Palliative Care & Social Practice

Original Research

Palliative Care & Social Practice

2021, Vol. 15: 1–10

DOI: 10.1177/26323524211038584

Traumatised, angry, abandoned but some empowered: a national survey of experiences of family caregivers bereaved by motor neurone disease

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Abstract

Background: There are few illnesses as disruptive as motor neurone disease, a fatal neurodegenerative condition, where diagnosis introduces a clinical narrative of inevitable decline through progressive immobilisation into death. Recent evidence suggests that bereaved motor neurone disease family caregivers are more likely to be at moderate or high risk of complicated grief.

Methods: Qualitative data from an anonymous national survey of bereaved motor neurone disease caregivers ($n = 393$) was examined through thematic analysis to explore the experiences of people who are at low, moderate, and high risk of complicated grief. Up to 40% responded to three open-ended questions: How caregivers viewed their coping strategies; the advice they had for others and what had been positive about their experience.

Results: Ten themes informed the narratives of illness and loss. All three groups shared similar experiences but differed in their capacity to address them. The low-risk group seemed to recognise the uncertainty of life and that meaning needed to be created by them. For the moderate-risk group, while motor neurone disease was a major disruption, they could with support, regroup and plan in different ways. The high-risk group did not have many resources, external or internal. They felt let down when professionals did not have answers and could not see or did not know how to change their ways of responding to this unwanted situation.

Conclusion: The differences in these three profiles and their narratives of loss should alert health and community service providers to identify and address the caregivers' support needs early and throughout the caregiving journey. Motor Neurone Disease Associations are involved throughout the illness journey and need to invest in a continuum of care incorporating end-of-life care and bereavement support. Community grief literacy and enhancement of social networks are keys to improved support from families and friends that can enable the focus to be on feelings of empowerment rather than abandonment.

Keywords: bereavement support, compassionate communities, coping, family caregivers, grief literacy, motor neurone disease, social support

Received: 5 April 2021; revised manuscript accepted: 22 July 2021.

Background

Motor neurone disease (MND) is a progressive neurological condition and terminal illness. While there is a degree of variability in the survival data, and some people live for many years before deterioration, the median survival time is 2 years after diagnosis.[1,2]

Given the complex nature of the symptoms, and the progression of the disease, the experience for

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both the person with MND and family caregiver can be traumatic and at times overwhelming. The bulk of care is provided at home and is demanding, with MND caregivers averaging over 40 hours per week of informal care.[3] Caregiver distress has been reported to be twice as prevalent when the person being cared for has a neurological condition,[3] with 53% of caregivers reporting their distress was related to the MND caregiving role.[3] Psychological symptoms such as depression and anxiety have also been found to be more prevalent for MND caregivers.[4–6] Mediating factors for distress include coping styles used for managing emotional demands and carrying out the tasks involved in care, the disease progression,[7] and family functioning.[8] In general, the way caregivers adapt to illness has an impact on their help seeking behaviour and their sense of control of the circumstances they face.[9] It also seems that the strategies used to adapt to illness continue to be employed in caregivers' response to bereavement.[10,11]

While adaptation can be considered in terms of strategies that are used, it is also important to consider the underlying attitude or narrative that informs those strategies. Bury[12] and Frank[13] identify three such storylines or sets of assumptions that are disrupted by illness or injury. We bring stories about our bodies, our social relationships, and our place in the world, and all three storylines are disrupted to a greater or lesser extent by the impact of illness and injury. All three have to be repaired or reconstructed if we are to regain a meaningful account of our changed situation in life. There are few illnesses as disruptive as MND, where diagnosis introduces a clinical narrative of inevitable decline by progressive immobilisation into death. To preserve a sense of identity, all those intimately involved need to integrate into their previous accounts of themselves, each other and the world the new experiences and fragmented understandings resulting from the disruptive impact of MND. Engagement with the three storylines is usually progressive, beginning with the immediate challenge posed by symptoms and diagnosis, expanding to include the ongoing challenges of changing social roles and then, once some reflective space is available, considering existential concerns arising from these individual and social challenges. But moving beyond one storyline to engage the next also involves revising perceptions of health and illness, of individual agency, and of the contributions that can be expected of professionals.

