

Social aspects of caregiving for people living with motor neurone disease: Their relationships to carer well-being

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ABSTRACT

Objective: To investigate social aspects of caregiving for people living with motor neurone disease (MND) and examine their relationships to carers' well-being.

Methods: A questionnaire was developed to assess carers' perceptions of their social support network (the Caregiver Network Scale, CNS), including measures of sociodemographic status and general well-being (GHQ-12), and mailed to carers of people living with MND.

Results: Seventy-five surveys were returned (response rate: 33%). In univariate analyses, relationships between well-being and carer age, time as caregiver, and four subscales of the CNS were found to be significant. However, multivariate analyses combining their effects revealed that stress on carer social networks was the best single contributor to predictions of carer well-being.

Significance of results: Results indicate that prolonged caring for others living with MND has substantial costs for the carer in terms of loss of social support, which affects carer well-being and impacts ultimately on those living with MND. The CNS offers promise as a measure for screening at-risk carers; those who are distressed become candidates for professional intervention to help them cope better. Further research, providing validation of the scale for this task, is recommended.

KEYWORDS: Social support, Caregiver well-being, Long-term caregiving, Motor neurone disease

INTRODUCTION

Caring for a person living with a progressive illness is acknowledged as both challenging and demanding (Levine, 2000; Sach & Associates, 2003; Aoun, 2004). Motor Neurone Disease (MND), also known as Amyotrophic Lateral Sclerosis (ALS), is a degenerative, progressive, neurological disease that affects over 350,000 of the world's population at any

one time. In Australia, on average one person dies from MND every day (Sach & Associates, 2003). There is considerable variability between patients with regard to early symptoms, rate and pattern of progression, and survival time (Small & Rhodes, 2000). However, as the condition progresses, symptoms invariably escalate and patients require increasingly complex care (Robinson & Hunter, 1998; Thomas, 2001). Australian figures indicate that 70% of people with MND are still living at home 4 weeks prior to their death (Sach & Associates, 2003). Professional care in the home can be provided by family physicians, community nurses, and palliative

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care services, but informal carers such as family members and friends provide most of the daily care (Australian Institute of Health and Welfare, 1999a).

There is little literature exploring the effects of caring on the carers of people living with MND (Goldstein et al., 2000) and even less that explores caregiver well-being (Young & McNicoll, 1998). As MND is usually diagnosed in mid-life, people living with MND are likely to be part of a potentially rich social network through their professional and community activities. However, many of their peers are also heavily committed and may not be available to provide supportive care or may only be able to perform this function in a limited capacity (Wilkinson & Bittman, 2001). Caring may be left largely to a family member who might also have other family and work responsibilities.

The demands of caring for a person living with MND can become a source of stress for informal carers and may impact on their social relationships (Richter, 2003). From the perspective of the stress-appraisal model (Monat & Lazarus, 1991), social support is an effective source of coping effectively with environmental demands and thus reducing perceived stress. Yet there is little known about the role of social networks in ameliorating sources of stress and their subsequent impact on the well-being of carers of people living with MND. Stress may accompany caring tasks such as administering medical procedures, organizing the household, managing finances, and maintaining household property (Levine, 2000). In addition, the caring role necessitates interaction with a wide variety of formal care and social service systems on another's behalf, which can also be stressful (Australian Bureau of Statistics, 1999; Levine, 2000). Carers can be reluctant to ask others for assistance and often weigh up the potential risks to their relationship with that person before involving another (d'Abbs, 1991; Stajduhar & Davies, 1998). These considerations may translate to a reluctance to use available help, possibly disrupting social relationships that would normally meet the social needs of carers of people living with MND (van Teijlingen et al., 2001).

