

Carers NSW Annual Clare Stevenson Memorial Lecture

November 2011

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Good afternoon,

I would like to acknowledge the Gadigal people of the Eora Nation who are the traditional custodians of this land. I would also like to pay respect to the elders past, present and future, of the Eora Nation and extend that respect to other indigenous people present.

It is a privilege to be invited to give the annual Clare Stevenson Memorial Lecture. I am particularly honoured to have the opportunity to speak in the presence of the many carers in the audience today. I would like to acknowledge, that most have likely had to go to great lengths and effort to be here. I would also like to acknowledge those family members and friends who are here to support them.

Thank you to Laraine Toms the President of Carers NSW, Elena Katrakis the Chief Executive Officer and Carers NSW Board Members for the opportunity to present the findings of my research involving carers, and their caregiving experiences.

Today, I will also be discussing the consequences of providing care, and present carer research that specifically examined:

- Bereavement experiences of women who had cared for a palliated spouse and
- Research involving carers who support frail older family members.

The importance and significance of carer research will be reiterated throughout the lecture, and I will conclude with the capacity of and the future investment Carers NSW aims to contribute to research involving carers.

I would like to begin by discussing the various terms used to describe people who care for family members or friends.

As Laraine mentioned, I have a nursing background. Nurses are a very privileged group of health care professionals. It is because of the nature of our work that we often have the opportunity to be closely involved with not only our patients but also with their main source of support - family members and close friends, who are often referred to, in the health care profession, as carers, although, many do not recognise or acknowledge this title.

During my research career there has been much debate about the term carer.

Global and international organisations and various national research reports often use the term “informal carer”. The national associations that represent carers in Australia and the United Kingdom suggest that the preferred term is carer (Lloyd, 2006). Whilst in the United States of America, Canada and several European countries, “caregiver” is the selected term.

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However, many people who are providing care to a family member or friend do not identify themselves as carers or caregivers, particularly if they do not perceive their caregiving activities as a burden.

This is generally because providing unpaid care and support *in a non professional manner to a family member or friend with a disability, mental illness, chronic condition, terminal illness or who are frail* (Carers Australia, 2008) is often a natural role, an extension of commitment, and a close mutually supportive and continuing relationship, although the provision of care can be motivated by obligation or a sense of responsibility (Fine & Glendinning, 2005, Hirst, 2005, Stalker, 2002; Sung, 2001).

The ‘language of relationships’ when describing the provision of care to a family member or friend may be more appropriate (Gooberman-Hill & Ebrahim, 2006), as family carers, in particular, are more likely to identify their caregiving activities within their familial role (Henderson, 2001, O'Connor, 2007). Husbands and wives often accept caregiving as part of their spousal commitment and/or responsibility (Stalker, 2002).

I have received many letters from carers who write back explaining that they would be very happy to participate in carer research, however they explain that they are not a carer, but rather a daughter or son who supports their parent.

For example one carer wrote:

*'We are very lucky, my mum is still very active at nearly 86 and living by herself. My sister and I visit mum most days of the week, we take her shopping and help her pay the bills. We cook her meals and help her to maintain her home. However, she never sits still and is always knitting and crotchetting or doing something with her hands. We are very proud of her'*

We should acknowledge that caregiving or the provision of care is not always task orientated, it can and often involves emotional support and or interaction with various health care services and systems, and it can be transitional or long-term.

Whilst, health care professionals including nurses, generally understand that the support of a carer is integral to providing health care, whether it is the acute, recovery or the palliative phase of one's life, carers are often not acknowledged.

Many carers are "left out of the loop", when it comes to planning care pathways for the patients, even though carers are heavily relied upon to engage in, encourage compliance to and monitor health care interventions (Kaufman, 1994; Sussman, 2009).

In 2005, I had the opportunity to be involved in a nursing research project; the purpose of the study was to explore bereavement as it was experienced by older women who had cared for their palliated spouse. The aim was to inform nursing knowledge and promote a more sensitive nursing practice. The research involved interviewing and listening to women's stories.

Women whose husbands had died of cancer talked about their caregiving experiences and the impact that those experiences had on their bereavement.

The women's stories portrayed feelings of despair and inadequacy. They expressed feelings of guilt and regret. They explained how they considered themselves the guardians of their partner's health during his illness. In their bereavement the women struggled with some of the decisions they had to make. One woman explained:

*'I was trying to help him...I think I have a deep regret that I didn't understand more fully exactly what was happening to him and that I wasn't able to do more than I did... I do regret that'.*

And whilst the women described their relationship with their partner as close, and one in which they did everything together, often neither partner was able to talk about emotional issues and or discuss financial concerns. This lack of communication resulted in the women experiencing feelings of remorse, abandonment and loneliness.

