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Barriers and enablers encountered by bereaved informal motor neuron disease (MND) caregivers when trying to access bereavement support: a qualitative cross-sectional thematic analysis of semistructured interviews with 6–36 months postbereavement informal MND caregivers in the UK

Liberty Braben ,[1] Deepsi Khatiwada,[2] Laura Cramond,[3] Belinda F Bradley,[1] Suresh K. Chhetri[4]

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For numbered affiliations see end of article.

Correspondence to
Dr Belinda F Bradley;
bfhornby@uclan.ac.uk

ABSTRACT

Background Caregivers of people with motor neuron disease (MND) face more negative consequences of caregiving than other terminal illnesses. The impact of this caregiver burden can negatively influence bereavement outcomes.

Objectives This study aims to explore the support needs of caregivers of people with MND, the types of bereavement services they use, or the reasons for not using bereavement services, and understanding the opportunities and barriers to accessing bereavement services.

Design The design of the study was a qualitative interview study using thematic analysis following the method of Braun and Clarke (2006).

Setting and participants Twenty bereaved caregivers of people with MND were purposively sampled. Participants were recruited through the Lancashire and South Cumbria MND Care and Research Centre.

Results Thematic analysis revealed four overarching themes: (1) type of support accessed, (2) the importance of people who understand, (3) barriers to accessing support, and (4) being (un)prepared for death and afterwards.

Conclusions Caregivers of people with MND require people who understand their unique needs to support them, alongside professional support, to prepare them for the death of their loved one and beyond. Barriers to accessing support included the need for in-person support, insufficient financial support or signposting to relevant services and being unprepared for death and bereavement.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Caregivers were interviewed by motor neuron disease (MND) nurses, who were involved in the care of their loved ones with MND, and this approach was invaluable as it fostered an environment where participants felt safe, supported, and understood, thereby enabling them to respond with openness and authenticity.

⇒ The extensive expertise of the research team comprised healthcare professionals involved in care and research of patients with MND, patient and public group, and academic psychologists with a wealth of experience in advanced data analysis.

⇒ This study provides comprehensive and nuanced insights into the bereavement support needs of caregivers of people with MND, which has important implications for future research, policy and practice.

⇒ A limitation of the study is that the data were collected in the context of the COVID-19 pandemic and this might affect the generalisability of findings.

INTRODUCTION

Motor neuron disease (MND) is a fatal neurodegenerative disease of unknown aetiology characterised by degeneration of motor neurons in the primary motor cortex, corticospinal tracts, brainstem and anterior horn cells of the spinal cord.[1 2] The condition predominantly affects middle-aged and elderly individuals.[1] The incidence varies from 1.5 to 2.7 per 100 000 population per year and median survival from onset is 2–3 years.[1]

The clinical presentation results from progressive wasting and weakness of the bulbar, limb and respiratory muscles.[1] The diagnosis remains a clinical one and

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investigations are undertaken to support the clinical diagnosis and exclude other MND mimics. There is no cure and management strategies are mainly symptomatic and supportive, aimed at preservation of quality of life (QOL) and independence.[2] Consequently, people living with MND, and their families often face significant decisions regarding how to maintain QoL.[3 4] Pharmacological treatment options are limited and patients will inevitably confront major decisions about accepting, deferring or relinquishing life-sustaining therapies.[2] Additionally, all of these can significantly impact the psychological well-being of people with MND and their caregivers.[5] Management therefore necessitates understanding of the medical, psychosocial and spiritual context of each individual patient and family.[2]

MND has a devastating impact on a person's health; people with MND usually progressively lose some or all their independence and become totally reliant on their families or friends for support.[6] The negative impact on caregivers is often described as 'caregiver burden'; this was defined by Zarit *et al* (1986, p261) as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering" due to their caregiving responsibilities.[7] Therefore, caregiver burden may impact almost all aspects of an individual's life. In addition, caregivers often experience frequent changes in their role, which can be understandably challenging and may impact the relationship dynamics between the person with MND and their caregiver.[8 9] This impact may continue beyond the death of a person with MND, and negatively impact the bereavement process, sometimes leading to prolonged grief.[10 11] Prolonged grief disorder is a recognised mental health condition that can have serious consequences for the person experiencing it.[12] However, there is lack of evidence-based interventions to improve caregivers' psychological well-being; understanding caregivers' needs and developing interventions may in turn improve bereavement outcomes.[13]