The early literature on caregiving in aged and palliative care focused on the burdens of caregiving (Flicker, 1992; Waltrowicz et al., 1996; Kinsella et al., 1998). More recent research has shown that, despite the emotional toll of "always being on call" (Levine, 2000), many carers experience satisfaction in caregiving and find that coping positively with the tasks enhances their self-images (Nolan et al., 1995b; Nolan, 1996, 2001). Nonetheless, family caregivers have to take measures if they are to avoid succumbing to the burdens of caregiving. Informal

carers cope well if they receive support from other family members, neighbors, or friends (Waltrowicz et al., 1996). Social network members can provide interaction, emotional support, personal care, and occasional practical help, as distinct from becoming involved in direct care (Australian Institute of Health and Welfare, 1999b; Jarrett et al., 1999; McGarry & Arthur, 2001). Literature discussing volunteering and caregiving identifies the need for encouragement from others or more formal structures, such as community agencies, before people will become involved in practical help, emotional support, or personal care (Bittman & Thomson, 2000; Hoad, 2002). Thus both carers and their potential social support network can often encounter barriers to ensuring that informal caregivers' social needs are met. This is vital as there is a clear relationship between the perception of stress and the capacity of informal carers to access and maintain continuing, supportive social networks. Those carers with more supportive networks, it can be concluded, will be better able to engage in effective coping strategies and have their psychosocial needs met.

In this article, we report on the findings of the first part of a study designed to investigate the support networks of informal carers of people living with MND. Drawing from previously validated scales to measure caregiver burden and coping (Nolan et al., 1995a), general health, and social capital (Wellman & Hiscott, 1983) we developed a scale to examine the relationship between caregivers' social networks and the well-being of those caring for people living with MND. In this article, we report on the development of the scale and its use to test the hypothesis that perceived stress on social relationships contributes to carers' overall well-being.

METHOD

Participants

Participants in the main study were drawn from the population of people in the state of Victoria who are the current primary caregiver for someone who has been diagnosed as having Motor Neurone Disease. They comprised 75 individuals who were aged between 15 and 75, with 22 (29%) between the ages of 55 and 64. Twenty-three (30%) were males, 51 were (68%) females, and 1 did not specify gender. Only 7 (9%) had never been married, 2 (3%) were separated or divorced, and the rest were currently living with their partners. Over half (39, 52%) earned less than \$25,000 per year and 43 (57%) were either retired or had resigned from their employment to become carers. Most (84%) were living in the same house as the person being cared for and did not

have dependent children living at home (85%). Thirty-four (45%) had been carers for less than 2 years, 22 (29%) for between 2 and 5 years, and 19 (25%) for more than 5 years.

Ethical clearance to undertake the study was obtained from the MND Association of Victoria and the University Human Ethics Committee (HEC03/30). The study was funded by the Motor Neurone Disease Research Institute of Australia.

Measures

The survey covered three areas: general demographic data, the extent and function of the carer's social support network, and the carers' perception of their own general health. The first comprised questions pertaining to age, gender, relationship with the person, household income, employment status, living arrangements and distance from the person's home, number of dependent children, and length of time as a caregiver. Response options were categorical and participants indicated which category for each item best described them.

The second area of the questionnaire, concerning the carer's social support network, was created for this study. A search of relevant databases using appropriate key terms, such as social support, revealed a set of relevant measures. After scrutinizing them all, a shortlist of 12 published scales was examined in detail and possible items for inclusion were identified. Where necessary, new items were written addressing unique aspects of caregiving for persons living with MND and added to the pool. In some cases, the wording of a scale element was modified from the original in order to allow consistency throughout the questionnaire. Similarly, the method of response was made consistent throughout, as we adopted a 5-point response scale: *completely disagree*, *disagree*, *neither agree nor disagree*, *agree*, and *completely agree*. The initial pool of 61 items was submitted to six experts in the field of MND and caregiving, for careful scrutiny rating them for relevance, readability, and theoretical importance. Following feedback on each of the items, the pool was reduced to 50 items that fulfilled the criteria for inclusion. The 50 items comprised four categories, all scored in a positive direction, covering different aspects of caring:

1. *Receive support* (21 statements). These items assessed the extent to which carers feel that someone in their family or their community provides support when it is needed.
2. *Self-care* (7 statements). These statements refer to the caregivers looking after their own physical, mental, or emotional well-being.
3. *Caregiver satisfaction* (14 statements). This category includes items assessing carers' perceptions of caring as an activity that provides them with a sense of satisfaction.
4. *Stress on relationships* (8 statements). The last category identifies whether the carer feels that family relationships or community relationships are functioning well or are under strain as a result of caring.