Our previous research has identified the prevalence of prolonged grief disorder (PGD), anxiety, and depression.[8] Compared to the general population, our national MND bereavement survey revealed a higher proportion of bereaved family caregivers to be in the high- (9.6 vs 6.4%) and moderate-risk (54% vs 35%) categories.[8] The predictors of high risk were found to be the death of a spouse/partner, having insufficient support during the disease journey, the deceased being under 60 years of age, and a shorter period of caring (<1.5 years). Furthermore, approximately 40% of all MND caregivers in this population sample did not feel their support needs were met.[14] In addition, the bereaved were eight times more likely to have complicated grief if they had anxiety, 18 times more likely if they had depression and four times more likely if they had poor family functioning. Therefore, there is growing evidence that the bereavement experiences of people following an MND death may be prolonged and/or complicated,[8,15–17] and more timely and tailored support needs to be provided before and during bereavement.[8,14] Although the importance of assessing and meeting MND caregivers' needs during end-of-life and bereavement is well documented,[4,18] little is known whether bereavement support needs have been met, or how caregivers who are at risk of complicated grief view these supports.

Objectives

The objectives of this study were to:

- Explore the experiences of family caregivers bereaved by MND
- Examine the differences in the narratives of loss and coping strategies between the low-, moderate-, and high-risk bereavement profiles.
- Inform more effective programmes to assist family caregivers.

Methodology

Ethics approval was granted by La Trobe University Human Research Ethics Committee (HEC19022). As this was an anonymous postal and on-line survey, returning the completed survey was considered as implied consent. The information sheet that accompanied the survey emphasised that participation was entirely voluntary.

Table 1. Summary of a high-level review of survey responses.

	Low risk	**Moderate risk**	**High risk**
Question 1 We would appreciate any further comments about your bereavement experience (such as experiences you have found most difficult since the death, things you have done which helped you cope)?	-Making meaning of the loss -Keeping busy and active is important -Accepting it -Allow negative memories to fade	-Death experienced as 'sudden.' -Distancing or avoidance of emotions -Unmet needs while caring and while grieving -Strong emotions such as guilt/regret/feeling abandoned	-Loss of loved one is part of multiple losses -Difficulty in adjusting to new roles -Feeling isolated and alone -Fewer perceived supports
	Low	Moderate	High
Question 2 What advice would you give to other people in your situation?	-Accepting support/help -Make end-of-life plans -Adapt and have no regrets	-Get professional support -Focus on others, family and dying person -End-of-life plans	-Professional supports specific to the MND grief process, it makes us vulnerable and makes everything harder -Do not have regrets
	Low	Moderate	High
Question 3 Have there been some positive aspects about your bereavement experience that you would like to share with us?	-Support experienced as comforting -Permission to accept grief -The experience of death and after death perceived as positive -Increased compassion for self and others -Positive memories	-Relationships are stronger, and family is closer, bonded by the experience -I am stronger -The person who died is no longer in pain	-Fewer responses to this question by people in the high-risk group -One of a few references to faith here. -Closer to family/comfort that person no longer suffering.

Study design

An Australian-wide, population-based survey assessed the bereavement experiences of caregivers after the death of a relative/friend from MND between 2016 and 2018. Postal and online surveys were used to collect information from clients of the five state MND Associations covering Australia (2019).

This research examines the qualitative data of this family caregiver survey, where participants were invited to respond to three questions about their bereavement experience and how they coped, their advice to others and if they like to share any positive aspects about their bereavement experience (Table 1).

Participants and procedures

Caregivers were eligible to participate if they had been bereaved through the death of a close family member or friend from MND between 2016 and 2018, were able to read, understand and write in English, and were over 18 years of age.

A total of 1404 study packages were posted to the five MND Associations in Australia, containing an invitation letter addressed from the corresponding MND association, an information sheet, the questionnaire, a reply-paid envelope, and a list of support services for the family to use in case the respondent became distressed. A link to the online survey was provided. The return of the completed survey implied consent. About 393 people completed the survey (response rate 30.5%).

