

# The social impact of caring for terminally ill people: sustaining the well-being of carers in rural Australia

Samar Aoun, Linda Kristjanson, WA Centre for Cancer and Palliative Care, School of Nursing and Public Health, Edith Cowan University

## INTRODUCTION AND BACKGROUND

Many individuals are finding themselves becoming the primary care providers for ill and disabled family members. Primary carers are defined as people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care (1). We live longer, but with compromising medical conditions and increased costs of health care. Consequently, families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care. The carer role has changed dramatically from promoting convalescence to providing high technology care and psychological support in the home (2).

Palliative care is the specialised health care of dying people, which aims to maximise quality of life and assist family and carers during and after death of a loved one (3). Although only approximately one third of all patients receiving palliative care services die at home, up to 90% of terminally ill patients spend the majority of their last year of life at home (4, 5). Thus, home palliative care would be impossible for many people without the support of carers (6). Yet there is considerable evidence in the literature that the burden of caring is adversely affecting family carers who lack adequate resources or who are insufficiently prepared for this new complex role (7) (2) (8) (9) (10).

Rural areas have particular needs associated with the lack of appropriate services for people with terminal illness and issues related to isolation, distance and transport, in addition to a culture of self-reliance associated with concerns about privacy and confidentiality. The National Census of Palliative Care Services (4) identified that population-based rates of admission to palliative care services in regional areas are 30 to 35% lower than in metropolitan areas. Sixty per cent of metropolitan services reported access to specialist palliative medicine resources compared to 36% in regional areas. Similarly, eighty per cent of metropolitan services reported access to a Clinical Nurse Consultant, compared to 61% in regional areas (4).

Rural carers have the added stress of relocation to metropolitan centres for specialist treatment required for care recipients with cancer (11, 12). The non-availability of regional or rural specialist treatment means that patients and their families must cope with the additional stress of relocating from their homes for lengthy periods of treatment. This entails significant financial problems in meeting travel and accommodation costs, additional medical costs, double grocery bills for family at home and family in the city, and loss of employment. Often rural and remote patients and carers learn about transport assistance schemes during or at the completion of treatment or when they reach financial crisis. Travel expenses of carers are not automatically reimbursed because an escort may not be considered medically necessary (13). Rural people may not know information is available and without it they report feeling out of control and have difficulty making decisions (14).

Upon returning to rural areas after specialist treatment in a metropolitan centre, the highest reported needs of carers are related to emotional support, the need to talk to someone who understands the patient's situation. Having left the comfort of the supportive relationships established with metropolitan health professionals, carers may not feel confident about local knowledge levels and medical expertise within the limited resources of rural health professionals (15, 16). Silveira and Winstead-Fry (17) reported that carers' needs in rural settings were three times more likely not to be met, compared to patients' needs. This lack of support may occur, in part, because family carers in rural settings are viewed as resources rather than as recipients of care themselves (18).

Palliative Care Australia (PCA) is the peak body representing palliative care in Australia. In mid-2003, PCA launched a National Inquiry into the Social Impact of Caring for Terminally Ill People to gather experience, opinion, policy and research related to the social impact of unpaid caring for the terminally ill. PCA invited public submissions from individual carers and their support organisations and service providers to complement a review of national and international literature (19). This article describes the experiences of carers and service providers who participated in this public submission process and in particular the special needs encountered in rural settings.

## METHODS

Submissions were invited by PCA from individuals, families and organisations in one or more of the following forms:

- letters or case studies describing unpaid carers' stories and experiences
- descriptions of unpaid carers' needs and the extent to which they are being met by government, other institutions and the community
- policy statements and/or recommendations relating to unpaid carers of the terminally ill
- copies of recent relevant reports or publications
- relevant research data and/or literature reviews.

A total of 131 organisations were contacted via letter and email and were invited to make a submission. In addition, a national advertisement was placed in the Australian newspaper and also circulated through: the PCA newsletter, PCA Member Association newsletters, PCA's email list, stakeholders newsletters and email lists, the PCA website, professional magazines and community newspapers around Australia.

## RESULTS

This analysis is based on the total submissions received from 20 individual carers, six volunteers in palliative care and 23 service providers, describing carers' experiences and unmet needs. Nearly a third of these submissions were from rural and remote areas of Australia. The majority of carers who responded were female, either wives or daughters, caring for partners or parents, the majority of whom had cancer (lung, prostate, renal, leukaemia, brain tumour) or dementia or Motor Neurone Disease (MND). Service providers came from a wide cross-section of services and support organisations such as cancer councils, carers associations, palliative care services, hospices, government departments, nursing and medical professional bodies.

