care of frail older people and people with a disability that is provided by family and friends. The Australian Institute of Health and Welfare (AIHW), too, has released a report on the future supply of informal care, based on a scenarios analysis of the ABS survey data. If 1998 patterns of care provision with respect to age, sex, living arrangement and labour force status are to continue, around 570,000 people are projected to identify themselves as a primary carer by 2013. The AIHW report compares this baseline propensity to care scenario to several other possible scenarios in a 'what if?' approach to some of the issues surrounding the future of informal care.

However, such projections need to be qualified by the complex relationship between one person's need for care and another's willingness to provide that care. This paper explores some less widely reported data collected in the ABS survey on what motivates people to take on the role of primary carer. It covers the psychosocial and physical conditions that primary carers attribute to the caring role, the level of satisfaction they derive from caring, and the needs they identify as most important to them as carers.

An appreciation of motivation and response to the caring experience can add to any discussion of the community's capacity to support those who need assistance with the activities of daily living in their own homes. Motivation to care is particularly relevant in the context of the aspirations of future generations of potential carers.

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Introduction

Australia's welfare, a flagship publication of the Australian Institute of Health and Welfare, has in successive editions emphasised the role of the family as *the* main source of assistance for people with severe disability or age-related frailty (see for example AIHW 2003, 2001, 1999, 1997). *Australia's welfare 1997*, considered caring in the family "in the context of differing and changing models of the family and the importance of family relationships across household boundaries" and the 2003 edition dedicated a special chapter to the subject of informal care.

Recently, the Institute completed an investigation of the impact of certain demographic trends that have led social commentators to draw various and varying conclusions on the sustainability of care in the community (AIHW: Jenkins et al. 2003). A main finding of that work was that population growth in the traditional primary carer age groups is likely to mask any impact of increasing labour force participation among older women, at least over the next decade. The report also quantifies future numbers of primary carers – people who provide ongoing assistance to a relative or friend who has a severe restriction in core daily activities – if there were to be an overall decrease of 10-30% in the propensity to provide unpaid assistance, across all age groups.

It is widely hypothesised that changing patterns of family formation and structure will influence the decisions that people take when confronted with the need to provide or arrange more than casual supervision and assistance for a relative or friend. This paper examines the factors that motivate people to become a primary carer, using data collected in the 1998 ABS Survey of Disability, Ageing and Carers. We will see that an intense caring role, seeded in the complexities of family relationship and emotional obligation, can also involve feelings of inevitability and inescapability. Many primary carers continue in their role for many years despite the high financial and personal costs involved.

Jones and Cullis (2003) argue in a broader sense that "it is impossible to dismiss the relevance of intrinsic motivation: behavioural experiments report that individuals give because they derive a 'warm glow' from the *act* of giving". We hope to raise awareness of the fine balance that seems to exist between intrinsic motivation and carers' reported experience of providing care. We suggest that people deciding to take on a primary carer role are informed largely by factors of intrinsic motivation but that their decisions may also be influenced by external signals of the value of unpaid caring work.

What do carers say about motivation?

The ABS surveyed 918 primary carers nationally in 1998, giving a weighted population of 450.9 million primary carers nationally¹. Of the 447.9 million primary carers aged 15 years and over, 89% specified one or more reasons for taking on the caring role (Table 1). Feelings of duty to care – wanting to provide the best possible care, family responsibility and emotional obligation – featured prominently in the responses, with 82% nominating at least one of these factors. Just over 10% of primary carers cited no available or accessible alternative carer or care

¹ The ABS defines a primary carer as a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities, communication, mobility and self-care (ABS 1999). Most primary carers care for a person with a profound or severe level core activity restriction.

arrangement, or simply 'no choice' as the reason for providing care, without simultaneous mention of family responsibility, emotional obligation or of a desire to provide the better care.