Bereavement and grief are considered a natural response to loss.[14 15] Bereavement is defined as experiencing "anticipation, death, and subsequent adjustment to living following the death of a loved one".[16] Grief is described as the "primarily affective reaction to the loss of a loved one".[14] People may experience anticipatory grief, post-death grief and prolonged grief.

The existing literature indicates that several risk factors are associated with poor bereavement outcomes. These include the place of death, experience of death, lack of preparedness and low perceived social support.[10 17–20] Findings that social support is beneficial for complicated grief have not always been replicated.[21 22]

Advance care planning enables people with MND and their families to define goals and future preferences for care and to discuss these with health professionals.[23] Research suggests advance care planning can improve bereavement outcomes for caregivers of people with MND.[20 24] In contrast, other researchers report that while advance care planning positively affected decision-making, bereavement outcomes were unaffected.[25] A recent systematic review exploring caregivers of people with MND highlighted the importance of targeting factors that could impact their anticipatory and post-death grief responses. This included knowledge about the progression of MND, changes in relationships, anxiety and/or depression among caregivers, and planning for death of the person with MND.[26] There are uncertainties about the role of social support, or advance care planning in bereavement outcomes, and a lack of literature exploring factors that impact bereavement in caregivers of people with MND. It is important to understand these factors so that evidence-based and targeted support can be provided.

Palliative care is described as active holistic care of patients; palliative care aims to achieve the best QoL for patients and their families.[27] Bereavement support is acknowledged as an integral part of palliative care in the UK.[28] However, bereavement services differ in what they offer due to lack of clear guidelines, being under resourced and under researched.[28 29] There are differences across countries in type of bereavement support provided. For example, in-person support is more common in the UK than in the USA, or Australia.[30] A systematic review found that caregivers and people with MND experience cycles of unremitting loss and uncertainty throughout the disease trajectory; despite this, many studies included in the review associate palliative care with the last few days of life.[31] There is current generic guidance for UK bereavement services, such as the National End of Life Care Strategy and a guide to commissioning bereavement services in England.[32 33] However, current guidance does not provide any specific recommendations for people with MND and their caregivers. Guidance for support from diagnosis of MND to beyond death is needed.[34] Enhancing palliative care with evidence-based guidance may support caregivers through anticipatory and post-death grieving, while limiting the risk of a caregiver experiencing prolonged grief.

Caregivers of people with MND are reported to face more negative consequences of caregiving than other terminal illnesses.[10] Caregiver burden can negatively influence bereavement outcomes. It is vital that research explores the views of MND caregivers on bereavement support so that services can adapt.

This study focuses on the perspectives of informal caregivers (unpaid caregivers who are typically a friend or family member) of people with MND. It aims to explore the support needs of caregivers of people with MND, the types of bereavement services they use or the reasons for not using these services and understand the opportunities and barriers to accessing bereavement services, with a view of identifying the best practices for effectively supporting bereaved MND caregivers. It is hoped that the insights gleaned from this study will be transferable and inform the development of tailored support strategies for caregivers of individuals with other neurological conditions.

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METHODS

Patient and public involvement (PPI)

PPI has been an extremely important element of this study, given its sensitive nature. Members of local support groups, including Motor Neurone Disease Association (MNDA) and George Barton MND Trust, also identified this study as being a priority area, given the impact of bereavement in MND.

