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Change in carers' activities after the death of their partners

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Abstract

Purpose When a person is dying, and during bereavement, family members often put their lives on hold to provide full-time care. Meaningful activities may be curtailed or forgotten. This study described the activities that changed between pre- and post-caring, and what factors assisted carers to re-engage in activities two years following the death of their partners.

Methods A mixed methods design included a cross-sectional survey and face-to-face interviews. The study occurred in 2009 with 40 females that cared for a partner who had subsequently died of cancer two years previously. Engagement in community and other activities was determined through use of the Activity Card Sort –Australia and semi-structured interviews. The SF-36v2 measured physical and mental health status and perceived social support was measured with the Multi-dimensional Scale of Perceived Social Support.

Results Most carers in our study were more engaged in household activities post-caring compared to their pre-caring activities, but had decreased social and leisure activities. Living as a single person meant they had taken on new roles and responsibilities. Leisure and social activities previously associated with subjective well-being and health were reduced or lost. Greater social support, a higher mental health status and being in receipt of counselling services contributed to a higher retention of activities post-caring.

Conclusions Retention of activities could be facilitated by participation in community services, bereavement counselling, recreational groups and other support and interest groups, both during and after caring.

Keywords Community activity, Participation, Family carers, Bereavement, Social activity, Leisure activity

Introduction

Taking on the informal care of a terminally ill family member can be life-changing, with many carers reporting they are 'different people' post-caring [1]. Understanding the challenges of caring, and supporting informal carers throughout the process of care, is imperative given this group are now considered the frontline of primary care. As an informal primary carer, a family member is primarily responsible for the needs of a person who is ill or who has a disability [2]. In 2010, primary carers provided 54 per cent of all needed care in Australia saving the government over 40 billion dollars [3]. The majority of these carers were women, aged between 42 and 70 years living in the same house as the person needing care [3].

When caring for a terminally ill partner, a carer is often required to quickly master new tasks including the physical and psychological care of the ill person, the administration of medication and the coordination of health service support [4] along with the provision of advocacy and anticipatory care. In addition carers have their own grief, loneliness and exhaustion to manage along with the possible financial consequences of taking on the unpaid caring role. The experience of caring can be particularly stressful and the physical health and emotional well-being of the carer may be compromised [5, 6]. One study of 61,383 carers in the USA found that carers were much more likely than non-carers to have symptoms of depression and anxiety [7]. Furthermore, undertaking physically demanding care tasks for the terminally ill person, such as bathing, toileting, dressing and assisting with mobility, often results in poorer physical health in carers [8].

The majority of informal carers experience major disruption to their usual daily activities when taking on the primary caring role as they have less time and energy to engage in a range of personally necessary and valued activities both at home and in the community [4, 9, 10]. With the majority of their time given to caring for the ill person the opportunities for participation in meaningful activities associated with personally valued life roles are limited [11]. Meaningful activity is therapeutically beneficial as it has an organising effect on behaviour, allows a sense of individual choice and control and contributes to an

individual's sense of purpose [12]. Engagement in meaningful activities is associated with subjective well-being and better physical and mental health status in several adult populations [13, 14].

Meaningful activity, beyond the caring role, both during and after the death of a family member may promote carer health by providing a sense of purpose, self-fulfilment and by giving the carer a chance for respite from the caring role. However, little is known about the types of self-care, household and community activities carers engage in, particularly before and after caring for a terminally ill family member. It is difficult to determine whether interventions aimed at supporting meaningful activity are warranted, and if so, how these might be structured. Of particular concern is how interventions may assist carers to re-engage in a range of these activities during bereavement. This study aimed to (i) determine if the level of engagement in activities among informal carers changes following the death of their terminally ill partners, (ii) determine what types of activities change post-caring compared to pre-caring, and (iii) what factors impact on re-engagement with activities post-caring.

Methods

Design

This study used a mixed methods design consisting of a cross-sectional design for the quantitative component of the study, and a semi-structured interview for the qualitative component of the study.