The women confirmed that they needed more information, reassurance and encouragement. They wished that they had had better decision making support from the health care professionals and suggested that sensitive communication during the caregiving phase would have better prepared them for the impending death of their partner and life without him.

Most of the women eventually accepted their loss. As the women confronted the reality that death is final and that they no longer shared a life partnership, they found strength and motivation, which helped them redefine themselves as a single identity and most maintained a strong need to belong. They agreed that a sense of belonging brings familiarity and comfort. Schedules and routines gave their daily lives structure and purpose.

Susan (I have used pseudo names) returned to teaching after many years. She described this move as a return to:

'... a familiar world. You know, it's mine. You know what it is like when, when you've been somewhere. Um, I um think it's just nice to have that sense of um, in a funny way, where you belong'.

May, volunteered at the local hospice, a place that was also familiar to her and one in which she felt needed: She recounted that her husband had had his chemotherapy at the hospice, and they would often comment on how busy everyone seemed. Now she helps the clerical girls get the files ready.

When May first took up the voluntary work at the hospice the staff commented that she was good to come back. May replied honestly:

*'No I'm selfish, I'm doing it for myself as well. I'm glad to be doing something useful. But I'm doing it for myself'.*

Volunteer work gave many of the women a sense of purpose and worth.

Participation in the study was driven by the strong desire of the women to tell their story and convey issues that were important to them, in the hope that it would help other women. Common comments throughout the interviews were *'have I told you enough?'* and *'have you found out enough from me to help other people?'*

By telling their story, the women deepened our understanding of the complexities of providing care, and the effect on their bereavement experience.

The significance of this research informed health care professionals working in the palliative care environment that timely facilitation of intimate communication between couples, may improve a carer's sense of accomplishment and satisfaction with their caregiving role and assist the carers to adapt to their loss. It would also improve one's confidence and self esteem in managing new roles, for example, having to deal with paying household bills and managing bank accounts for the first time.

Sensitivity and the willingness to listen to carers following spousal death were also determined as important aspects in the facilitation of the women's adjustment in bereavement.

Results also indicated that the carers required improved access and better knowledge of palliative care services.

Following this study, I was keen to continue research that focused on carers, particularly in light of the current Australian ageing health and community care systems that rely on carers to provide support to older people so they can remain in their homes.

This provision of care is a less costly measure than institutional placement. Australian carers, provide an estimated 1.32 billion hours of unpaid care to a family member or friend, with the economic value estimated at 40.9 billion per annum (Access Economics, 2010).

It is well known, that the support from family members or friends results in a better quality of life for the care recipient. This is generally, because the care is individualised and flexible and provided in a familiar and caring environment.

However, the amount and load of caregiving assistance required has increased and is being provided in a more complex and demanding environment. Many carers are challenged to learn to deal with complicated treatments and medications. They often monitor side effects and provide symptom management. In addition, carers often have to learn to navigate and negotiate complicated health care systems and coordinate and facilitate a complex network of community resources often supplied by multiple service providers (Travis et al., 2007, Henderson & Caplan, 2008, Pearson et al., 2006).

The availability of carers will affect the efficiency and sustainability of many community aged care programs (Productivity Commission, 2008, Roth et al., 2011). Whilst the Australian government recognises the importance of carers, and is aware that providing carers with appropriate support will be vital in order for them to continue to deliver care in the home environment many carers remain unidentified or acknowledged. Recent reports

suggest that carers' health and support needs are overlooked, particularly by GPs and health care services, with the focus continuing to remain only on the person being cared for (Cummins 2007, Casado 2011).

Research involving carers has informed us that carers generally have poorer health and wellbeing than non carers, especially if they have been caring for a long time (Butterworth et al., 2010; Cummins et al., 2007; Gonzalez, Polansky, Lippa, Walker, & Feng, 2011).

Research has also shown that caregiving is a risk factor for depression and mortality (Cummins et al., 2007).

Providing care has been linked to increases in blood pressure, fatigue and sleep disturbances (90% of carers report sleep disturbances), increased blood sugar levels and Cardiovascular Disease (some reports suggesting 20% of carers die from heart problems potentially exacerbated by stress (Rausch et al., 2007, Fredman et al., 2008). These problems existence mainly because carers tend to have increased health risk behaviours. Carers generally put the care recipient before their own wellbeing: they often neglect their own health care needs, do not get enough rest and exercise, are more likely to forget to take their own medication and rarely fully recuperate from illness (O'Connell, Heslop, & Fennessy, 2010; Schulz & Beach, 1999, Burton et al., 1997).