Members of the MND PPI group, an established group at the MND centre, were invited to contribute to this study and three PPI members were selected, based on their experience and active involvement in MND volunteer activities. One of the PPI members is a local MNDA Association volunteer; another PPI, a retired general practitioner as well as a bereaved family member; and the other PPI, a MNDA association visitor as well as a bereaved family member. The PPI team, through their lived experiences, actively contributed to the design and wording of the interview questions, that was initially informed by the extant literature. Advice on acceptability of the interview guide and practical aspects of interviewing a bereaved caregiver/family member were also provided by the PPI group. The PPI members are also part of the study steering committee to ensure active PPI involvement in management and oversight of the study.

Setting and participants

This qualitative study used data from semistructured interviews (n=20) conducted to explore support needs of bereaved caregivers of people with MND.

Participants were recruited through the Lancashire and South Cumbria MND Care and Research Centre. Inclusion criteria included adult (>18 years) English speaking caregivers of patients with MND, at 6–36 months post-bereavement stage, who were able to provide informed consent.

Standard bereavement support service at the MND centre consists of a telephone call to the caregiver within days of the MND team being informed of the bereavement; this will typically be from the nurse who looked after the person with MND. With consent, a member of the MND team visits the family within 2–3 weeks post bereavement. Caregivers also receive condolence cards 6–8 weeks after the death, and at the first-year anniversary. Caregivers receive an invitation to an annual memorial service. The MND centre also signposts to the local hospice or caregivers' General Practitioner for bereavement support. Caregivers are also invited to a caregiver support group which includes people who are currently caring for a person with MND, and those who are bereaved.

Participants (see table 1) were assigned a pseudonym.

The mean age of participants was 66 years old (n=20, SD=9.08). Fifteen caregivers were women (75%) and five were men (25%). Seventeen caregivers were partners (husband or wife) of the person with MND (85%), along with two caregivers who were siblings (10%), and one caregiver who was a child of the person with MND (5%).

Table 1 Demographics of caregivers

Pseudonym	Age	Gender	Relationship to person with MND
Jackie	60–69	Female	Wife
Betty	50–59	Female	Wife
Sandra	50–59	Female	Wife
Martin	70–79	Male	Husband
Abbie	70–79	Female	Wife
Esther	Unknown	Female	Wife
Jacob	Unknown	Male	Husband
Bill	60–69	Male	Husband
Cathy	60–69	Female	Sister
Daisy	Unknown	Female	Wife
Fiona	50–59	Female	Wife
Guy	70–79	Male	Husband
Heidi	60–69	Female	Wife
Isobel	80–89	Female	Wife
Katie	50–59	Female	Daughter
Callum	70–79	Male	Husband
Lola	Unknown	Female	Sister
Nora	80–89	Female	Wife
Olivia	60–69	Female	Wife
Phoebe	60–69	Female	Wife

Procedures

A study protocol was developed and can be found in the online supplemental file 1. Sixty-three people completed questionnaires relating to another project (in preparation for publication) and were asked if they would like to be contacted regarding a semistructured interview to expand on their experiences. Interested and eligible participants (n=48) were phoned by a member of the MND research team who explained the study. Following the call, interested participants were sent an information sheet and consent form, which they returned by post if they chose to participate.

All participants gave verbal and written consent prior to the study being conducted. MND staff, who are also trained in undertaking research, conducted semistructured interviews with individual participants. Data were collected between 19 May 2022 and 14 July 2022. Interviews were audio recorded and transcribed verbatim, by a staff member of the MND care and research centre, with extensive experience in data transcription, and anonymised.

The semistructured interview explored the following topics: bereavement support received, experiences of advance care planning, barriers to accessing support, and what could be improved about bereavement support services.

This article was written in line with the Standards for Reporting Qualitative Research (online supplemental file 2).[35]

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Materials used included the participant information sheet, consent form, interview schedule and debrief sheet.

Data analysis

Qualitative interview data were analysed by two researchers using an inductive approach based in social constructionism, and following Braun and Clarke's (2006) thematic analysis methodology.[36] This involved familiarisation with the interview data by reading it iteratively, prior to beginning to conduct line by line coding and then drawing out themes that are prevalent in the data. The thematic analysis approach was chosen to analyse the data due to the limited research available exploring bereaved MND caregivers' experiences, and its ability to provide an accessible way to explore the present data in depth through analysing patterns and identifying themes. The themes are discussed to generate recommendations, and new hypothesis for future research and further qualitative exploration.