Table 1: Primary carers 15 years and over ('000), reason for taking on a caring role, Australia 1998

Why took on the caring role	Number of responses ¹
Could provide better care	196.8
Family responsibility	257.0
Emotional obligation	173.9
No other family or friends available	112.7
No other family or friends willing	65.9
No other care arrangements available	15.2
Alternative care too costly	95.4
Had no choice	97.3
<i>One or more specified reasons (as above)</i>	398.5
Other reason or not stated	49.4
Total primary carers	447.9

1. More than one reason could be given.

Source: ABS 1999: Table 36

However, of those carers who mentioned duty to care considerations, 49% also felt that they had had less than complete control in the decision due to one or more external factors including the absence of available or willing alternative family carers, lack of access to other care arrangements; and/or a feeling of having had no choice in the matter.

We turn now to some bi-variate explorations of the data. To ease graphical presentation and statistical analysis 'duty to care' factors (provide the best possible care, family responsibility, emotional obligation) and 'choice' factors (no other available or willing carer, availability or cost of alternative arrangements, feeling of having had no choice) were grouped by constructing two indicator variables:

DUTY TO CARE = 1 for a positive response to one or more of: 'provide better care', 'family responsibility', 'emotional obligation'
= 0 otherwise

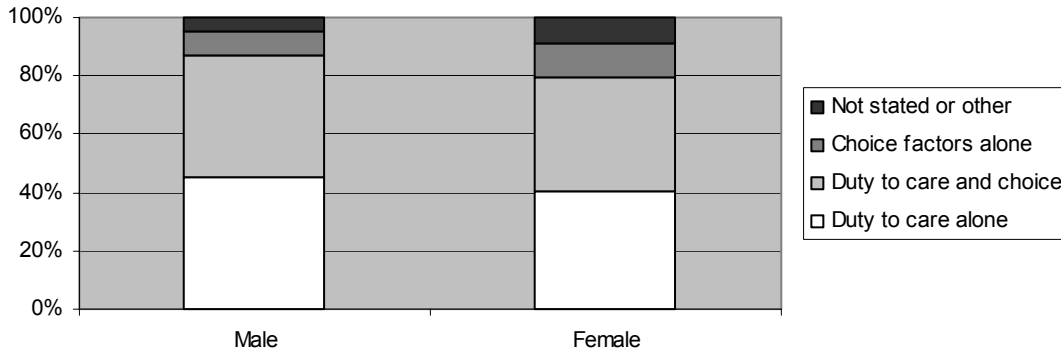
CHOICE = 1 for a positive response to one or more of: 'no other family or friends available', 'no other family or friends willing', 'no other care arrangements available', 'alternative care too costly', 'had no choice'
= 0 otherwise.

Using these variables, the Pearson chi-square statistic was calculated to test the association between selected carer characteristics and the duty to care and choice responses.

DUTY TO CARE features prominently for both male and female primary carers (Figure 1). Female primary carers in 1998 were more likely to nominate choice factors in the absence of duty to care factors, possibly supporting Cahill's (1999) observation that daughter and daughter-in-law carers more often feel they have no real choice but to take on the role of primary carer. An estimated 70% of primary carers in 1998 were female; only at older ages, 75 years and over, is a man just as likely as a woman to be a primary carer (AIHW 2004). Assuming that men of working-age are just as likely as their female counterparts to have a

family member in need of assistance, they are clearly less likely to choose, or feel obliged, to respond to this need by taking on the role of primary carer (see Stohs 1994 on the subject of women's "ethic of care"). The results presented in Figure 1 therefore need to be interpreted as conditional upon a person having accepted a primary carer role.

