

Promoting the health and well being of older carers: A proactive strategy

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Abstract

Research has indicated that carers are concerned about their ageing status, their deteriorating health and their ability to continue to care for their dependants. Given that the health care system will become increasingly reliant on carers the health care needs of carers should be a concern for all health care professionals. This paper describes the first stage of a project designed to enhance older carers health promotion knowledge and skills and improve their health promoting behaviors. This stage investigated the mental and physical health status of older carers. It also sought information on older carers' levels of participation in health related and social activities and identification of barriers to participation in these types of activities. The results highlighted that carers responding to the survey experienced compromised physical and mental health. Many carers reported being unable to participate in social and health-type activities as they were unable to leave the care recipient. Of note, is that carers identified their own mental fragility and felt they needed further emotional support.

Background

There are increasing numbers of older people in Australia who are the primary carers of dependent individuals with disabilities and illnesses (Ageing and Disability Department [ADD] 1999). In 1998, the Australian Bureau of Statistics (ABS) reported that 2.3 million Australians provided some form of care to individuals with a disability or illness. Of these people, approximately 450,900 identified themselves as primary carers, that is, the person who provides the most informal, unpaid, on-going home-based care to dependent individuals for one or more of the core activities of self care, mobility or communication (ABS 1999). These statistics may be conservative as many primary carers do not identify with the term 'carer', and are not formally known or counted (Carers NSW 2001).

The ageing carer population deserves urgent attention, as, in 1998, 21% of primary carers in Australia were aged 65 and over, with 81% of these older carers caring for people in their own age group, most often their partner (Australian Institute of Health and Welfare 2002). Research has indicated that carers are concerned about their ageing status, their deteriorating health and their ability to continue to care for their dependants (O'Connell, Bailey & Pearce 2003). This study also reported, that many carers experienced poor quality of life associated with profound social isolation and a large burden of care. Clearly, caring responsibilities negatively impact on the overall health and well being of carers (Carers Association of Australia [CAA] 2000; Gibbons 1999; ADD 1999; Savage, Bailey, O'Connell & Austin 2002; Schofield et al. 1998; Syron & Shelley 2001).

In addition, a longitudinal study of approximately 1000 carers in Victoria found that, on measures of self-rated health and well being, carers reported significantly lower health ratings, and were found to have significantly less life satisfaction, less positive affect, more negative affect and greater overload than non-carers (Schofield et al. 1998). Similarly, a national survey of 1449 carers around Australia assessing carer health and well being found

that providing care comes at a cost to the carer's own physical and mental health (CAA 2000). Health care professionals should be concerned that compromised health of carers can result in increased burden on the health care system and residential care services (Browning & Schwirian 1994).

Older carers experience a more profound impact of their caring role as the stress of continual care giving responsibilities is compounded by their age-related deteriorating health. Normal ageing brings physiological changes and pathological decline in various organ systems, resulting in lower levels of fitness for this group (National Health and Medical Research Council [NHMRC] 1994). In addition, as older carers are often caring for someone in their own age group, they may also have to cope with the growing dependence of the care recipient (Gibbons 1999), which usually leaves the older carer with little time and energy to engage in health and social activities and attend to their own health care needs. In addition, due to lack of social contact carers report feeling lonely and isolated, which impacts on their mental well-being (Boland & Sims 1996).

The importance of regular activity cannot be over emphasized as it improves fitness levels, health and enables activities of daily living to be conducted without undue fatigue (NHMRC 1994). In addition, exercise has been shown to have beneficial effects on carer's stress levels and the quality of their sleep (Zamora 2001). Older carers who are restricted by their caring role may be unable to participate in regular physical activity. In keeping with health belief model theory, Elder, Ayala & Harris (1999) reinforces the need to reduce factors that hinder optimal health promotion behaviour. Within this context, it is necessary to acquire greater understanding of carer perspectives of the factors/issues that impede them from participating in social and health type activities. This knowledge can assist policy planners to accommodate carer needs and better design health care services.