The following strategies were used to ensure the quality and robustness of analysis: assessing the qualitative research at regular stages using the Quality Framework Tool[37] (online supplemental file 3)); regular supervision and a reflective diary were used at all stages of the research process; two researchers independently analysed the data thematically, before coming together to agree on overarching themes.

Self-reflexivity is paramount to qualitative research.[38] The research team with experience in provision of MND care and bereavement support, included trained research nurses who conducted the interviews, and a consultant neurologist with years of experience supporting people with MND and their caregivers, and PPI group. The researchers who analysed the data included an academic psychologist, palliative clinical psychologist with experience of qualitative methodology and two independent clinical psychology master's students with training and supervision in qualitative methods. The research analysts had no prior contact with participants in this study. The research analysts regularly reflected together on their observations and interpretations of the data. The differing experiences in the team allowed for exploration of the emerging themes within a wider context of an awareness of the theory, and clinical practice of supporting bereaved caregivers. This provided a collaborative, rich and nuanced reading of the data.[38]

RESULTS

The analysts identified 173 initial codes across the transcripts. The codes were then refined, or removed depending on their relevance to the research aims which supported the search for themes and this left 99 codes. The researchers then continued the process of searching for themes by collating codes into potential themes, and generating a thematic framework map (See figure 1 below) and checking this against the original transcripts, following the process of Braun and Clarke's (2006) guidelines.[36]

The analysts eventually identified four overarching themes, with subthemes, capturing the experiences of bereavement care from the perspectives of caregivers of people with MND: type of support accessed, the importance of people who understand, barriers to accessing support and being (un)prepared for death and

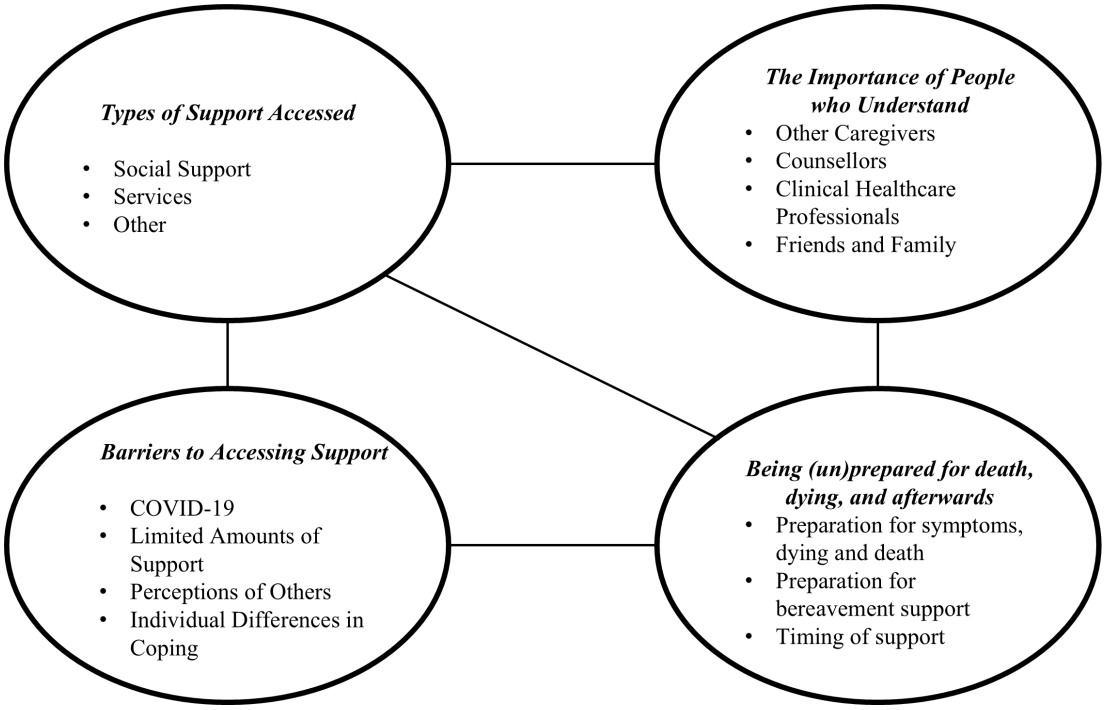

Figure 1 Thematic framework map. This figure depicts the four overarching themes, with corresponding subthemes.