Participants

In 2009, 133 female informal primary carers who cared for a spouse or partner who had died of cancer two years previously were purposively selected from the database of a prior study of 1,071 primary carers of people who had died of terminal illness in Western Australia between 1 January 2005 and 31 December 2005 [15]. In that prior study, McNamara and Rosenwax accessed the carers via death registrations available from the Registrar of Death, Births and Marriages, Western Australia. The carers had provided care in the family home as none of the people who had died had been admitted to a residential aged care facility, such as a nursing home, prior to their death. Additionally, the bereaved carers had to be residing in Western Australia and contactable by telephone. The carers were surveyed on

a range of perceived issues of concern to both the deceased family member and the carer [15].

Participants for our study were selected purposively from this original sample of 1,071 based on carer's gender (female), perceived severity of the decedents' physical symptoms, and the decedent and carer being aged 70 years or younger at the time of the McNamara & Rosenwax study [15].

Eighty of the 133 eligible carers for our study were randomly selected and contacted via an initial telephone call and invited to participate by the first author, who was a senior researcher in the prior study by McNamara and Rosenwax [15]. Forty of the 45 carers that could be contacted agreed to be in our study (response rate of 89%). There was no difference in the characteristics of these 40 participants and the remaining 93 eligible participants.

Instruments

Instruments for the quantitative data collection included the Activity Card Sort – Australia (ACS-Australia) [16, 17], and the SF-36 version 2 (SF-36v2) [18, 19]. Information on participation in, and retention of, activities pre and post caring was gathered using the ACS-Australia and semi-structured interview questions. The ACS - Australia consists of 82 'cards' displaying photographs of activities (e.g. driving a car, shopping, playing cards, going to the library, paying bills) in three domains (household (12 items), leisure (24 items), social/educational (46 items)). It was used to measure each carer's perception of their level of engagement in activities at two different periods, pre- and post-caring. Each carer sorted the cards into one of six piles; 'Never done as an adult', 'Done as an adult but given up prior to caring', 'Given up due to caring', 'Beginning to do again', 'Continuing to do/never gave up' and 'New activity'. Scoring of the ACS provided a percent of retained activity level. The ACS-Australia was found to have moderate concurrent validity ($r = 0.43$), moderate convergent construct validity ($r = 0.35$), and strong discriminative construct validity between adults aged 60-75 years and 75-95 years ($p < 0.001$) among older adults aged 60-95 years [16]. Reliability of the ACS-Australia has not yet been determined; however, test-retest reliability of the original American version is 0.89 [20], and $r=0.98$ in the ACS-Hong Kong version [21].

Caring for a terminally ill person has been found to negatively impact on the physical health [22] and mental health [7] status of carers. To determine the health status of the carers in this study compared to the general Australian female population, the SF-36v2 was used to provide data on eight health domains, Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional and Mental Health and composite scores from Physical Health and Mental Health.

Carers were asked if they received any informal, unpaid assistance from family members or friends while caring. The perceived social support received by the carer at the time of this study was evaluated using the Multi-dimensional Scale of Perceived Social Support (MSPSS) [23]. The MSPSS is a 12-item measure that requires respondents to rate how they feel about statements pertaining to the perceived availability and access to social support from friends, family and significant others, using a seven-point scale where 1=Very Strongly Disagree and 7= Very Strongly Agree. The MSPSS has demonstrated strong internal consistency for sub-scale and total scores ($\alpha = 0.87-0.94$) and adequate to strong test-retest reliability ($r=0.73$) among older adults aged 55-82 years [24].

Carers were asked semi-structured interview questions to obtain their perception of how their daily activities had changed post caring compared to pre-caring, what had influenced the change(s) and what factor(s) assisted them to re-engage in activities. A sample of the guiding questions for the interviews is presented in Figure 1. Interviews were audio recorded and transcribed verbatim for later analysis. This data was used to support and help explain the quantitative findings.