Given that the health care system will become increasingly reliant on carers to support individuals with a disability at home, the health care needs of carers should be a concern for all health care professionals and policy makers. The needs of carers should be considered at the point of discharge from hospital as a matter of routine. Some consideration should be given to developing a discharge plan educating the carers on available services in the community and should include the involvement of community nurses in the on-going assessment of carer burden (Browning & Schwirian 1994). More specifically, it is important to consider developing a proactive health promotion model that addresses carer needs rather than a reactive illness treatment model that addresses issues when they are problematic.

The aim of this project is to develop and evaluate a wellness guide designed to enhance older carers health promotion knowledge and skills and improve their health promoting behaviors. The aim of the wellness guide is to enhance the physical and/or mental health and well being of older carers by improving their ability to solve problems they encounter as carers. The wellness guide will also provide information about health-related issues to older carers that will assist them to maintain or improve health and well-being. The use of a wellness guide to promote health has been successfully implemented in California, USA. It has been shown to improve people's confidence in their ability to solve problems creatively, and to enhance people's abilities to control their own destiny (Neuhauser, Schwab, Syme, Bieber, & King Obarski, 1998). The focus of the wellness guide will be potentially preventable, postponable or improvable 'health conditions' rather than specific diseases.

The first stage of the project involves gathering base line data of carer needs. The second stage of this project will actively involve older carers in the development, implementation and evaluation of a wellness guide for older carers.

This paper describes the first stage of a three-year project. This stage investigated the mental and physical health status of the older carer population in the Barwon-South West Region of Victoria. It also sought information on older carers' levels of participation in health related and social activities and issues that hinder participation in these activities. The project commenced after ethics approval was obtained from a University's Institutional Ethics committee.

Method

This descriptive study was conducted in the Barwon-South West Region of Victoria. Data were collected using two procedures, focus group interviews and a survey instrument.

Focus group Interviews

Initially, two focus group interviews consisting of seven and eight participants respectively were conducted with older carers. The participants were volunteer carers recruited through advertisements of the project in the local media and with appropriate carer agencies throughout the region.

During the focus group interviews, participants were asked to provide information on:

- Social and/or health type activities in which they participated and reasons for non-participation in activities;
- Services used to assist in the caring role and reasons for not using services; and
- How emotional support was obtained.

The focus groups were tape-recorded, transcribed and thematically analysed and the data was used to generate items for the survey. Examples of survey questions included types of activities that carers participated in, reasons why they were unable to participate and the types of services they commonly used.

Survey

To observe privacy regulations, a convenience sample was recruited through advertisements in the media, as well as through local organisations providing carer respite and support. A total of 226 surveys were sent to carers over the age of 60. Of the 226 surveys posted, 85 were completed and returned, a response rate of 38%. Given the vulnerability of this group and the limited accuracy of carer details on organisations' databases this rate, though not ideal, was higher than expected. Four of the returned surveys were incomplete and not used in the data analysis. The final sample size was 81 participants.

Measures

The survey instrument used in this study was developed using a combination of pre-existing measures and measures developed specifically for this study. The survey consisted of three sections assessing the following:

1. general demographic characteristics of the carer and care recipient;
2. an instrument measuring the physical and mental health status of the carers; and
3. carers participation rates in social and/or health-type activities as well as carers use of services and support.

Physical and mental health status was measured using the SF-12 a shortened version of the SF-36, which measures eight health concepts: physical functioning, role limitations due to physical health problems (role-physical), bodily pain, general health, vitality, social functioning, role limitations due to emotional problems (role-emotional), and mental health. One or two items measure each concept. The SF-12 yields two summary scales: the Physical Component Summary (PCS) measured by physical functioning, role-physical, bodily pain and general health, and the Mental Component Summary (MCS) measured by vitality, social functioning, role-emotional and mental health. The SF-12 has been shown to have acceptable internal validity with test-retest reliabilities of 0.89 for the PCS and 0.76 for the MCS (Ware, Kosinski & Keller 1998).