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afterwards. An overview of the overarching themes and subthemes can be seen in the thematic framework map (figure 1).

Type of support accessed: "It was nice to know that we are not forgotten." [Phoebe]

This theme highlights support that was accessed by bereaved caregivers of people with MND. This included support from their own social networks, services and other activities. The two main types of support caregivers accessed included their own social network, and counselling. The elements of social network mentioned included friends, family and pets, to support them through the grief they experienced after their loved one's death. Connecting with these supported caregivers to remain resilient in the face of the grief. Cathy stated:

> The support has mainly come from my family especially my mum. *[Cathy]*

Guy shared:

> I think my dog is the one who helps. I have to take him out so it's good. He's kept me going. *[Guy]*

Caregivers discussed the types of support accessed from services. The main support accessed was bereavement counselling. Caregivers were supported to use this mainly through their local hospices, and occasionally through their local hospitals and General Practitioners; caregivers described how support from hospices was helpful.

Many caregivers discussed how attending the MND memorial service was a helpful support for them. This type of support is specific to the MND service that the bereaved caregivers in the present study had accessed. Caregivers expressed how it was supportive to be in a shared place with others who had experienced a similar journey, as well as to hear meaningful poems.

> I appreciated the memorial service; it was nice and the poems were nice. *[Daisy]*
>
> The first memorial service 'a time to remember' was cancelled due to lockdown. The video service was lovely and this year's [service] was lovely. *[Callum]*

For those who did not wish to access support from services providers, it was still important for them to be offered support. This supported caregivers to feel less alone, and being offered support showed them there was always someone available to support them, should they need this in the future.

> It was nice to know that we are not forgotten. The cards and the invite to the memorial service strengthened the feel that you [MND team] really knew us and hadn't forgotten us. *[Phoebe]*
>
> Sometimes you don't need them [professional support] but it's knowing that they're there… it' s a comfort. It's like the MND team who are just at the end of the phone line. *[Jacob]*

Other strategies that caregivers used to enhance their well-being included taking part in creating artwork, and fundraising for MND charities. This supported them to do something practical, and meaningful when experiencing their grief, and supported them to feel connected to the services that had supported them and their loved ones through a difficult time. Sandra shared:

> I took up crafting and I like to go to fairs to sell them for the Motor Neurone Disease Association [charity]. *[Sandra]*

The importance of people who understand: "Getting the right person to talk to." [Abbie]

This theme highlights how caregivers want support from people who understand MND and what it is like to be an MND caregiver. MND is a condition that impacts heavily on caregivers.

Betty shared:

> One of my local Doctors said people talk about cancer but one of the most devastating diseases I know is MND because there is no respite… the impact on the people who live with that person is far more than people outside can imagine. *[Betty]*

Due to the difficulties, and the unique journey that caregivers of people with MND experience, it was very important for caregivers to access support from people who know the disease and understand the journey. The present theme explores this in relation to other caregivers of people with MND, bereavement counsellors, clinical healthcare professionals and caregivers' family or friends.

Caregivers often discussed how helpful it was to connect with other bereaved caregivers of people with MND. As previously discussed, caregivers were able to connect with other caregivers at events such as the MND memorial service.

> After the service we could spend time with people [other bereaved caregivers] over coffee. We've never been able to do that. We shared our stories which was again that intimate bereavement. Unless you are in it and [you have] experienced it no one knows what it's like. *[Fiona]*

Due to the deep understanding that caregivers of people with MND have with each other, caregivers often expressed a wish to have more connection with each other. Caregivers suggested that regular informal meetings with other bereaved caregivers of people with MND may have helped.