Materials

This qualitative study used data that came from a larger study examining the rates of prolonged grief symptomatology. PGD was measured by the PG-13, a 13-item tool designed to identify people who are exhibiting prolonged grief reactions.[19] The PG-13 does not measure symptoms of grief in general; rather, it alerts the user to maladaptive symptoms of grief. For an individual to be assessed as having prolonged grief, they must meet each of five criteria: the death of a loved person; separation distress (feelings of longing and yearning, or feelings of intense pain relating to the loss, at least daily); duration criterion (symptoms of separation distress must be present at least 6 months after the loss); cognitive emotional and behavioural symptoms (e.g. preoccupation with thoughts of the deceased, searching and yearning for the deceased, disbelief about the death, crying, being stunned by the death and inability to accept the death); and significant impairment in social, occupational or other important areas of functioning (e.g. domestic responsibilities). A further categorization of 3–4 criteria indicates moderate and 1–2 criteria indicates low risk.[8]

Data analysis

The research team completed a theoretical thematic analysis using the six steps outlined by Braun and Clarke.[20] Using a semantic approach, the researchers initially read and re-read the qualitative responses to familiarise themselves with the data. The qualitative data sets for each three survey questions were categorised using the PG-13 categories, that is, risk low moderate risk and high risk. This created nine transcripts that were reviewed to reveal initial patterns and potential themes for each of the three questions across the PG-13 categories.

This initial review revealed differences in participants' responses to these three questions that correlated with their scores on the PG-13 (Table 1). Transcripts were then reviewed systematically to generate initial codes keeping in mind the survey questions, and this process generated an initial 113 codes. Coding was then completed using Dedoose software.[21] The themes were then generated from this initial coding and again reviewed to ensure they were a good fit with the data and to refine and review the coding.

Results

One hundred and twenty four (32% of survey respondents), 157 (40%) and 118 (30%) bereaved family caregivers responded to questions one, two and three, respectively.

Profile of the bereaved and deceased

The mean age of the bereaved was 63·5 years (SD 12·3), range 22–91 years. The majority were female (73·0%), widowed (71·2%), retired (53·6%) and Australian (78·7%). Their relationship to the deceased was mostly as a spouse/partner (73·7%) or child of the deceased (18·9%). The mean period of bereavement was 1.8 years (SD 0·8). Respondents had cared for a median of 1.5 years, range 0.4 to 22.5 years, and 80% had provided day-to-day hands on care for an average of 18 hours (SD 6.76) per day in the last 3 months before death. The mean age of the deceased was 68.5 years (SD 10.9), range of 31–94 years. More than half were male (59·1%). Further details on demographic characteristics are in publication by Aoun and colleagues.[8]

A thematic analysis of the responses to these three questions has provided insights into the caregivers' experiences. Themes are summarised in Table 2.

The MND bereavement experience. Overall analyses of the first question generated four themes: The individual grief response; what helped their grief; the difficulties they experienced in adjusting to the loss; and the strategies caregivers used to help them re-engage in life.

The individual grief response. Participants in every risk category reported experiencing a range of emotions such as anger, depression, regret, guilt, sadness, and shock as part of their grief. Family caregivers frequently described the impact of the caring experience, the symptoms and the MND disease process and the challenges they experienced coping with the loss of their family member.

The bereavement experience for people in the low-risk category was often described as sadness and longing: 'I miss most the companionship of my wife of 44 years together' (221) and as 'alone, but not lonely' (162). It was common for caregivers to say 'I miss my husband every day, but I do not miss the MND illness. It made life very difficult at times' (353) and 'MND is an awful disease. In the end, Mum just laid there, couldn't eat, speak, walk' (176). For these caregivers at low risk, there was an emphasis on the future: 'I cannot change the past, there is no cure of MND, I appreciate every day I have and enjoy the small things in life' (521).

Caregivers at moderate-risk were more often distressed by remembering the MND symptoms: 'I find it very difficult to put the images of my husband's body wasting away before my eyes out of my head' (340) and 'I couldn't bear having anything that reminded me of MND' (370). Others were more stark in their assessment of the experience 'I am traumatised'(211)and 'still to this day I am full of anger'(311).