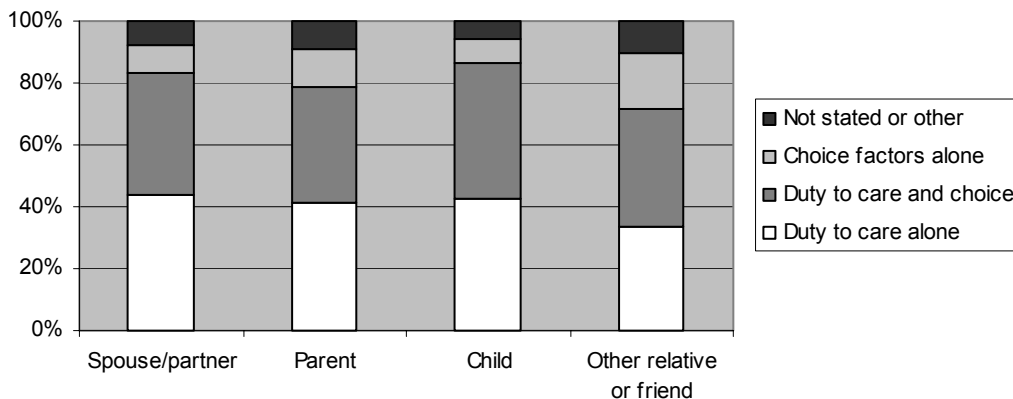
Figure 1: Reason for taking on a caring role by sex of primary carer



Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

Figure 2 shows a fairly consistent pattern in reasons for becoming a primary carer across relationship groups. Carers in the 'Other relative or friend' group appear more likely to provide care because of a perceived lack of choice in the matter, as might be expected. Mention of DUTY TO CARE, with or without mention of CHOICE, was highest amongst son and daughter carers (including sons- and daughters-in-law), whose response profile is most similar to that of spouse/partner carers.

Figure 2: Reason for taking on a caring role by relationship of primary carer to care recipient



Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

Analysis of the association between relationship of primary carer to care recipient and DUTY TO CARE yielded a significant result (X^2 on 3 degrees of freedom: 8.8; $p=0.03$). The main sources of

significance are a substantially *lower* than expected number of DUTY TO CARE responses from other relative or friend carers and, a somewhat *higher* than expected number of DUTY TO CARE responses among people caring for a parent. There is no significant difference between the relationship groups in the CHOICE variable (X^2 on 3 degrees of freedom: 3.3; $p=0.35$).

The relationship of a primary carer to their care recipient is interwoven with co-residency and age of both parties. Unsurprisingly, high rates of co-residency were seen among spouse/partner carers (99%) and parent carers (96%) in 1998. Fewer than half of the people who were caring for a parent (45%), or another relative or friend (43%) lived with the care recipient.

Carers of older people are a special interest group in the context of an ageing population, particularly given the projected steep increases in the number of older people living alone. After spouses and partners, adult children are the next most likely group to take on a primary carer role for an older person. As is evident in the wider population with a profound or severe level of disability, informal care is the main source of assistance to people aged 70 years or over in need of assistance with the core daily activities of self-care, mobility, and communication (Table 2; see also AIHW 2003: Tables 3.4 and 3.5). However, this is by no means limited to assistance provided by a primary carer; wider informal care networks are vitally important to many older people in the community who are in need of assistance with core activities.

Table 2: People aged 70 years or over with a severe or profound core activity restriction, living in households: number in need of assistance^a, by area of need, source of assistance and availability of a primary carer, Australia, 1998

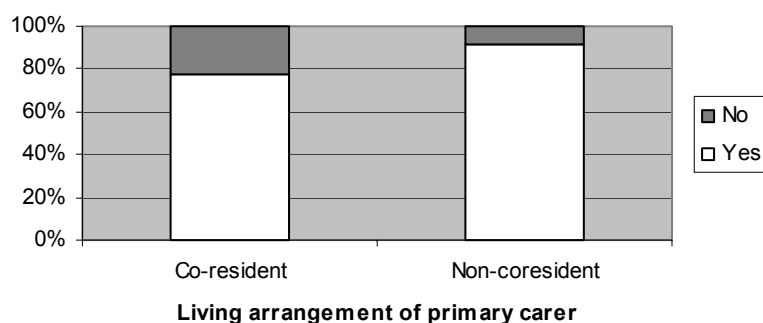
Type of core activity assistance	People in need of this type of assistance ('000)	Main source of assistance is informal care (per cent)	Availability of a primary carer (per cent)
Mobility	233.8	87	38
Self care	126.5	80	61
Communication	26.3	89	75

(a) Includes people who either received or did not receive any type (formal or informal) assistance in each area. Excludes 'Not applicable' responses.