AND not only can carers physical and mental health decline, they can also endure a negative impact on their employment and education prospects, and their financial position, and often their ability to participate in social and community life (Cummins et al., 2007).

This is an excerpt from a letter from Cathy who cares for her mother who has a degenerative spine disease and is wheelchair bound.

*'It has been wonderful to be around my parents in their later years (her father died in 2006). They are both special caring people, but we do not get on all the time and I have found myself becoming rather isolated and I do need to be in the workforce, but it is extremely*

*difficult for me to get employment that allows me to care for my mother and my two children who are 20 and 15 – as I am a single parent’.*

Another carer: Pat and her husband were health care professionals, who led a very and active life, up until her husband had his stroke. She is now his full time carer.

She recounted:

*‘John had his stroke while we were at a conference in NZ, his medical expenses on top of flying him home were costly. I am aware that services are available, but they are expensive. Our superannuation is drying up quickly and we are struggling with paying the bills’.*

Many carers are elderly themselves and incur their own medical costs. Comments such as this one were not unfamiliar:

*‘7 years ago it just wiped out our super. You know scans and everything that he, we had to have. At that time his heart bypass, my AAA’s, it was a whole disaster’.*

Another carer, William whose wife suffered from incontinence, explained:

*‘The cost of materials is helped by the government with an annual payment of approx \$449.00. My cost to date from 25/11/09 to 6/3/10 (less than six months) has been \$2516.14. Being a pensioner, sometimes finances are a little stretched but up to now I have managed to cope’.*

Whilst many carer struggle, they also experience joy and reap rewards from their caregiving experiences (López, López-Arrieta, & Crespo, 2005). The opportunity to provide care is often an essential part of a close relationship and can result in a sense of general well-being, improved relationships, strengthening of bonds, increased self-esteem and a sense of personal achievement in being able to care (López, López-Arrieta, & Crespo, 2005).

Most carers want to care for their loved ones at home.

Joyce, who cares for her husband with progressive vascular dementia, wrote:

*'I feel that each day is so different, particularly the mood swings, that it is very much a case of taking each day as it comes'.*

She said:

*'My major concern is for my husband and trying to make his life as comfortable as possible and as bearable as this disease will allow. This doesn't leave me with much time for my own interests or would be activities. None the less – this has been my decision (no regrets) to nurse my husband at home and provide as much care and love in the environment to which he is accustomed'.*

As I mentioned earlier, the incidence of care for older people being managed in the home with the support and involvement of a family member or friend is set to increase. Currently, an estimated 2.9 million Australians are providing unpaid support to a family member or friend, many of whom are elderly themselves (Access Economics, 2010).

In 2008, I had the opportunity to be involved in a large trial funded by the National Health & Medical Research Council, the aim of the trial was to reduce frailty and improve functional mobility of older people over the age of 70 years, so that they could maintain their independence and remain living at home, rather than long-term hospitalisation or entry into a residential aged care facility.

The intervention involved at least ten home visits, management of chronic health conditions and psychological issues, nutritional advice and supplements, and or change of diet. There was a physiotherapy component which consisted of an exercise regime and for some it incorporated hydrotherapy twice a week, three if possible and at least 10 visits from a physiotherapist (Fairhall, Aggar et al 2008).

This type of intervention is typical of aged care community programs being introduced globally to address issues associated with a frail ageing population. As you can imagine the

support of a carer is very essential to the implementation of these patient interventions, however, the emphasis remains typically one of a patient centred approach with little research committed to understanding the impact of the intervention on the caregiving situation.

And so our research (one of the very few to date) examined the caregiving experience during the intervention and three months post intervention.

Demographic results:

88% of the frail older participants in the trial relied upon the support of a family member.

The average age of the carer was 66 years, their ages ranged from 37 – 94 yrs of age. The average age of the care recipient was 85yrs. 60% of the carers were females. The majority of the carers were daughters. Just over half of the carers were retired and lived with the care recipient and had been providing care for an average of 5 years.

We examined the caregiving experience in 5 domains, and found that the carers reported the most negative caregiving experiences in the first three domains; 'schedule', 'finance' and 'health'.

1. daily schedule
2. finance,
3. health,
4. self esteem and
5. family support

Our research findings have been published and our results used to inform several policy recommendations. The next few slides briefly illustrate the reason for the research, the significance of the research and the results and recommendations.

Depression is a major health problem for carers.

Research indicates carers have higher rates of depression than non carers, and that carer depression is linked to higher morbidity and mortality (Cummins et al., 2007). It is also a predictor of the early discontinuation of care and nursing home placement of the older care recipient (Segal, Qualls, & Smyer, 2011).