Family caregivers at high-risk typically described the bereavement experience as 'extraordinarily hard' (384) with the 'illness taking a toll on our lives' (338) and it being 'difficult to erase the pain and anger I have with the hospital' (201). Furthermore, two people in the high-risk category described 'not wanting to be here' (210) and that they were 'not coping' (210, 358).

Things that helped the bereavement experience. Various experiences were identified as 'helping' grief. For people in the low and moderate categories, these included having prepared for the death and being a caregiver. The idea that 'The more you do to look after the MND patient, the better you will feel after the loss' (216) was important, as was developing coping strategies such as self-care.

The strong theme across all the categories was that social and family support was essential. Caregivers in the low-risk category frequently provided statements such as: "one gets on with life and keeps in touch with family, friends and hobbies (70) and "I was very fortunate to have the friend and family I have. They have been with me whenever I needed support, distraction or someone to reflect with" (184).

Caregivers in the high-risk category typically noted the 'complete failure' (386) of services and when services were available, they 'were very little help'. There was a sense of being let down by the formal support system, so that even if family and friends were available, this difficult experience remained at the forefront of their experience.

Difficulties adjusting. Being alone and struggling with loneliness was a common experience for people in the moderate and high categories. Caregivers reported 'it being difficult suddenly living alone' and a feeling of 'loss of purpose … nothing prepares you for being alone'(217). This experience was exacerbated when caregivers also felt abandoned by services and service providers.

Caregivers in the moderate and high categories also described the challenges of dealing with estate and legal issues. Caregivers reported: 'having significant legal issues to deal with due to being the executor' (181), 'dealing with estate was very draining and we only had pension so it is a struggle with bills' (225) and 'I found it stressful finding another house' (294).

Table 2. Summary of themes.

Survey questions	Themes
1. MND bereavement experience	1.1 The individual grief response 1.2 Things that helped 1.3 Difficulties adjusting 1.4 Re-engaging in life
2. Advice for other caregivers	2.1 Accepting help and accessing support 2.2 Adapt the best you can 2.3 Get informed
3. Positive bereavement experiences	3.1 Strengthening of relationships 3.2 Self-reflection and self-improvement 3.3 Positive memories of the caregiving experience

Re-engaging in life. 'Doing new things' and 'keeping busy' were the most common ways family caregivers coped with their loss in the low- and moderate-risk categories. Caregivers described actively needing to re-engage with their life, for example, 'I re-joined the bowling club' (320) 'I just did an amazing overseas trip' and 'I went on a three day walk, and it was better than any drugs the doctors gave me' (346). Re-engaging also involved distraction, with a number of caregivers in the low and moderate categories sharing directly that 'distractions are helpful' (339).

Responses from people at high risk were notably underrepresented in this theme. Their re-engagement activities were often connected to the person who died. 'People say go on a holiday but not having someone to share the experiences with makes it a sad experience, not a happy one. I spent a lot of time carving a small headstone for her grave' (236) and

> The first few months there were a number of things to finalise such as closing bank accounts etc. It would have been wonderful to have someone offer to come with me and other than family. Always tried to be strong in front of family so did most things by myself. (201)

Advice for other caregivers. Analyses of responses to the second question revealed three key themes: first, caregivers empathised the importance of both accepting help and accessing support; followed by the idea that caregivers ought to adapt as best they can and finally caregivers emphasised the importance of getting informed about MND.

Accepting help and accessing support. There was a clear message from family caregivers that accepting help and accessing support was important, and for some caregivers, an essential part of both caregiving and the subsequent bereavement experience. 'Reach out for support as early as possible' (277), 'don't be afraid to ask for help' (258) and 'without tremendous support from family, friends and faith I don't know how other people would cope' (253). People identified in particular support from family and 'community and neighbourhood' (262) and MND specific support organisations.

Those people at moderate and high risk were more likely to recommend professional support 'It is a learning curve for the carer, the person and families. Keep talking to family, professionals and services and seek support' (224) and 'Get as much counselling throughout the caring period and after for at least six months' (356).