Source: AIHW analysis of ABS 1998 Survey of Disability Ageing and Carers confidentialised unit record file.

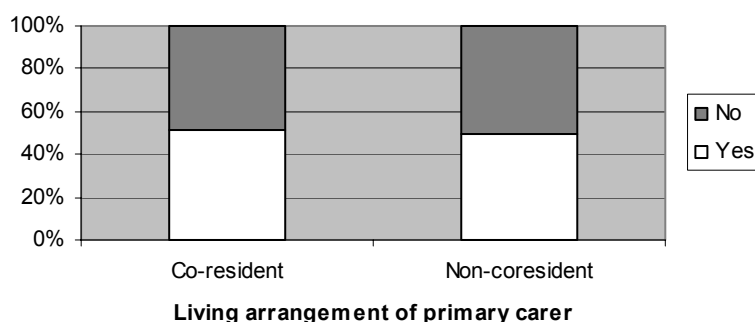
Given the relatively low rate of co-residency among primary carers caring for a parent, we examined the association between co-residency and motivation among offspring carers (Figures 3 and 4). This revealed a significant association between co-residency and DUTY TO CARE (X^2 on 1 degree of freedom: 8.9; $p=0.003$), but not between co-residency and CHOICE (X^2 on 1 degree of freedom: 0.02; $p=0.88$). It appears that strength of relationship is a deciding factor for a higher proportion of non-co-resident son and daughter primary carers than co-resident sons and daughters. We can only speculate as to whether this result reflects selection bias – the difficulty of taking on a role as primary carer of a parent when living in a different household may preclude individuals with lower sensitivity to duty to care. The main point is that relationship, rather than perceived lack of alternative, is expressed by so many non-co-resident carers of parents.

Figure 3: Primary carers caring for a parent: duty to care response



Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

**Figure 4: Primary carers caring for a parent:
choice response**



Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

The caring experience

Many factors influence the impact of the caring role on carers, including the personal characteristics and circumstances of care-giver and receiver, the nature and strength of their relationship, living arrangements and the level of support available from social networks and formal services. We will briefly consider some of these issues, borrowing from material in an upcoming AIHW report, *Informal care in Australia: current and future trends*.

High demands on primary carers are reflected in the amount of time consumed by caring activities. In 1998, unpaid caring work occupied one in three primary carers aged 15 years or over for 40 or more hours per week. On average, older carers reported spending more time on caring than younger carers, with one-half of primary carers aged 65 or over indicating that their role involved 40 hours or more per week. The higher caring workload among older carers is associated with a higher rate of co-residency. Co-resident primary carers report higher caring workloads on average than non-resident carers.

Three-quarters of primary carers in 1998 had spent at least 5 years in the caring role, and 40% had been caring for at least 10 years (AIHW 2000: Table 16.4). Among those caring for a person aged 15 or over, 177,700 primary carers could not leave their main care recipient for more than a few hours without supervision and 63,800 carers could not leave their care recipient unattended for an hour or more (ABS 1999: Table 33). Findings of research on carer experience for the Victorian Carers Program are consistent with the ABS data (Schofield et al. 1997). Caring time in the Victorian study ranged from the minimum qualifying period for inclusion in the study of 4 hours per week to the reported maximum of 168 hours of care provision per week. Twenty-seven per cent of carers reported spending over 100 hours per week in direct care. Duration of care ranged from 1 month to 50 years, with carers of children most likely to have provided care for 5 years or more. The constancy and time consuming nature of long-term caring have been cited as specific causes of carer stress (CAA 2000: 30).

Paid labour force participation

The time demands of caring for a person with a severe disability are reflected in lower rates of labour force participation among primary carers compared to non-carers. Carers of working age are less likely than non-carers to be in paid employment. Part-time employment rates are similar for primary carers (23%), non-primary carers (21%) and non-carers (20%). However, carers report lower rates of full-time employment; 22% of primary carers and 41% of non-

primary carers in 1998 were employed full-time compared to 51% of non-carers. To some extent, these results are confounded by differences in the age and sex distribution of carers compared with the general population aged 15 to 64 years.