1. For how long did caring for your partner take up most of your day?
2. Are there any activities that you did before your husband died, but are not included in the Activity Card Sort? If so, what are they?
3. Have you started any new activities that are not included in the Activity Card Sort? If so, what are they?
4. Compared to your daily routine before your husband became ill, has the way you spend your time during the day changed since your husband passed away? If so, can you describe how?
5. You've spoken of a change in some of your usual activities from before your husband became ill and after he died. Can you think of any one thing, or things, that have most influenced that change in your activities?
6. What has been most influential in helping you re-engage in activities after your husband passed away?

Figure 1. Guiding questions used in the semi-structured interviews

Information pertaining to decedent characteristics, carer access to specialist palliative care services and support services were obtained from the database developed by McNamara and Rosenwax in their prior study [15], and confirmed by participants in our study during the semi-structured interviews.

Analysis

Descriptive statistics were used to describe carer demographics. To determine how common it was for carers to give up and/or take on new activities for each of the ACS activity domains post caring, the proportion of retained activity level was calculated by dividing the current activity level by the previous activity level x 100 as recommended by the authors of the original American version of the Activity Card Sort [20]. The overall per cent of retained activity level for each of the six categories was also calculated.

The SF-36v2 normed t scores were computed for the eight domains and two composite scores following the standard SF-36v2 analysis procedure. It is recommend that the SF-36v2 scores be presented as norm-based t-scores to enable easier and more accurate statistical comparisons between different samples and versions of the SF36 [18]. The health status of the 40 carers was compared to the Australian norms for females [25] using a one-sample t-test with a 95% confidence interval. Australian norms for the SF-36v2 were developed using a sample of 3,015 (females, n=1537) with a mean (SD) age 45.29 (18.87) years who were participants in the 2004 South Australian Health Omnibus Survey [27].

Quantitative data was analysed using the Statistical Package for the Social Sciences (SPSS v.16.0). Data related to each of the semi-structured interview questions was thematically analysed by the second author using constant comparison within and between interview transcripts. Interview data was also used to explain participants' responses to the ACS-Australia.

Ethics approval for this study was provided by the Human Research Ethics Committee at Curtin University.

Results

Characteristics of carers and decedents

At the time of death of their partners, the carers were aged between 45 to 75 years, with a mean (SD) of 59.5 (7.2) years. Except for one carer in a de facto relationship, all carers were married at the time of death of their partners. The age at death of the decedents ranged from 49 to 70 years, with a mean (SD) of 62.7 (6.0) years. All decedents had cancer listed on their death certificate as either a cause of death, antecedent to their death or a contributing factor to their death. Co-morbid conditions were present on the death certificate of 30 per cent of the decedents ($n = 12$).

Carers were asked, 'For how long did caring for your partner take up most of your day?' The number of months of caring ranged between one and 132 months with a mean (SD) of 16.0 (29.3) months and a median of six months. Twenty three carers spent six or less months caring full-time, while four carers spent 35 or more months caring full-time. In general, carers who cared full-time for more than two years did so because their husbands had other health conditions before developing advanced cancer. Carers' employment status before caring was casual (24%), part time (33%) and full-time (43%). At the time of the study, being two years after the death of their partner, carers were employed casually (28%), part time (44%) and full-time (28%).

Carers' health status

When comparing the health status of carers in this study with Australian females overall as assessed by the SF-36v2, there were no significant differences in the mean (SD) normed t-scores on the Physical Health Composite Score (50.1 (7.8) versus 49.0 (10.9); $t_{(39)} = 0.946$; $p = .350$); and on the General Health Score (51.8 (8.1) versus 49.6 (10.5); $t_{(39)} = 1.739$; $p = .090$). Likewise, there was no difference between carers in this study and Australian females with regard to mean (SD) normed t-scores on the Mental

Health Composite Score (47.1 (9.8) vs. 48.9 (10.8); $t_{(39)} = -1.164$; $p=.252$). At the time of the study, 27.5% of carers reported health problems that limited their daily activities. After the caring role ceased, 18% of carers reported that they developed a chronic health condition.