Adapt the best you can. Across all risk categories, caregivers who responded to the survey encouraged other caregivers to be pragmatic: 'deal with things when they come up ... be with it don't fight it' (314) 'It is a learning curve for the carer, the person and families. Keep talking to family, professionals and services and seek support' (224).

It was common for caregivers in the low-risk category to view expressing and allowing grief as a critical part of adapting, suggesting 'The grieving process to wash its way through. Don't ignore it. Don't rush it and have tools/people on hand for when it gets too much' (190) and 'Stay open. Allow yourself to grieve. Recognise that not all days are going to be bad' (66).

Get informed – access education and information about MND. Those participants who responded to the survey encouraged caregivers to learn about MND, the care that people with MND need and the dying process. "To connect to your local MND Association asap and use the support they offer" (357); "take advantage of the support & education available through MND (137) and "don't listen to uninformed comments from friends. Let people grieve at their own pace. Get counselling. Take in as much information as possible. Don't isolate oneself from society (328).

Positive bereavement experiences. In the third question, caregivers reflected on the positive impact caring had on the strength of their relationships, on self-reflection and self-improvement and finally, they shared stories about the positive memories that occurred amid the challenges of caring.

Strengthening of relationships. Many of the caregivers in the low-risk category reflected on the positive impact on their relationships. Caregivers noted the 'enormous amount of love and support from family, friends and community' (295) and 'my relationship with sisters is much improved' (197).

Caregivers were also explicit about the impact, saying

> My husband's illness and death brought many people together again, so longstanding friends and family actually enjoyed sharing special birthdays and events with my husband, right to the end. He enjoyed and understood the deep love that was shown. I have a deepened love and respect for my two children. It was incredibly demanding but fulfilling so I have no regrets. (128)

and 'We were always close, not a day goes by without speaking to one of them' (95).

Self-reflection and self-improvement. The next important finding in positive bereavement experiences is related to self-reflection and self-improvement. Once again, caregivers who were in the low-risk category are most represented in this section. Caregivers expressed feelings of gratitude, empowerment and positive emotions:

> 'Gratitude for my life and what I have/ Yes I now realise more than ever the shortness of life and need to live for now, in the present be more mindful and patient and understanding of others and self. I feel more able to make my own decisions – empowered and feel I am now on a reflective learning journey. It's the quality of the journey NOT the end result' (233); 'Other than not having [deceased name] here I seemed to have a very positive and life growing experience during the end of life and bereavement stages'. (283)

Caregivers were also accepting of the bereavement experience as a part of life:

> I have learned that it is OK to feel grief, loss, despair, loneliness and anxiety – I give myself permission to feel these emotions, knowing that tomorrow will be a better day. I have learned (and still learn) that doing things in a "mindful manner" helps in times

> of stress, anxiety and uncertainty (i.e. Mindfulness meditation and practice). (259)

Finally, caregivers talked about being 'stronger than I thought I would be on my own. I now enjoy some alone time' (35).

Caregivers in the high and moderate categories expressed positive experiences less frequently, and when they did, it was often in the context of grief that was described as overwhelming or complex. For example:

> The only positive thing out of this experience is that my outlook on life (Taking things for granted, the beauty in nature, appreciating the small things) has entirely changed for the better. Although I feel like I am drowning in grief. It has ripped our family apart. But made us stronger, more resilient and more loving at the same time. (384)

Positive memories of the caregiving experience. Several caregivers in the low-risk category shared positive memories about the caring experience. One caregiver said:

> The most positive bereavement aspect was her celebration of life ceremony that my sister planned – my brother and I just had to make it happen as she wished. No-fuss but a lovely gathering of the friends and family who supported us in a beautiful place and a beautiful day, spreading her ashes in the ocean in a beam of moonlight was extremely special to me. It brought 'closure' knowing she would be very happy with her special day. (246)

Other caregivers shared memories about the time of death, including: 'We had a beautiful death experience of him surrounded by family and friends and peacefully leaving after saying our goodbyes. "That all helped so much" (016) and "I am so glad I was with her in the end, I wouldn't trade that for anything' (014).