Survey items assessing older carers participation in social and/or health type activities and older carers use of services and support were developed specifically for this study using the focus group data discussed previously.

Results

Demographics

Demographic data revealed that 70% of the respondent carers were female and 30% were male. Most of the carers (85%) were aged 65 years or older, most were Australian born (74%) and English was the main language spoken at home (94%). Eighty-two percent of the carers were married, and for 57%, secondary schooling was the highest level of education achieved. In addition, 75% of the carers noted that they suffered from various health problems, with arthritis (26%), high blood pressure (25%) and impaired mobility (21%) being cited as the most common health problems for this group of carers.

Of the care recipients, 60% were male and 40% were female. Almost all of the care recipients lived with the carer (95%) and most were the spouse (68%) or child (22%) of the carer. In addition, 63% of the older carers spent more than 15 hours caring each day, 57% had been caring for the dependent person between 1 and 10 years, and 18% had been caring for the dependent person between 10 and 20 years.

Each respondent was asked to indicate the main illness or disability of the care recipient. These were categorised into seven types and are displayed in Table 1, along with the frequencies of each category. Within the Physical Disability category, Parkinson's Disease, Multiple Sclerosis and Rheumatoid Arthritis were most commonly cited. The most commonly cited Mental Illness was Schizophrenia. The sampling procedure makes it difficult to describe the non-respondent group of carers as their identity was not known. Hence no comparisons between respondent and non-respondent groups of carers can be described.

Table 1: Main illness or disability of care recipient

Illness/Disability	Frequency	Percentage
Alzheimer's/Dementia	20	25%
Physical Disability	17	21%
Mental Illness	12	15%
Stroke or Heart Disease	11	14%
Intellectual Disability	8	10%
Visual Impairment	6	7%
Frail Aged	6	7%
Total	80	99%

Note: One carer failed to identify the illness/disability of the care recipient

Physical and Mental Health

The SF-12 was used to calculate the overall Physical Component Summary (PCS) score and the overall Mental Component Summary (MCS) score, with the items weighted using US general population weights, and standardised to a mean of 50 and a standard deviation of 10 (Ware, Kosinski & Keller 1998). Australian weights for the SF-12 are not currently available, but previous research has found that US weightings are not significantly different from the scores obtained with the SF-36 using Australian weights (Baum et al. 2000). Similar to the research of Baum et.al. a cut-off score of 50 or below was used to indicate low physical health where a physical condition may be expected. A cut-off score of 42 or below was used to indicate low mental health, where symptoms of depression may be found. As a result of missing data, a total of 78 older carer surveys were available for the physical and mental health status analysis.

For this group of older carers aged 60 years or more, a mean PCS score of 39.55 (SD = 11.52) was obtained, with a range of 17.05 to 61.27. For MCS the mean was 45.08 (SD = 10.64), with scores ranging from 8.54 to 62.03. The mean PCS and MCS scores of the older carers in the present study were compared with two other Australian sample groups. Australian SF-12 norm data is not currently available, as such SF-36 Australian population norms for participants similar in age were used (ABS 1997), as well as mean scores obtained by similarly aged non-carer participants in the Barwon and Otways Region Health and Community Participation (HCP) study (Savage, Bailey, O'Connell & Austin 2002). Tables 2 and 3 display a comparison of the mean scores obtained by the three groups. To enable valid comparisons, the scores are presented for ages 65 – 74 years (Table 2) and for ages 75+ years (Table 3). The mean PCS score did not vary greatly across the three groups in either the 65 – 74 or 75+ years age groups. T-tests conducted between the older carer group and the HCP study were not significant. Of concern however, are the mean MCS scores. In both age groups the older carers obtained notably lower MCS scores, and the scores were close to the low mental health cut-off score of 42. T-tests revealed significant differences between the mean scores of the older carers group and the HCP study for both age groupings ($t = 4.944$ $df = 197$ $p = 0.00$ for the 65 – 74 years group and $t = 2.227$ $df = 134$ $p = 0.03$ for the 75+ years group). In addition, when compared with the Australian norm data, the older carers MCS

score for ages 65 – 74 years is in the lowest 25% of the population (Australian norm data MCS = 45.50 at the 25th percentile). For the 75 and over age group the older carers MCS score is slightly above the 25th percentile, but below the 50th percentile score of 52.8.