Carers' post-caring activity levels

Carers demonstrated a mean (SD) overall per cent retained activity level of 92.3 (12.1) at data collection (see Table 1). That is, on average, carers gave up eight per cent of their activities post-caring when compared to pre-caring. Differences were noted between the levels of engagement in activities, reflected as per cent retained activity level, between the three activity domains. It was most common for carers to give up community activities (e.g. social, educational, leisure) such as “Going out for a meal or drinks” and “Talking with friends and neighbours”. It was most common for carers to engage in more household activities post-caring than pre-caring.

Table 1. Proportion of activities retained by carers from pre- to post caring

	Retained activities			
	Overall (%)	Household (%)	Social (%)	Leisure (%)
Range				
Minimum	57.2	86.4	27.5	56.6
Maximum	117.4	166.7	125.0	119.6
Median	92.3	100.0	88.8	91.7
Mean (SD)	92.2 (12.1)	111.6 (20.8)	83.9 (19.0)	90.8 (13.0)

The majority of carers ($n = 35$) received informal assistance from children/children-in-law (62.5%) and friends (70%) during the caring period. Most commonly it was emotional support (55%), respite (47%) and domestic assistance (25%). Specialist palliative care services were received by 65% of carers/decedents. Carers in this study reported a high level of perceived social support, with nearly all mean subscale scores on the MSPSS ranging between 6.0 and 6.4 (i.e. Strongly agree). The one exception was to the statement “My family is willing to help me make decisions”, to which the mean score was 5.7 (i.e. between Mildly agree to Strongly agree).

There were changes to household activities pre- and post-caring, with the mean number of new household activities taken on by carers being 1.3 activities (see Table 2). Most carers stated that the reason for taking on more household activities post-caring was due to circumstance as opposed to choice; carers shared household and domestic chores with their partner pre-caring, and became solely responsible for these chores post-caring.

Table 2. Proportion of household activities either ‘Given up due to caring’, ‘New activity’ or ‘Beginning to do again’ by carers two years after death of partner

Activities	Number (%) of carers changing their activity levels (n=40)
Given up due to caring	
None	0 (0.0)
New activity	
Home maintenance	11 (27.5)
Yard maintenance	10 (25.0)
Taking out the rubbish	10 (25.0)
Money management	9 (22.5)
Paying bills	9 (22.5)
Beginning to do again	
Yard maintenance	7 (17.5)

Only activities with a change > 10 per cent of carers are listed

Carers were most likely to give up community activities (social, educational, leisure) post-caring, as reflected by this domain having the lowest per cent retained activity level. The mean number of community activities given up was 1.6 activities with nearly 60 per cent of carers (n = 23) giving up these activities ‘Due to caring’. Thirty carers placed cards in the ‘Beginning to do again’ category, indicating that while it was common for carers to give up social and educational activities while in the carer role, many carers re-engaged in these activities post-caring (see Table 3).

Table 3. Proportion of community activities either ‘Given up due to caring’, ‘New activity’ or ‘Beginning to do again’ by carers two years after death of partner

Social and educational activities	Number (%) of carers changing their activity levels (n = 40)
Given up due to caring	
Entertaining at home or club	10 (25.0)
Care-giving	7 (17.5)
Volunteering	5 (12.5)
Going to a place of worship	4 (10.0)
Going out for a meal or drinks	4 (10.0)
Going to the theatre	4 (10.0)
New activity	
Using public transport	7 (17.5)
Participating in interest group/club	5 (12.5)
Beginning to do again	
Going out for a meal or drinks	14 (35.0)
Entertaining at home or club	14 (35.0)
Going to the theatre	14 (35.0)
Visiting with friends	13 (32.5)
Parties/picnics/barbeques	12 (30.0)
Attending concerts	12 (30.0)
Doing favours and helping out	11 (27.5)
Visiting friends who are ill	9 (22.5)
Family gathering	7 (17.5)
Gardening/growing flowers	7 (17.5)
Community/civic activities	7 (17.5)
Going to art/craft classes/groups	7 (17.5)
Interest group/club	6 (15.0)
Going to grand/children’s activities	5 (12.5)
Spectator sports	5 (12.5)
Playing cards	5 (12.5)
Using public transport	4 (10.0)
Table games	4 (10.0)
Going to a place of worship	4 (10.0)

Only activities with a change > 10 per cent of carers are listed

Nearly two-thirds of carers (n = 26) gave up leisure activities due to caring. The leisure activities engaged in by carers were found to be varied; 32 of the 46 activities in the leisure domain had been given up by at least one carer in this study ‘Due to caring’. Additionally, 83 per cent of carers (n = 33) had given up activities while they were caring but were “Beginning to do again”. Over one-half of carers (n = 24) listed new leisure activities they had commenced post-caring (see Table 4).