One caregiver in the high-risk category responded by saying 'My first reaction is NO. But then I'm not being real and honest. The last three days were the best – I will never forget'(360).

Discussion

This article is part of a larger national population-based study investigating the bereavement risk profile of MND family caregivers.[8,14] The thematic analysis of the qualitative responses provided additional insight into the MND bereavement experience. In particular, it offered a perspective about how caregivers viewed their coping strategies, the advice they have for other caregivers and what if anything, has been positive aspects about the experience.

Consistent with the previous published findings, MND caregivers expressed a range of emotions and strong reactions to caring and being with a family member who is living with a terminal illness.[15,16,22] Previous research has also pointed to the mediating role of psychological distress on the coping of caregivers[7] and the role of the caregivers' perceived ability to provide care.[23] The qualitative survey findings were consistent with previous quantitative research that reported heightened distress in MND caregivers.[24] This distress is related to fears about coping with MND symptoms and the progression of the disease[7] and provides further evidence that bereaved MND caregivers at higher risk of PGD than the general bereaved population.[8]

Caregivers in the moderate- and high-risk categories for bereavement frequently described distressing emotions such as anger, suicidal ideation, intrusive memories and trauma when responding to the survey. Previous research has found that the perceived quality of caregiving, and a passive coping style were associated with high levels of distress.[17,23] Likewise, when caregivers were able to construct positive memories from the caring experience, these were helpful in the bereavement process.[17] In this research, caregivers reflected on positive experiences such as spending time together as a family and positive memories of the caring experience. As noted in previous research, negative caregiving experiences tend to be perpetuated into grief.[17] In this survey, MND caregivers in the moderate and high-risk categories were less likely to respond to the survey question about the positive aspects of bereavement.

The importance of accessing support (both formal and informal) was also stressed by caregivers in the qualitative survey data. This was consistent with the larger published quantitative studies that reported the people in the moderate- and high-risk categories were more likely to use general practitioners (GPs), MND associations, bereavement support groups, counsellors and psychiatrists.[14] Seeking out support, accepting help and being informed about MND were strategies emphasised by the caregivers in this research.

Interestingly, family caregivers at moderate and high risk reinforced the importance of accessing professional help despite a number reporting that their own support needs had not been met from these sources. Aoun and colleagues[25] reported on the likelihood of achieving better bereavement outcomes when caregivers had their support needs regularly identified and addressed throughout the caregiving period.

In terms of the narratives of illness and loss,[12,13] the three levels of bereavement risk might be distinguished by differing narrative structures. All three groups (low, moderate and high risk) have experiences in common, but the data revealed differences in their capacity to address the concerns and stressors that arise from these experiences. People at low risk overall were more likely to respond in terms of the resources they have discovered within and around them and the assets they have developed for dealing both with the impact of illness and bereavement and for moving into a future altered through loss. Their narrative allowed them to create meaning about the loss and adapt to circumstances that they would not have chosen but could nevertheless engage in constructive ways. The narrative informing the high-risk group contrasted with this. Rather than develop the assets of family and social network, they expected support from the professional experts and were frequently disappointed in these expectations. Regret, a sense of unfairness, and a focus upon what has been lost more than anything that has been gained, hampered their capacity to re-engage with life. The largest group of MND caregivers, those in the moderate-risk group, had elements of both the low- and high-risk narratives. They were typically pragmatic, negotiating strategies to manage the changes in their family and social lives, but they wavered between appreciating the informal assets emerging through these negotiations and the hope that, somewhere, there might be an expert with a solution for the problems they faced.