When we examined the relationship of carer depression & anxiety with the 5 domains of the caregiving experience

Our results demonstrated that:

Carers assessed as experiencing a disruption to their daily schedule and health problems, were highly susceptible to symptoms of depression and anxiety (Aggar et al 2010a).

This was an important finding, because if we can identify those carers who report problems with maintaining their usual or daily schedule or poor self perceived health as result of their caregiving activities we can identify carers who may be at particular risk of depression and anxiety and provide them with the appropriate support.

During the course of the research we received this comment from a carer in the study:

*'Cleaning poo from undies and carpet, is not fun.*

*Cleaning ascities fluid from a wound off the bed and lounge is not fun.*

*Lifting a fallen man from the floor at midnight is not easy.*

*Still, the world is wonderful,*

*Life is still sweet'.*

We know that positive emotions have been shown to protect people against depression and anxiety (Cohen et al., 2002), and so it prompted us to ask:

What positive reactions to caregiving have an independent effect on depression and anxiety levels in carers of frail older people?

We know that self esteem is a carer resource (Bachner et al., 2009), and if understood it may play a significant role in preventing or treating depression and anxiety symptoms. So our next analysis explored specific aspects of self esteem and its relationship with carer depression and anxiety levels. We found that that resentment of one's caregiving situation predicted increased anxiety and depression symptoms (Aggar et al 2010b).

Initial analyses suggest that the provision of regular assistance to carers, rather than intermittent support, particularly in terms of respite, may assist carers to maintain or pursue their usual activities, such as caring for their immediate family, employment, social commitments and relaxation.

So in the next phase of our research we describe the aged care health services that were being utilised & looked at their effect on the caregiving experience; the results indicated that the financial strain experienced by the carers was associated with the utilisation of respite care (Aggar et al 2011a).

Currently, residential respite care and financial assistance are the main govt initiative to support carers. However, only 21% of carers eligible to receive respite have taken up the support of the service. Of those 21%, only small numbers have been satisfied with the care provided (Productivity Commission 2008).

Despite the fact that respite is usually offered or taken up when a caregiving situation has reached crises, we found that one common reason for not utilising the service a second time around, is that the older person returns home confused and often incontinent, the carer is physically exhausted from visiting (usually daily if they are a spouse) and mentally drained from feelings of guilt.

Carol who cares for husband wrote:

*'It is quite stressful; I never know if Ray is well looked after. If I am not there he is left to feed himself (Ray is blind and has early dementia), one time I arrived in the morning to find him asleep on the floor. Another time he returned home with plaster on his arm and a knock on*

*his head. I worry, because if I am not there, the staff don't know what makes him comfortable and calm'.*

Whilst Jennifer who cares full time, for her 94yr old father found respite gave her some time out:

*'It was so lovely to just be at home and go to sleep when you wanted to. You know I think that I went out twice to the shops and I didn't look for anything more than that. It was just nice to have time to do this and that. Not to worry about Dad and his breakfast and things like that'.*

It would appear that respite in the form that it currently exists (residential respite) may provide short-term relief for some but it does not improve or relieve negative caregiving experiences.

For many, residential respite care is stressful and most cannot afford in-home respite. When we asked carers had they considered in-home respite, some stated they had and agreed it was a good idea, but costly and that they had no room to accommodate another person over night.

Our final analyses compared the caregiving experience between those carers whose care recipient received the intervention and carers whose care recipient did not receive the intervention. Just to recap, the aim of the community intervention was to reduce frailty and improve functional mobility of frail older person, so that they could maintain their independence and remain living at home. The intervention involved at least ten home visits, nutritional advice a physiotherapy component, an exercise regime which and at least 10 visits from a physiotherapist (Fairhall, Aggar et al 2008).

Results (Aggar et al 2011b)

For both groups of carers there was an increase or (worsening) of anxiety levels over the duration of the study and 3 months beyond.

Anxiety is defined as a normal reaction to a difficult or threatening situation. Generally periods of anxiety are brief; however, providing care to a frail older person can be a prolonged experience involving multiple stressful incidents, problems and challenges. And so this result is disturbing because increasing levels of anxiety have been significantly associated with a high risk of depression and mortality.

We also found that those carers involved in the intervention sustained an improvement in health scores. However health scores deteriorated once the intervention had ceased. This slide shows the relationship graphically.

However until further work is done we can only speculate the reasons for this improvement in health scores. Whilst there was no explicit intervention for the carers, their involvement in the frailty intervention was assumed, and any caregiving concerns were addressed by a case manager (Fairhall, Aggar et al 2008).