Data were collated by content analysis and by grouping stories and accounts on the impact of caring into financial, physical and emotional aspects, which were often intertwined.

## The financial impact of caring

Carers experienced difficulties in maintaining employment, and were forced to give up work and rely on government assistance, which was frequently inadequate, particularly in light of the increased expenses they encountered on a daily basis. The cost of drugs and equipment hire for palliative care can be extremely high and have placed an enormous financial burden on carers who tried to maintain their family member at home. Transport and accommodation were major cost concerns for rural carers, as well as the lack of understanding by Centrelink about terminal illness and how it affected carers. The following reflections from the rural and remote sub-group highlighted these issues:

Everyone needs support when there is a serious illness especially country people who have the added expense of travelling and the upheaval of leaving their own home and all that is familiar.

Country people have to go away from their homes to see specialists, have tests, operations and treatments. It is very expensive and not often do we have people to stay with, so it is very taxing on the patients, their families and their pockets.

As my husband had less than 12 months to live, doctors were not prepared to place him on a "terminal account" for his oxygen needs, stating that to be "terminal" you should only live three months. We were forced to buy two oxygen concentrators at a total cost of \$6000. My husband needed equipment that were not available in country loan pools such as Roho mattress and wheelchair seat, electric hi-lo bed, special padded commode/bathseat with back, high backed manual wheelchair and electric wheelchair ... The emotional stress of purchasing all these items to enable us to return home in the country was huge and I spent three weeks in Sydney running around purchasing all the items from various suppliers.

I gave up a successful well paid job (to look after the two parents who died of cancer). The Carers' pension is way too low. If you have financial commitments you can't live on the pension. The person who is ill has enough to worry about without your financial situation ... Maintaining the garden, washing, ironing or housework came out of my pension. I wanted to keep life as normal as possible and some days I just could not do it all, so I'd pay someone to do it. Needless to say I used up all my savings.

My first daughter left her job in Sydney to become a carer for her father as we lived in the country. She was not eligible for the Carer's Allowance and Benefit but received Newstart Allowance after some delay ... My second daughter interrupted her university degree to become a carer and lost on her Youth Allowance ... I was not allowed to take all my sick leave at work and had to exhaust my extended leave. There was no flexibility in my workplace despite receiving a brochure on "Family Friendly Workplaces" ... I was away from home for many weeks while husband was having his treatment in Sydney, which made it impossible for me to work part-time ...

Refusal of Centrelink to fund the carers pension due to the terminal nature of the diagnosis – expectation that the carer will continue to seek work despite the fact that they are caring for someone with terminal illness.

Centrelink forms are not user-friendly. They are inappropriate to the needs of palliative care patients and carers and not flexible for short-term situations.

## The physical and emotional impact of caring

Carers experienced an increase in adverse health effects related to stress, a change in eating patterns leading to weight loss, and a disruption in sleeping patterns leading to fatigue. Carers had reduced opportunity for social and physical activities, further reducing their own physical

well-being, which has often led to their social isolation. Carers often ignored or diminished the importance of their own needs to the point of foregoing their own health checks.

I cancelled my mammogram as I could not afford the petrol required to travel to the appointment and the cost of seeing the doctor. I later found a lump in my breast and was diagnosed with advanced breast cancer.

The care was constant. While for a couple of months, we were able to leave him at home alone for about half an hour, as time went on, we all felt increasing discomfort leaving him alone and made sure someone was there all the time. At this late stage, he really needed the three of us to provide his care, if we were to remain 'sane'.

Carers who escort their loved ones to metropolitan centres for treatment often have to care (for the loved one who is generally unwell, in pain and nauseated) as well as drive. This is stressful and causes a safety problem on the road.

The effort of taking him out to make small purchases was enormous. Our checklist included oxygen cylinders, oxygen conserving device, wheelchair, Roho cushion, mask as well as nasal prongs, morphine, nasal spray, ventolin, mobile phone in case of breakdown, it seemed endless. For a doctor's appointment at 11.00am, we needed to make a start at 7.30am.

Family isolation from the patient who needs hospital care – carers experience genuine conflict between the requirements of rural living and separation from their loved one who is dying.