Implications for practice

The task before both formal and informal services is to be alert to the operational narrative of a family or social network and to support them, if needs be, to expand or enrich that narrative. This can be undertaken by social network enhancement in a compassionate community model of care,[26] introducing additional members who can offer different perspectives and approaches. Improving grief literacy, in terms of skills and knowledge to support the bereaved, is vital for informal networks to be effective: recognising grief, knowing how to find quality information, being cognisant of warning signs of more complex matters, careful listening that supports comments and questions with the potential to broaden perspective, knowing how to ask questions in a sensitive manner and how to help the bereaved find resources.[27,28] Thus, among the recital of everyday problems, a comment wondering aloud about implications for changed social roles and relationships should be noted and nurtured. Likewise, in the midst of negotiating changing roles and relationships, the question about a different way of looking at life should be acknowledged. No-one, formal or informal service providers, should be promoting solutions, but creating space in which possibilities can be explored, and supporting this exploration, is a vital aspect of the caregiving role.

For a disease like MND, where from diagnosis families face the rapid progression into profound disability and death with no indication yet of a treatment or cure, it seems obvious that families need to be supported in their loss and grief before and after death. Yet no MND Association in Australia, and possibly elsewhere, has considered having a staff member on board who is experienced in this field. Respondents to the national MND bereavement survey expressed feeling abandoned post-death of the person with MND.[29] Furthermore, about 60% of MND caregivers needed bereavement support beyond that provided by family and social networks.[8] At a minimum, all Associations should be able to provide referrals linking the bereaved to grief counselling services where necessary and provide information leaflets how to locate these services in their communities. A further initiative is to organise support groups where bereaved caregivers can meet and share their common experiences. Peer social support has been one of the benefits appreciated by the survey respondents.[29] The feeling of abandonment following death and the need for peer support from others with shared experiences have been reported in other studies.[30,31]

Conclusion

There is now greater evidence to indicate that MND caregivers are at greater risk of complicated grief than the general bereaved population. Currently, it is not standard practice to screen MND caregivers for mediating risk factors such as family functioning, personal distress or support needs. It is also not standard practice to assess the perceived quality of support or the efficacy of formal and informal supports as these have again been identified as a crucial mediator of distress and coping. More integrated care needs to happen between MND Associations, MND clinics, palliative and end-of-life care services and GPs during the caregiving journey for the benefits to flow on to the bereavement phase. MND Associations and bereavement support programmes are ideally placed to take a more active role in the care of people bereaved by MND. This can be achieved by a national approach to a systematic and consistent assessment of caregiver needs, staff training that includes attention to the resources available to caregivers for understanding their circumstances and best practice protocols for service delivery before and during bereavement.

Acknowledgements

The authors are grateful for the cooperation and assistance of the state-based MND Associations and for the bereaved families who agreed to complete the survey.

Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: The authors acknowledge the financial support of The MND Research Australia (MNDRA) MSWA research grant.

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References

1. Couratier P, Corcia P, Lautrette G, *et al.* Epidemiology of amyotrophic lateral sclerosis: a review of literature. *Revue Neurologique* 2016; 172: 37–45.
2. van Es MA, Hardiman O, Chio A, *et al.* Amyotrophic lateral sclerosis. *Lancet* 2017; 390: 2084–2098.
3. Mitchell LA, Hirdes J, Poss JW, *et al.* Informal caregivers of clients with neurological conditions: profiles, patterns and risk factors for distress from a home care prevalence study. *BMC Health Serv Res* 2015; 15: 1–12.
4. Aoun SM. The palliative approach to caring for motor neurone disease: from diagnosis to bereavement. *Euro J Person Center Healthcare* 2018; 6: 675–684.
5. Goldstein L, Atkins L, Landau S, *et al.* Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: a longitudinal study. *Psychol Med* 2006; 36: 865–875.
6. Rabkin JG, Albert SM, Rowland LP, *et al.* How common is depression among ALS caregivers? A longitudinal study. *Amyotroph Lateral Scler* 2009; 10: 448–455.
7. Siciliano M, Santangelo G, Trojsi F, *et al.* Coping strategies and psychological distress in caregivers of patients with amyotrophic lateral sclerosis (ALS). *Amyotroph Lateral Scler Frontotemporal Degener* 2017; 18: 367–377.
8. Aoun SM, Kissane DW, Cafarella PA, *et al.* Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national study. *Amyotroph Lateral Scler Frontotemporal Degener* 2020; 21: 593–605.
9. Foley G, Timonen V and Hardiman O. Understanding psycho-social processes underpinning engagement with services in motor neurone disease: a qualitative study. *Palliat Med* 2014; 28: 318–325.
10. Kissane DW, McKenzie DP and Bloch S. Family coping and bereavement outcome. *Palliat Med* 1997; 11: 191–201.
11. Meichsner F, O'Connor M, Skritskaya N, *et al.* Grief before and after bereavement in the elderly: an approach to care. *Am J Geriatr Psychiatry* 2020; 28: 560–569.
12. Bury M. Illness narratives: fact or fiction? *Sociol Health Illness* 2001; 23: 263–285.
13. Frank A. *The wounded storyteller: body, illness and ethics*. Chicago, IL: University of Chicago Press, 1995.
14. Aoun SM, Cafarella PA, Rumbold B, *et al.* Who cares for the bereaved? A national survey of family caregivers of people with motor neurone disease. *Amyotroph Lateral Scler Frontotemporal Degener* 2021; 22: 12–22.
15. O'Brien MR, Kirkcaldy AJ, Knighting K, *et al.* Bereavement support and prolonged grief disorder among carers of people with motor neurone disease. *Br J Neurosci Nurs* 2016; 12: 268–276.