Research has found that barriers (e.g. preferences, resistance, lack of information) in obtaining health care services (e.g. transport) are associated with low self-rated health (Hong et al., 2004; Keith, Wacker, & Collins, 2009). We suspect that the case management feature of the frailty intervention may have assisted in removing some of the barriers to service utilisation. We need to do more work.

Given these findings, there is a need to recognise and include carers in interventions for frail older people and for health care professionals to understand the prevalence of anxiety experienced by carers, and to encourage and reinforce to carers the importance of maintaining and managing their health.

In addition, this information is fundamental in assisting health care professionals to identify and detect carers at-risk and provide them with appropriate support.

Overall, the study's recommendations are for

- Regular formal support that lessens the hours spent caregiving.

However, the support services need to be reliable, of good quality, meet the requirements of both care recipient and carer and be implemented prior to the carer reaching crisis. We also found that carers who needed support generally do not ask for it due to feelings of guilt, loss of privacy and cost.

For some, having people come into their home took some getting use to. One lady recounted how the first time she had help, she spent the previous two days cleaning and preparing the place and found the whole exercise exhausting.

Further recommendations include:

- Public awareness of available support services and their benefits may improve the acceptance and use of support services by carers.
- Targeted health care initiatives and financial support that assists carers to improve their health status. This result supports a previous government proposal to provide a primary health care program for carers, including free influenza & hepatitis vaccinations, health care card and annual health checks.
- Consideration of carers' financial barriers and concerns, particularly with regard to respite services
- Inclusion of carers in the assessment and referral process for community aged care services

The results of this study highlight the need for health care professionals to consider carers individually, particularly their general wellbeing, caregiving circumstances and their specific support needs. Therefore the final and most important recommendation of this study is for:

- Structured, individual and regular carer assessments

An assessment of the carer and their individual needs, and of the caregiving situation, has the potential to support or improve carer health and well-being and ensure the provision of timely and appropriate support services.

Assessment of the caregiving situation and the needs of individual carers will ensure they receive flexible and quality support services. Currently, in Australia, carers are not routinely or individually assessed. Rather their well-being may be taken into consideration when their care recipient is assessed by the Aged Care Assessment Team (ACAT) for eligibility for aged care services.

Recent legislation titled the “Carers Recognition Bill” is a step forward for all carers. However, even where legislation has provided carers with rights to an individual assessment, for example in the UK, existing assessment practice and the expertise of implementing carer assessments has remained inadequate.

An aspect to emerge from the descriptive findings of this study was the implications of caregiving on employment. Approximately 38% of the carers in this study were employed; their mean age was 54 years.

These carers were simultaneously providing care for an older parent and their own children and or grandchildren whilst in employment, otherwise referred to as the “the sandwich” generation.

The disparity of employment opportunities, predominantly for women carers, include the relinquishment of wages and associated losses, such superannuation benefits. The extent to which carers make work related adjustments in order to provide care to their frail older family member requires further investigation.

Questions such as

Do carers want to be able to both care and work?

Will carers forgo their caregiving role so they can engage with the workforce?

These questions need to be asked and answered, particularly in light of the baby boomer generation entering the aged care system and whose preference for aged care will be in their own home.

It is anticipated that Baby Boomers will generally be healthier in older age and more able to live independently (Wanless et al., 2006). However, the evidence for the health and general well-being of Baby Boomers' who care for frail older parents and their own children, whilst in employment is sparse. Increasing levels of anxiety and detrimental health implications as a consequence of caregiving may result in the next generation of older care recipients experiencing added mental and physical health problems.

In light of the recent Carer Recognition Act, the release of a National Carers Strategy (Commonwealth of Australia, 2011), and the Australian Government's National Health Reform (Australian Government, 2011) in which carers of older people have been acknowledged, and the need for better support has been specifically identified, carer research is timely.

The National Health reform, of a coordinated and integrated system of care for older Australians, includes a single point entry system for aged care, with coordinated case management and assessment (Australian Government, 2011). The incorporation of carer assessments into the planning and review of such client initiatives will ensure carers are individually and systematically assessed in order to facilitate a comprehensive perception of their caregiving support needs.

Carers NSW aims to continue and expand its research capacity to address these issues and others, including current collaborative work with higher education facilities, in order to support the rights of carers, provide information and strategies on practice guidelines to inform policy and the development of services to support carers.

I would like to conclude with my thanks to the many carers who volunteer to take part in carer research, their willingness to put aside precious time, and complete questionnaires and give interviews, is driven by their determination to "make it better" for future carers.

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