Table 4. Proportion of leisure activities either ‘Given up due to caring’, ‘New activity’ or ‘Beginning to do again’ by carers two years after death of partner

Leisure activities	Number (%) of carers changing their activity levels (n = 40)
Given up due to caring	
Preparing for an outing/trip	9 (22.5)
Taking a day trip	6 (15.0)
Going to the library	4 (10.0)
Going to the beach	4 (10.0)
Fishing	4 (10.0)
Cooking as a hobby	4 (10.0)
New activity	
Gardening/growing flowers	5 (12.5)
Sitting and thinking/reminiscing	4 (10.0)
Travelling	4 (10.0)
Beginning to do again	
Travelling	17 (42.5)
Walking	14 (35.0)
Recreational shopping	14 (35.0)
Taking a day trip	12 (30.0)
Exercising	12 (30.0)
Watching movies (home and theatre)	9 (22.5)
Hand crafts	9 (22.5)
Preparing for an outing/trip	9 (22.5)
Health-related activities	8 (20.0)
Reading magazines and books	8 (20.0)
Resting	7 (17.5)
Gardening/growing flowers	7 (17.5)
Swimming	7 (17.5)
Watching television	6 (15.0)
Crosswords and word games	6 (15.0)
Going to the library	6 (15.0)
Sitting and thinking/reminiscing	6 (15.0)
Looking at coloured slides or photos	6 (15.0)
Reading the newspaper	5 (12.5)
Going to the beach	5 (12.5)
Listening to the radio	5 (12.5)
Listening to music	5 (12.5)
Sewing	5 (12.5)
Puzzles	5 (12.5)
Photography	5 (12.5)
Internet (locating information, browsing)	5 (12.5)
Storytelling with children	4 (10.0)

Factors impacting on retained activity levels

A number of factors were investigated to determine their impact on the carers' overall per cent of retained activity level (measured by the ACS-Australia). The factors included carer age group, level of perceived social support (MSPSS), carer mental health and physical health (SF-36v2), and receipt of specialist palliative care services and receipt of helping services (e.g. counselling).

Age group: carers aged 60-69 years had the lowest mean (SD) overall per cent retained activity level (89.7 (12.4)); while those aged 50-59 years and 70-79 years had the highest; 95.3(11.3) and 95.3 (12.7), respectively. The differences between groups were not significantly different.

Perceived social support: carers with an overall level of perceived support one standard deviation below the mean (SD) score of 6.1 (0.71) on the MSPSS had the lowest mean (SD) overall per cent retained activity level of 86.9 (6.4) per cent. Interestingly, those carers with a mean overall level of perceived support one standard deviation above the mean (i.e. with the highest level of perceived social support) did not have the highest overall per cent retained activity levels.

Mental health status: carers' mean overall per cent retained activity levels rose with mental health status. Carers with a mental health composite score on the SF-36v2 of at least one standard deviation below the sample mean had a mean (SD) of 84.3 (16.0) overall per cent retained activity level. By contrast, carers with a mean mental health composite score of at least one standard above the sample mean had a retained activity level of 100.7 (10.2) per cent.

Physical health status: In contrast to the impact of mental health status on activity level, carers with the highest physical health status (at least one SD above the sample mean) demonstrated the lowest mean (SD) overall per cent retained activity level (87.8 (20.4)). Those with the lowest physical health status had a higher mean (SD) of 92.6 (16.4) per cent retained activity level.