Table 2: Comparison of SF-12 mean physical and mental health scores for older carers, Australian norm data and HCP study aged 65 – 74 years

	Older Carers (N = 27)		HCP Study (N = 172)		Australian Population Norms (N = 1658)	
	Mean	SD	Mean	SD	Mean	SD
Physical Health	43.58	9.54	43.25	11.32	42.8	Not listed
Mental Health	45.10	9.49	53.74	8.26	51.3	Not listed

Table 3: Comparison of SF-12 mean physical and mental health scores for older carers, Australian norm data and HCP study aged 75+ years

	Older Carers (N = 33)		HCP Study (N = 103)		Australian Population Norms (N = 878)	
	Mean	SD	Mean	SD	Mean	SD
Physical Health	35.23	11.71	36.90	10.67	38.5	Not listed
Mental Health	46.31	9.82	50.82	10.21	51.8	Not listed

The number of older carers above and below the physical and mental health cut-off scores is displayed in Table 4. For this group of older carers, 73% fell below the physical health cut-off score of 50, indicating that most of the older carers may suffer from a physical health condition. This result is consistent with the question in the demographics section that asked the carers to note their health related problems, with 75% indicating a health problem of sorts. Nearly one third of the older carers (31%) obtained a mental health score below the cut-off of 42, indicating that symptoms of depression could be expected among this group (Baum et.al. 2000).

Table 4: Number of older carers above and below the SF-12 physical and mental health cut-off scores (N = 78)

	Number below cut-off	Number above cut-off
Physical health (cut-off = 50)	57 (73%)	21 (27%)
Mental health (cut-off = 42)	24 (31%)	54 (69%)

Participation in Social and/or Health-type Activities

Almost half of this group of older carers (48%) indicated that they regularly participate in social and/or health-type activities, mostly on a weekly basis. Table 5 displays the various types of activities that the older carers participate in, whilst reasons for non-participation are shown in Table 6. Walking and having coffee or meals with friends were the most frequently cited social and/or health-type activities for this group of older carers. Not being able to leave the care recipient alone was a commonly cited reason for non-participation.

Table 5: Social and/or health-type activities that older carers regularly participate in

Type of Activity	Number of Carers	Percentage
Walking	33	41%
Coffee/meals with friends	25	31%
Volunteer work	15	19%
Playing bowls	9	11%
Going to movies	9	11%
Going to concerts	8	10%
Playing tennis	7	9%
Swimming	7	9%
Playing cards/bingo	5	6%
Hobby groups	4	5%
Taichi/yoga	3	4%
Going to gym	1	1%

Note: Does not equate to 100% as carers selected more than one activity

Table 6: Older carers reasons for non-participation in social and/or health-type activities

Non-participation reason	Number of carers	Percentage
Unable to leave care recipient on their own	26	32%
Unable to take care recipient along	21	26%
Too tired or lack energy	21	26%
Do not have any spare time	15	19%
Suffer from poor health/physical disability	12	15%
The activities are too long	5	6%
The activities are too expensive	4	5%

Note: Does not equate to 100% as carers selected more than one reason

Most of the older carers surveyed (70%) indicated that they used some type of services and/or support on a weekly or fortnightly basis to assist them with their caring role. The range of services and/or types of support used is displayed in Table 7. Home help and respite were the most commonly cited services and/or types of support used.