The third aspect was addressed with the 12-item version General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). This is an "extensively researched and well validated instrument for the identification and measurement of psychological problems" (Campbell et al., 2003, p. 475). The GHQ-12 assesses respondents' perceptions of their own emotional health. They are asked to indicate whether they believe each of the statements, such as "Have you recently felt constantly under strain?" applies to them. After reverse coding of positively worded items, scores are totaled to create an overall index of general emotional well-being with high scores implying that respondents evaluated their own emotional well-being as poor.

Procedure

The survey was carried with the cooperation of the Motor Neurone Disease Association of Victoria (MND-DAV), which agreed to post the surveys to people living with MND with the instructions to pass the survey on to their primary carer, if agreeable and applicable. Of these, 75 were returned in the reply-paid envelopes provided, representing a response rate of 33%. Seven people contacted the researchers to indicate that they were newly diagnosed and did not need a carer as yet.

Once the surveys were collected, they were deidentified, issued a code number, and scored for entry into a computer spreadsheet. In obtaining scores for both the Caregiver Network Scale and the GHQ, occasional missing values were encountered. Most cases did not have missing values, and of those that did, most commonly only one value was missing. One case had three missing values. In all instances where missing values occurred, the case mean was substituted. Statistical analyses were all conducted using SPSS version 11.5.0 (SPSS Inc.).

RESULTS

Internal consistency of the four subscales of the Caregiver Network Scale was examined using Cronbach's alpha. Each of the subscales had an accept-

able degree of internal consistency, ranging from 0.77 for Caregiver satisfaction to 0.92 for Receive support.

Scores on the GHQ-12 ranged between 0 and 12, with a mean of 4.47 and a standard deviation of 3.3. Modal score was 0, and the distribution was skewed toward lower scores, indicating that, on the whole, the respondents reported generally good well-being levels. An exploratory analysis of the scale's structure, using Principal Components Analysis with varimax rotation, yielded three components accounting for 62% of the variance, which is consistent with a recent confirmatory analysis that also found a three-factor solution to the best fitting model for the GHQ-12 (Campbell et al., 2003).

Age-related differences in scores on the GHQ-12 were noted. Participants below the age of 64 ($N = 48$) had higher scores on average ($M = 5.04$) than those aged 65 or older ($N = 27$, $M = 3.46$). The difference was significant, $F(1,73) = 4.07$, $p = 0.047$. Thus older carers reported slightly, but significantly, better levels of general well-being. Female carers ($N = 51$) reported higher levels of distress, on average ($M = 4.92$), than did male carers ($N = 24$, $M = 3.50$), but this difference did not reach conventional levels of statistical significance, $F(1,73) = 3.05$, $p = 0.085$.

Scores on GHQ-12 were also related to time as a carer. Those participants who reported they had been caring for less than 2 years ($N = 34$) had lower scores on average ($M = 3.58$) than those who reported caring for 2 or more years ($N = 41$, $M = 5.21$). Thus the latter group, which had been caring for persons living with MND for 2 or more years, reported significantly greater levels of distress.

Other variables, including household income levels, employment status, relationship to and living arrangements with the person receiving care, dependent children living at home, and adult children living at home, were all nonsignificantly related to GHQ-12 scores.

Relationship between General Well-being and Caregiver Networks

The GHQ scale was regressed against all four CNS subscales combined using a multiple linear regression analysis. The four subscales accounted for 39% of the variance ($R = 0.62$, $F[4,70] = 11.17$, $p = 0.000$). It can be seen that by far the strongest and the sole significant contributor to predicting GHQ scores was the Stress on Relationships subscale (beta = -0.37 , $p = .013$). This suggests that the more people feel that their familial and social relationships are placed under stress as a result of caring for someone with MND, the lower they rate

their overall well-being. To examine the robustness of this proposition, a second multiple regression was carried out on the GHQ scale against all subscales as previously, but using the stepwise method of adding variables. Stress on relationships subscale entered at the first step and none of the other three subscales contributed significantly at the subsequent steps. Thus the results confirmed the conclusions drawn for the first analysis.