Receipt of specialist palliative care services: those carers who received specialist palliative care services had a mean (SD) overall per cent retained activity level of 93.8 (10.1), compared to those who did not receive these services (89.3 (15.1) per cent); however these differences were not statistically significant ($\chi^2=0.040$; $p=.842$).

Receipt of helping services: Those who received helping services such as counselling post-caring had a higher mean (SD) level of 95.5 (11.0) per cent retained activity, compared to those who did not receive a helping services (90.8 (12.4)).

During the semi-structured interviews carers were asked “What has been most influential in helping you to re-engage in activities after your husband passed away?” Several themes emerged; the most influential being social factors that were identified by 32 of the 40 carers. Carers varied in terms of what types of social support they reported were most helpful in helping them re-engage in activities. Some carers reported that simple telephone calls from family and friends asking how they were doing were helpful, while others mentioned that having friends who were more directive or forceful were most helpful in assisting their re-engagement with activities.

About one third ($n=13$) reported that their inner motivation, strength, or knowing what type of person they did not want to become were important in assisting them to re-engage in activities. The desire to ‘keep occupied and engaged in enjoyable activities’ to prevent boredom, loneliness and keeping mentally alert was one theme reported by a majority of carers ($n=17$), as influencing their re-engagement in activities post-caring.

“If I didn’t do embroidery I would be at home a lot more. It would be 100 times worse than it is, if I was just sitting at home; especially because I have no family. The days are very long on your own.”(ID 21)

Six carers identified that a change in their post-caring activities was because they had ‘more freedom now’. The flexibility they now experienced related to being able to complete household activities when they wanted to, rather than to a set schedule. In addition, two of these carers were recently retired from work and one carer had learned to drive after the death of her partner.

“It doesn’t matter so much. It’s only me I’m pleasing. There is less pressure to be organised and clean. I’m not as worried about routine and organisation as I was before. I am more spontaneous now, because I can be.”(ID 19)

Conversely four carers reported their routines had changed out of necessity and no choice. Household activities that they now had sole responsibility of included home maintenance and managing the household finances and accounts. A change in their financial circumstance was also reported as an influencing factor by six carers. Half of them reported an increase in their disposable income, while the remainder had less disposable income now compared to pre-caring.

“My financial situation [has influenced a change in activities]. [Husband] didn’t have a life policy. Two-thirds of my income is now gone.” (ID 26)

A change in priorities after the death of their partner was identified among the responses of three carers. They reported taking more ‘me time’ and working less in order to have more time for leisure.

“I go play golf on a Friday now. I never used to do that. I’ve realised you can always make time to do things. The fact is you’ve got to live life. If you are able to go, then go.” (ID 15)

Having a partner with whom they could do activities was seen as an influencing factor by eight carers. New relationships after their partner’s death were seen as influential in re-engaging in activities. Those who had no partner (n=5) were either too nervous to go out socially on their own, or had not replaced activities that were jointly performed with their husbands.

“Sometimes I am nervous to go places on my own, even when I’m with family. Everyone is in couples – it hits you [that your partner is gone].” (ID 20)

Discussion

The primary objective of this study was to determine if carers' level of engagement in activities changed post-caring compared to pre-caring. The main measurement tool used to answer this question was the Activity Card Sort – Australia. At approximately two years post-caring, carers in this study gave up an average of eight per cent of the activities they had engaged in pre-caring; at face value this is not a high proportion of activities. The average per cent retained activity level of carers in this study was higher than expected because it has been established that many carers cease meaningful activities and experience significant disruption to daily routines [1, 28].

The range of overall per cent retained activity levels in this study was wide, with carer's activity levels ranging from 57.2 per cent to 117.4 per cent. Although most carers in this study only lost a small proportion of their activities post-caring; one quarter of carers experienced a drastic increase in the amount of activities they engaged in post caring. The ACS – Australia findings were supported by semi-structured interview findings in which 90 per cent of carers stated they had experienced some change in daily activities and routines post-caring. The semi-structured interview provided explanations to the ACS – Australia findings. While the ACS – Australia indicated that carers were tending to do fewer activities post-caring, the interviews indicate that carers perceived they were busier with activities – in particular home and domestic tasks. Carers were most likely to take on and retain activities in the household domain, while giving up community activities; particularly social and leisure activities.