Given the disparate age and sex structures of the primary carer and general populations, it is perhaps more valid to compare employment rates of carers and non-carers of prime working ages, 25–54 years. This confirms lower labour force participation among primary carers compared to non-carers in the same age-group, with reduced participation mainly at the expense of full-time employment. Approximately 47% of male primary carers were employed full-time in 1998 versus 80% of men who were not primary carers. Similarly, 18% of female primary carers aged 25–54 years were in full-time paid employment versus 39% of women who were not primary carers.

Paid employment is reported to have protective effects for carers by offering respite from the caring role and helping to maintain social networks (Schofield et al. 1997; Spiess and Schneider 2003; Doty, Jackson & Crown 1998; Turvey and Thomson 1996). Schofield et al. (1998) identified caring and not having full-time work as significant predictors of major health problems in the past year among primary carers who participated in the Victorian Carers Program study. However, the physical, psychological and time demands of caring place paid employment out of reach for many carers of working age. Table 3 summarises income, living costs and employment outcomes reported by primary carers in 1998. Further breakdown of the data by primary carer sex is not possible due to the high sampling error associated with small numbers of male carers in detailed reporting categories. According to the 1998 ABS survey, 11% of primary carers aged 25–54 years and 17% of those aged 55–64 years had left work in order to commence caring or increase their hours of care. Around 21% of employed primary carers had reduced their hours of paid work, and the same proportion of employed carers reported a reduction in income that was directly associated with caring (Table 3).

The impact of ceasing or reducing paid employment to perform unpaid caring work can extend well beyond the actual or intended period of caring. Among 108,700 primary carers aged 25–54 years who were not in the labour force at the time of the 1998 ABS survey, 57% (61,600) said that return to work was not relevant and a small proportion (2%) did not anticipate any difficulty. The remaining 47,100 primary carers expected to face problems that could prevent a return to paid employment. Making suitable alternative care arrangements was the most commonly anticipated difficulty in a list that included inflexible work hours, disruption to the care recipient, and loss of skills while caring. However, almost one-third of this group (15,700) cited 'other reasons', suggesting that more research is needed if such problems are to be addressed (AIHW 2004).

Table 3: Primary carers aged 15 years and over, impact of caring on hours of work, income and living costs (per cent), 1998

	Age group				Total
	15–24	25–54	55–64	65+	
Effect on income					
Income not affected	71.5	39.3	49.2	57.2	45.9
Income has increased	**2.4	*2.8	**2.0	**1.9	2.5
Income has decreased	**5.4	27.2	18.8	*6.8	20.7
Has extra expenses	**16.7	25.5	26.0	28.1	25.8
NA/not stated	**4.0	5.2	**4.0	*6.0	5.2
	100.0	100.0	100.0	100.0	100.0
Effect on living costs					
Difficulty meeting costs	**14.5	34.6	28.3	17.1	29.1
No difficulty meeting costs	**7.6	17.5	16.3	15.8	16.6
NA/not stated	77.9	47.9	55.4	67.2	54.3
	100.0	100.0	100.0	100.0	100.0
Effect on hours of paid work					
Applicable	42.8	51.4	22.4	*3.7	35.8
No effect	*86.4	71.5	64.9	*76.6	71.4
Reduced hours	—	21.8	*22.7	**10.4	20.9
Increased hours	**13.6	*6.7	**12.3	**13.0	7.7
Not applicable	*57.2	48.6	77.6	96.3	64.2
	100.0	100.0	100.0	100.0	100.0
Reason left work					
To commence or increase care	—	11.4	17.2	*4.4	10.6
Total number ('000)	13.6	259.0	79.1	96.4	448.1

— Nil or rounded to zero

* / ** Estimates marked with an asterisk are subject to high relative standard errors (* for RSE of 25–50%; ** for RSE of over 50%). These estimates should be interpreted with caution.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