16. Ray RA, Brown J and Street AF. Dying with motor neurone disease, what can we learn from family caregivers. *Health Expect* 2014; 17: 466–476.
17. Whitehead B, O'Brien MR, Jack BA*, et al*. Experiences of dying, death and bereavement in motor neurone disease: a qualitative study. *Palliat Med* 2012; 26: 368–378.
18. Aoun SM, Deas K, Kristjanson LJ*, et al*. Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care* 2017; 15: 32–43.
19. Prigerson HG, Horowitz MJ, Jacobs SC*, et al*. Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med* 2009; 6: e1000121.
20. Braun V and Clarke V. Using thematic analysis in psychology. *Qualit Res Psychol* 2006; 3: 77–101.
21. Dedoose. *Dedoose web application for managing, analysing, and presenting qualitative and mixed method research data*. Los Angeles, CA: Dedoose, 2018, www.dedoose.com
22. Breen LJ, Aoun SM, O'Connor M*, et al*. Effect of caregiving at end of life on grief, quality of life and general health: a prospective, longitudinal, comparative study. *Palliat Med* 2020; 34: 145–154.
23. Creemers H, De Morée S, Veldink JH*, et al*. Factors related to caregiver strain in ALS: a longitudinal study. *J Neurol Neurosurg Psychiatry* 2016; 87: 775–781.
24. O'Brien MR, Whitehead B, Jack BA*, et al*. The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study. *Disabil Rehabil* 2012; 34: 247–256.
25. Aoun SM, Ewing G, Grande G*, et al*. The impact of supporting family caregivers before bereavement on outcomes after bereavement: adequacy of end-of-life support and achievement of preferred place of death. *J Pain Symptom Manage* 2018; 55: 368–378.
26. Aoun SM, Abel J, Rumbold B*, et al*. The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia. *Palliat Care Soc Pract* 2020; 14: 1–9.
27. Breen LJ, Kawashima D, Joy K*, et al*. Grief literacy: a call to action for compassionate communities. *Death Stud*. Epub ahead of print 19 March 2020. DOI: 10.1080/07481187.2020.1739780.
28. Aoun SM. Bereavement support: from the poor cousin of palliative care to a core asset of compassionate communities. *Prog Palliat Care* 2020; 28: 107–114.
29. Aoun SM, Cafarella PA, Hogden A*, et al*. Why and how the work of Motor Neurone Disease Associations matters before and during bereavement: a consumer perspective. *Palliat Care Soc Pract* 2021; 15: 1–18.
30. Harrop E, Morgan F, Byrne A*, et al*. 'It still haunts me whether we did the right thing': a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliat Care* 2016; 15: 1–8.
31. Harrop E, Morgan F, Longo M*, et al*. The impacts and effectiveness of support for people bereaved through advanced illness: a systematic review and thematic synthesis. *Palliat Med* 2020; 34: 871–888.