> Maybe a coffee morning may be nice to talk to people who knows what it's like. *[Esther]*
>
> I think it might be good to have a regular meeting to talk to people who have been in my position. *[Sandra]*

In addition to other caregivers, caregivers also wished for support from services who understand MND. As explained previously in the theme 'types of support

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accessed', many caregivers accessed counselling support. One caregiver expressed how counselling did not help, as the counsellor did not understand MND; another caregiver explained how they would not access counselling due to this lack of understanding.

> The counsellor was lovely but it didn't make me feel better or change anything for me. Now moving further down the line, I think the counsellor didn't know about the illness. If people don't know about it and what it is, it's really difficult to talk to someone as you can't describe your feelings and the feelings what you have gone through. Particularly when you have to start by explaining what the illness is. *[Betty]*

> I cannot speak to a total stranger I find it pointless as they have no inkling or understanding about MND. I am not speaking to a brick wall. *[Sandra]*

As well as needing counselling provision from people who understand MND, some caregivers also expressed the need to speak to people who understand MND symptoms, and death or dying, such as clinical healthcare professionals. For some caregivers, services such as counselling did not provide the knowledge that they required to help them process their experiences and grief. Cathy shared how not understanding why her sibling had died so quickly impacted her grief:

> What has compounded my grief is not knowing what [was] happening in the last 60 hours of [my sibling's] life. I maybe should have spoke to the bereavement team. But I have arranged to speak to the matron, sister, and consultant on the ward as I feel it's been an obstacle to my grief as I don't really know why he died so quickly. *[Cathy]*

Abbie discussed how she wanted to speak to healthcare professionals to understand the symptoms of MND and what was happening during her partner's last few days:

> The barrier was getting the right person to talk to. I wanted to talk through the clinical side. With some people, bereavement [support] will help but I needed the [healthcare] professional help. *[Abbie]*

As previously mentioned, caregivers' families and friends are a vital source of support for caregivers. This is likely because family and friends often understand a caregiver's journey of supporting someone with MND more deeply than a professional.

Cathy and Nora shared:

> My mum is the most significant support. We have supported each other. *[Cathy]*

> Family was the most important part of my support. *[Nora]*

This theme highlights the need for caregivers to access support from people who understand MND. This includes the need for provision of support that facilitates caregivers meeting others who have had a similar journey. Also, services need to be knowledgeable on MND and the caregivers' journey, as well as caregivers having access to healthcare professionals who may be able to explain and support caregivers to process the dying experience of their loved one.

Barriers to accessing support: "It's difficult because you have to ask for it." [Esther]

This theme highlights barriers to accessing support; in relation to limited amounts of support offered, the impact of the COVID-19 pandemic, the perceptions of others and individual differences in coping which impact access to support.

Bereaved caregivers need to be supported in a wide variety of ways to meet their needs, including support for their psychological well-being, practical and financial support as well as support to maintain their social network. However, caregivers discussed that there was a lack of support offered. Many caregivers expressed that their GPs only offered medication, without the option of other support to manage their psychological well-being. In addition, many carers shared they were unaware of financial bereavement support that was available. As previously expressed above, caregivers also requested more opportunities to connect with people that understand, such as other bereaved caregivers of people with MND, as there was a lack of these opportunities available.