Carer health and wellbeing

Primary carers experience high rates of disability and long-term health problems. Of those surveyed by the ABS in 1998, just over 39% (177,500) had a disability and 9% (41,900) had a severe or profound core activity restriction. Many primary carers are themselves older people, so that a high rate of disability is not entirely unexpected. Elsewhere, however, the AIHW has reported substantially higher age-specific rates of disability among primary carers (AIHW 2000: 141). Many primary carers provide an intense level of support for someone who is severely restricted in their activities, while also coping with their own severe level of physical restriction. The physical and psychological demands of the caring role itself can lead to adverse health outcomes for carers.

On the impact of caring on various aspects of physical and emotional wellbeing, high numbers of primary carers reported a changed overall state of wellbeing (29%); feelings of dissatisfaction (67%); fatigue and weariness (34%); and feelings of worry or depression (31%) (AIHW 2000:

Table 16.10). Many said that caring work had taken a toll on personal relationships. While one in three primary carers felt that caring had strengthened their relationship with the care recipient, 22% said that the relationship was strained. Nearly a quarter of primary carers said that they had lost, or were losing, touch with friends because of caring commitments.

Bergquist and colleagues (1993) highlighted the strain that caring for aged parents can place on people in their fifties and sixties because of competing priorities and family responsibilities. At this stage of life many people experience changing life patterns while continuing to work and provide support to adult children and possibly grandchildren. Two factors said to contribute most to a positive experience of caring for an elderly parent are having the support of other family members and having a sense that there was some choice in the decision to provide care (Millward 1999).

Carers of people with dementia are at particularly high risk of anxiety and depression as a result of their caring role. Morris et al. 1988 (cited in Henderson & Jorm 1998) remark that *Institutionalisation may have more to do with the attitudes and wellbeing of the caregiver than the impairment of the dementia sufferer.*

Discussion

Acting out of internal moral and ethical concern for another person, the primary carer is said to be 'intrinsically motivated' – the caring role is accepted for no reward other than for the activity itself (Deci 1971; Deci & Ryan 1980, 1985; cited in Jones and Cullis 2003). At the same time, caring for another person can involve high personal costs. The fragile counterbalance between interpersonal relationship and perceived lack of self-determination expressed by primary carers raises again the question of whether intrinsically motivated informal care will be resilient to fluid family structures. Jones and Cullis, among others, argue that individuals' perception of the intrinsic value of action will respond systematically to signals that intrinsic value has been acknowledged.

Public policy measures emit such signals by helping to reduce the financial, opportunity and social costs of providing care, and by increasing benefits to carers in terms of acknowledgement and empowerment (RIS 1998). In a practical sense this highlights the importance of national programs that raise public awareness of the value of unpaid caring work and deliver support to carers in the form of financial assistance (e.g. carer payments and/or tax breaks); access to services, particularly respite care, counselling and education; workplace flexibility for employed carers; and training in occupational health and safety aspects of caring work, such as manual handling. Briggs (1999) and NHPF (2002) give examples of the role of government policy in maximising the caring potential of families.

Public support for carers in all its forms may influence both the instrumental response of people whose caring role is established *and* the motivation of potential future carers. McDonald (1997) suggests that there is a fear in Australia that additional public funding for aged care services would see the family 'free-ride' on a public good. Such fear is based in economic rationalism that recognises only instrumental responses in human behaviour. There is little empirical evidence to support this concern when provision-in-kind is for services with high intrinsic value. Roy (1998), for example, found that individuals' charitable giving increased as people became aware of increased levels of official international aid. Jones and Cullis (2003) have concluded that "perceptions of the intrinsic value of altruism rely on signals that intrinsic value is acknowledged and... increased reliance on welfare state spending can act as such a signal." To rely solely on intrinsic motivation as a driver for the provision of informal care is unlikely to fully realise the capacity of families to care for their own. Equally, external signals, delivered

effectively, may help to counteract the effects of changing family dynamics in Australian society.

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