Table 7: Services and/or types of support used by older carer to assist in the caring role

Type of service and/or support	Number of carers	Percentage
Home help	43	53%
Respite	41	51%
Half price taxi fares	39	48%
Carers support group	16	20%
Support services provided by case management organisations (e.g. Karingal/Pathways)	13	16%
Case worker	12	15%
District nursing services	9	11%
Meals on wheels	9	11%
Accommodation services	2	3%

Note: Does not equate to 100% as carers selected more than one service/type of support

Approximately half of the carers (47%) who regularly used these services and/or types of support had found out about them from their doctor or local hospital. This group of older carers were also asked to indicate their beliefs about why some carers may not use services and/or support to assist them with their caring role. The reasons given for not using services and/or support are displayed in Table 8.

Table 8: Older carers beliefs about why some carers do not use services and/or support to assist in the caring role

Reason for not using services and/or support	Number of carers	Percentage
Believe they can cope on their own	42	52%
Do not know what services/support is available	36	44%
Care recipient will not accept use of services/support	30	37%
Think others need services/support more than they do	24	30%
Too embarrassed to ask for help	16	20%
Services are too expensive	12	15%

Note: Does not equate to 100% as carers selected more than one reason

Forty-three percent of this group of older carers indicated that they would like more emotional support in their caring role. The older carers received emotional support from friends (67%), children (63%) and other family members (40%), while 24% indicated that a carers support group might provide more emotional support.

Discussion

The results of the first stage of this project highlighted that 73% of the respondent carers' physical health scores fell below the cut off score of 50 and that 31% were below the mental health cut off point, indicating compromised physical and mental health. They also indicated that older carers' mean mental health scores were significantly lower than a similar aged non-carer group. These findings are not surprising given that most of the carers in this study were over 65 years and reported having a health care problem. Additionally, the low mental health scores reported by approximately one-third of the group are consistent with the literature (Browning & Schwirian, 1994) and are consistent with carers' requests for further emotional support. It is interesting that although the majority of carers stated that the reasons for not using support services was that they believed they could cope without support, 43% stated a need for emotional support, thus identifying their mental fragility.

Thirty-two percent of carers stated that they did not participate in social and health type activities as they were unable to leave the care recipient on their own. This unrelenting burden of care and social isolation coupled with mental fragility has the potential to lead to both the carer and the care recipient being compromised. Potentially, it can also lead to some form of physical or emotional abuse between these groups. Additionally, if this carer group continue to remain isolated their compromised well-being is likely to go undetected by health care professionals. The request for emotional support by carers should not be ignored by health care policy makers as some expenditure on services that provide continuing emotional support to carers, before their health is compromised, is likely to prevent deteriorating carer health and prevent greater consumption of health care services or hospitalisation.

The findings that approximately one-third of the respondent carers did not participate in social and health related activities as they were unable to leave the care recipient on their own and that only fifty percent of carers used respite facilities requires attention. The reasons for this may include lack of trust in respite services to deliver appropriate care or a lack of realisation of the on-going burden of the carer role until entrenched behaviours, expectations and care recipient dependency have developed. It is important therefore to highlight this dependency issue to carers and provide information on the potentially negative effects this could have on them and the care recipient. The sometimes twenty-four hour nature of the caring role multiplied across days and years cannot be under estimated in terms of the potentially negative effects on carers' health. Clearly, the level of dependency of care recipients reported in this study (where some carers provided more than fifteen hours of care a day) indicates the unrelenting pressure experienced by this group.

This study provided base-line data of a sample of older carers' physical and mental status and their engagement in social and health related activities. The findings suggest a need for further attention to be given to this group. It also highlighted a need for a proactive approach to this issue so that carers' needs are addressed at the commencement of their carer role. There may be a need for a resource that addresses some of these concerns and bridges the gap in knowledge, skills and access to relevant information and services for older carers. A useful strategy to consider is the use of a carer wellness guide (Neuhauser et al., 1998). Disseminated from a number of health care and government agencies, a wellness guide could provide carers with information and contact telephone numbers for social support and available services before they reach crisis point. It should also reinforce to the carers the importance of attending to their own health and well-being requirements from the onset of their carer roles. Clearly, the value of carers' work to the community and the health care system should be recognised and further programs that provide carers with support in this demanding role should be given some priority.

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