Lack of respite care and other support services have also led to social isolation, exhaustion, illness and negative feelings towards the dying patient and carers putting their own health at risk. Upon returning to rural areas after specialist treatment in a metropolitan centre, carers lacked emotional, practical and professional support. Carers reported feelings such as guilt, fear, frustration, anger, resentment, anxiety, depression, loss of control and a sense of inadequacy. Periods of caring may be brief or quite long and protracted, with a roller coaster of emotions, reactions and frequent crises.

There needs to be more practical support. I was given the equipment and left to work it out on my own. I had to work out levels and doses of medication. Need more support from people who have been in the situation themselves and not got their information out of a book. There should be a book for carers, what sorts of easy to eat meals to prepare, a list of things to buy ie stable tables, seats for bathrooms, non-spill cups. Things that make life easier for both patient and carer. Especially when you live in the country often things are hard to obtain.

I feel many doctors, specialists etc don't explain enough to patients and don't explain what options are available as to treatments and where these treatments can be given (ie in centres closer to the rural area than Sydney is).

Having come from a wonderful rehab unit in the city, by contrast the facilities in the country rehab unit were appalling and staff morale seemed low and the experience was depressing. My husband could not receive the drip at home. We went to the "day procedures" which did not have a bed to lie on, just a very hard recliner chair. There was a feeling of "how dare you ask for a bed?"

We had a palliative care lady call on us a couple of times and this irritated Dad. He didn't need someone to come in and tell him (more than once) to "get his affairs in order". We needed to know more of who to contact for assistance, what to do after the death, who to call first etc. Fortunately a friend was an RN and she was with us soon after Dad died and helped with everything.

I continue to feel guilty that I was unable to fulfil Mum's wish to die at home. If there had been more support available perhaps this would have been possible. To be offered a nurse at night so that carers could get some sleep or just spend time with their own family would make a huge difference.

Other issues that caused added stress for carers in rural areas pertained to the erratic electricity supply and the access to medication:

My husband required two oxygen concentrators to supply him with enough oxygen and was lying in an electric bed which he relied upon to sit him up to get out of bed. The stress of electricity blackouts in the country without warning was always present, up to 12 hours at a time, despite as palliative family having registered with the electricity supplier to obtain rebate for electricity. Surely an updated database with personal warnings was not too much to ask.

Our biggest problem was getting the large quantities of morphine from the chemist. A pump was connected to administer the morphine at regular intervals over a 24 hr period plus we were taught to administer extra morphine as required. We would go to the chemist in the morning and most times they would have to get what was required from chemists in larger regional centres and deliver to the house later in the day, sometimes after dark.

## Recommendations for enhancing carer support in general

Recurring themes emerging from the submissions by carers and support organisations on service gaps, that were common for both rural and metropolitan areas, can be grouped into four interrelated categories:

- *Information and communication needs:* carers needed information and education about the ill relative's condition and its implications, the treatment options, managing medication and recognising and reporting changes in health and functional status of the patient. Carers needed to have increased knowledge about available services and how to access individual and family counselling services and physical support, such as appropriate respite care and domestic help. Carers also recognised a need for better communication with health professionals and better co-ordination of services.
- *Financial and employment needs:* carers required better support from government agencies to assist them in their role and identified the need for assistance with the costs related to medications, equipment hire and co-payments for community services. Health care and social welfare (eg Centrelink) forms needed to be more user-friendly and appropriate to palliative care recipients. More flexible carer's benefit schemes were required to meet the unique needs of this population (eg. increased amounts for shorter periods of time). Employers should be encouraged to provide flexible employment arrangements for carers in the workplace, to enable carers to balance work and care.
- *Increase in respite and other support services:* carers identified the need for improved access to allied health services for provision of care in the home and improved access to counselling services for themselves and their care recipients. There was also a need for bereavement counselling as carers often felt neglected after the death of their care recipients. More respite care was required particularly at night and at weekends.
- *Community recognition:* carers and service providers reported that current policy and financial assistance to carers failed to recognise the value of unpaid carers and underestimate the benefit to our community of the unconditional, 24 hour a day, 7 day week dedicated service to people with terminal illness. Therefore, carers were keen "to convey to the outside world the physical, mental, financial and emotional mountains that carers have to climb".