Results of a multiple regression analysis predicting GHQ-12 scale scores with the four Caregiver Network Scale subscale scores using enter method: beta weights and significance tests for the four predictor variables are presented in Table 1.

A similar regression analysis was conducted, this time including the four subscales of the CNS plus caregiver age and length of time as a caregiver. The results were substantially the same as the previous analysis, and the beta weights of the two new variables did not reach significance.

DISCUSSION

As was predicted, perceived stress on carers' social relationships made a major contribution to the statistical prediction of the emotional well-being of carers for people living with MND. More specifically, of the four subscales of the CNS, perceived stress on relationships with others, such as friends and family, was the most important contributor to the relationship between the two constructs. Higher levels of stress were associated with lower levels of well-being. Factors such as perceptions of receiving support from others, finding time and opportunity for self-care, and the level of satisfaction experienced by the caregiver were not statistically significantly associated with emotional health.

In addition, although significant univariate relationships existed between the age of the caregiver and the length of time he or she had been caring for the person living with MND, these results did not remain significant once the variables were intro-

Table 1. Multiple regression analysis predicting GHQ-12 scores from the four Caregiver Network Scale subscores using the direct enter method: Beta weights and significance tests

Subscale	Beta	<i>t</i>	Significance
Receive support	-0.15	1.096	0.277
Self-care	-0.15	1.086	0.281
Caregiver satisfaction	-0.05	0.505	0.615
Stress on relationships	-0.37	2.556	0.013

duced into the multivariate analyses with the CNS subscales. Only perceived stress on carers' social relationships continued to associate significantly with carer well-being.

The results are consistent with previous research indicating that prolonged caring for others living with a debilitating disease such as MND has substantial emotional costs for the carer in terms of loss of social support that might be otherwise available (Aoun, 2004). This loss, in turn, has a significant impact on the well-being of caregivers. The impact manifests as symptoms of anxiety, depression, and psychosocial distress. Although such distress deserves attention in its own right, it has to be recognized that if left unchecked, distress can have negative consequences for individuals' capacity to function in various social and familial roles. As caregivers of people living with MND have to devote so much of their time and energy to this single role, it follows that role dysfunction as a result of distress will have negative implications for the care of those living with MND.

This study indicates that there is a need for interventions designed to maintain or improve social support for carers throughout the caregiving trajectory. Although awareness of the need for continuity of care has grown markedly in recent times, the need to ensure support for carers themselves is not as well understood by health professionals. Interventions designed to improve and maintain social relationships with carers will not only ensure that their well-being is enhanced, it will also help to optimize the quality of care provided to people living with MND.

A major methodological weakness of the study is that the data are cross-sectional. Thus although an association between these variables can be demonstrated, as we have done, and a statistical prediction calculated, the data do not permit us to draw causal inferences. Hence, it is an equally plausible interpretation of the results to say that high levels of distress cause loss of social support. Although this is unlikely, given the theoretical analysis outlined in the introduction and indications that length of time as a caregiver is related to higher levels of distress, the evidence from the current study does not allow a definitive conclusion. Only a prospective study, following the progress of carers over time from when they first assume the role, will permit an analysis of the causal relationships between these two constructs. We recommend that such studies be conducted.

CONCLUSION

Despite the design limitations, it can be concluded that the CNS is a relatively brief, easily adminis-

tered, and reliable research tool for assessing carers' perceptions of their social networks. Gathering evidence in support of the tool's validation is another priority for further research. However, the evidence from this makes a contribution to the limited literature on caregiver well-being and the role of strong social relationships. This ultimately has implications for the standard of care that can be provided to people living with motor neurone disease.

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