Although carers in the current study demonstrated a relatively high proportion of retained activity level, which would generally be considered to be indicative of better health status [11], this high proportion of retained activity level was primarily due to the retention of activities in the household domain. Many carers in this study said they resented the household activities post-caring, having taken on many of the household tasks previously done by their partner. One qualitative study investigating differences in perceptions of which activities were considered 'work' and which were considered 'leisure' by older adults found that household activities were almost unanimously considered 'work' by participants [29].

There is the possibility that carers experience substantial work/life imbalance due to having more 'work', or obligatory household activities to complete post-caring, which could have potentially negative implications for carer's health status [30].

The finding that carers were not engaging in leisure and social activities to their pre-caring level is troubling, as both social and high-demand leisure activities have been associated with better physical health status in older adults [13]. Previous studies have found that carers commonly give up leisure activities while caring [31, 32], with one study reporting that 60 per cent of carers either ceased or had reduced time spent on one of more activities they personally considered as leisure while a carer [31]. The current study findings suggest that carers may struggle to re-incorporate leisure activities into their daily routine post-caring.

It is important for health professionals to be aware of the changes in carer level of engagement in activities and changes in types of activities carers' may experience post-caring. Health professionals can assist carers to achieve work/life balance by enabling engagement in meaningful activities and educating carers on the importance of making time for their own interests. Aoun [1] outlined the social and physical effects of caring on carers' health, including carers' not having the money or energy to make doctor's appointments while caring. Further research might investigate if carers re-commence visiting health professionals and other health-related activities post-caring.

Carers in our study displayed a relatively high level of perceived social support; receiving the most support from friends and family. The carers displayed a similar level of perceived social support to a non-married control group of American older adults (aged 55 to 82) who had the same mean level of overall perceived social support as carers in our study, and also received the most support from significant others [24]. Importantly, carers in our study who had a higher level of perceived social support tended to have a higher per cent of retained activity level than carers with a lower level of perceived social support. These results might indicate that carers with the lowest level of perceived social support could have more

trouble re-engaging in activities than carers with higher perceived social support; findings in line with a larger study of primary family carers which found that they were more prone to poor health if they perceived that health services did not provide them with enough support [5]. Theoretically, by improving carers' social networks and social integration into their communities, health professionals could assist carers to develop their social networks and engagement in social activities.

Limitations

Limitations of the study include a small sample size of only 40 carers; however, purposive sampling was used to ameliorate this effect. Regardless, inability to identify differences in retention of activity levels based on factors such as access to specialist palliative care services, and physical health status may be a result of insufficient statistical power. Additionally, only female carers were included in the study to try and achieve a homogenous sample to decrease the effect of confounding variables on the findings, especially when exploring factors that potentially assisted in carers re-engage with activities. Level of engagement in pre-caring activities was determined retrospectively; with the time between pre-fulltime caring duties to data collection being an average of around three years. Thus there is the potential for recall bias to impact the findings. While the study aimed to measure factors which impact on the level of engagement post-caring, factors such as socio-economic status, receipt of counselling and acceptance of the partner's death were not measured. Further research of this type might also consider the length of time caring as well as perceived severity of the partners' symptoms.

As Hudson et al. [33] suggested, researchers need appropriate instruments to explore the family caregiver experience. Our study took a novel approach by using the Activity Card Sort – Australia to understand the activity levels of female carers both pre- and post-caring for a terminally ill partner and their effect on engagement in community activities. Implications from this study include the need for health professionals to assist carers to retain an acceptable level of engagement in a range of activities during and after caring. Concurrently, carers could be assisted with mastering some of the 'household chores' previously undertaken by their male partners. The retention of activities and the mastery of new skills

could be facilitated by participation in community health services, bereavement counselling, recreational groups and other support and interest groups both during and post caring.

Conflict of interest

The authors declare they have no conflict of interest.

The authors have full control of all primary data.

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