## Recommendations for enhancing carer support particularly in rural areas

Within the rural and regional context, considerable differences existed in the level and type of support available to carers. The current systems of support could be substantially improved to ensure equitable access to regional and metropolitan based palliative care by patients and carers from rural and remote areas. Some of the recommendations put forward by service providers working in rural and remote areas included:

- a review of reimbursement schemes for travel and accommodation with a view to national consistency in eligibility criteria and reimbursement rates appropriate to the cost of living in the city concerned
- access to reimbursement for patients and carers made available on the basis of specialist care received, not medical authorisation
- automatic eligibility for reimbursement for the travel and accommodation costs of a carer for patients requiring palliative care
- access to respite care services – which are often non-existent in rural areas
- back-up plans to be put in place in case the responsibility of caring for a terminally ill at home becomes onerous, or if the family did not realise the an enormous commitment of time. Also back-up for the usual home duties is required
- co-ordinated provision of equipment to assist the person to be cared for with dignity – there is often not enough locally available equipment such as commodes, shower curtains, mattresses, syringe drivers, mobility aids, etc. Without appropriate equipment and training, the patient may be at increased risk of injury and pressure ulcers and carers may also be at risk of injury from inappropriate lifting.
- improved mobile phone coverage in rural areas, as mobile phones provide reassurance for carers should they need to leave their care recipients home alone for a short while.
- warnings about planned electricity blackouts for those using life support equipment.
- more palliative care workers who can support each other and provide cover to clients they know when their co-worker is on-leave.

## DISCUSSION AND CONCLUSION

The authors acknowledge that these findings are constrained by the small, self-selected group of carers who responded to this submission. However, the issues raised by these carers and reinforced by a wide cross-section of service providers confirm that the majority of carers share the same unmet needs and had experienced similar challenging aspects of caring.

The picture that emerged from the public submissions is that carers for dying people “make do” with whatever information and support is available to them or comes to their attention, should they happen to be at the right place and at the right time, or have the know-how to navigate the system. Unfortunately rural and remote areas do not happen to be “the right place”. Those fortunate to have received comprehensive and co-ordinated health professional support mostly felt positive about their caring experience, while those less fortunate undertook caring responsibilities at the expense of their physical, emotional and financial well-being. The

experiences of carers suggested that a considerable amount of service contact/access occurred on a random or ad-hoc basis.

To sustain the well-being of carers in rural Australia, carers need to access adequate and flexible resources, fairer remuneration and more respite care. Support for carers would also be enhanced with better training and preparation for the carer role, access to equipment for caring tasks, the availability of quality psychosocial support, home help, improved access to the paid workforce and more financial support for transport and relocation. On a social level, the challenge for the community is to improve understanding of the contribution carers make to society. The National Inquiry by PCA has ensured that carers gained greater exposure and visibility in the community (19).

It is worth noting that the Australian Government has recently undertaken several initiatives to address the unmet need through the National Palliative Care Program (20). One particular initiative, the Rural Palliative Care Program, is piloting a number of multi-disciplinary models of palliative care over three years, aiming to demonstrate that access to an integrated palliative care service is achievable and sustainable within a rural setting. Other global initiatives targeted medication, equipment, respite care, training and education. These initiatives will be evaluated in due course and it is anticipated that, while not all gaps can be addressed by these initiatives, the benefits would not by-pass carers in rural and remote areas of Australia.

Findings from this project have informed a strategic national agenda aimed at enhancing the well-being of family carers. Evidence collected by the National Inquiry reinforced the importance of policy responses and resource allocations that are focused on helping carers perform a vital and important role into the future, particularly as carers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for the terminally ill.

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## PRESENTER

**Samar Aoun** is an adjunct Associate Professor with the School of Nursing and Public Health at Edith Cowan University, a project manager with the WA Centre for Cancer and Palliative Care and the Director of the WA Centre for Rural Health and Community Development. Samar has a Doctorate in Medical Demography from London School of Hygiene and Tropical Medicine and a Masters in Public Health from the American University of Beirut. In 2001 she was awarded the "South West Woman of the Year" for her dedication to rural health and community development and last year she received a national award – the "Centenary Medal" – for her voluntary work in the rural community. She will be presenting her work with Palliative Care Australia on the National Inquiry on The Social Impact of Caring for Terminally Ill People. The report on this inquiry was launched in May 2004 by the Commonwealth Minister for Health and is entitled: *The Hardest Thing We Have Ever Done: the social impact of caring for terminally ill people in Australia, 2004*.