> I spoke to the GP as I was feeling down. He only wanted to put me on anti-depressants which I didn't really feel I needed. *[Jackie]*

> Day to day financial planning, I didn't get any advice. I now get a benefit called bereavement support benefit. I missed the first few months because nobody told me about it. I only found out about it from a friend. *[Betty]*

In addition to a lack of opportunities available, caregivers expressed how the COVID-19 pandemic meant they could not access the type of support they needed—face-to-face support:

> I asked for face to face but they couldn't help. I asked at the Hospice but again they weren't doing any face to face. They did ring me on a regular basis but couldn't offer me face to face due to covid. *[Daisy]*

Other barriers to accessing support included interpersonal barriers. Many carers felt that services or their own friends or family were too busy support them, which meant some caregivers did not reach out to their social network or services:

> My daughters do help me and make sure I am OK. They are busy and working so don't want them to fuss over me. *[Guy]*

> The MND team can't spend time with us as you are busy with people with MND. *[Esther]*

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Other caregivers explained how they noticed friends and family appeared to ignore their bereavement or caregivers felt that others were not able to 'handle it', or cope with it, which may act as a barrier to the caregiver reaching out to their social network:

> Friends were great but kept their distance. *[Callum]*
>
> Some people ignored what was going on. *[Olivia]*
>
> I went to see a friend when things were really bad and I think she felt out of her depth. He had died but I still didn't want to be here and she didn't know how to handle it. I was in a really bad *way. [Phoebe]*

As some caregivers experienced barriers to accessing their social network, it would seem they may benefit from support from services instead. However, some caregivers found it difficult to reach out and ask for support from services. Caregivers expressed the alienation they felt when they had transitioned from having intense support from professionals prior to the death of the person with MND, to then having no visitors. This was difficult as it meant caregivers need to reach out to ask services for help which can be incredibly difficult.

> Every time we saw the MND nurse I couldn't say how I was feeling. I knew I had to get through this and then had to carry on and live my life. *[Phoebe]*
>
> It's difficult because you have to ask for it. You have a lot of visits while there, he was here, and then that's it. No-one. And you have to ask for support. *[Esther]*
>
> Care was coming into the house three or four times a day. District nurses started coming twice a week now. Then we're going to start coming every day and night sitters every night. And then all of a sudden, there's nothing and nobody, you know, you don't see people. And suddenly I never see anyone. *[Jacob]*

In contrast, individual differences meant that caregivers may not wish to access certain types of support. These included caregivers wishing to support themselves independently, or disliking certain form of support due to their own individual differences. For example, Phoebe explained how she is an introvert and discussed how group support would not have helped her:

> I am quite an introvert so I don't have a lot of people around me. So, it wasn't a natural thing for me to ask for people to talk to me. Having a support group would have filled me with horror. *[Phoebe]*

Other caregivers did not wish to seek support as they feel they should cope independently:

> I've always been that there is only one person who can sort you out and that's you. I had a lot of let downs when I was little so it helped me cope now. I coped so long and kept control and no one was going to dictate what I needed to do. *[Sandra]*
>
> When people say 'how are you?' they don't really want to know how you are. They don't want to hear you keeping moaning. It's not what a man does, you should not show how you are feeling. Stiff upper lip and all that. *[Guy]*

The present theme expresses a multitude of barriers to bereaved caregivers accessing support. Caregivers need a variety of support offered for their differing needs, including financial support. Services need to reach out to bereaved caregivers to offer this support, as this can be difficult for caregivers to do, while also being respectful of individual differences of coping with bereavement. Services need to be mindful of these barriers when creating opportunities to support bereaved caregivers, and consider ways of supporting caregivers with engagement of meaningful support.

Being (un)prepared for death, dying, and afterwards: "No one particularly sat me down and said this is what we can offer." [Betty]

This theme highlights how caregivers need to feel prepared to manage their loved one's symptoms and what they may experience at their death in the prebereavement stage. This theme also discusses the need to feel prepared to access timely support in the postbereavement stage. Caregivers reflected how grief often begins at diagnosis of MND and that they would have hoped for support from the point of diagnosis:

> The bereavement process starts once the diagnosis has been made. We are on the path. *[Esther]*
>
> If the support could have been one to one at diagnosis, I think I needed it. I think after death would have been good too. I think if anyone had asked me, I would have said no. It would have to be formally assessed to be able to get through to me. *[Phoebe]*

Some caregivers shared how they thought they would have more time to prepare for death in the prebereavement stage than they were given. The trajectory of MND in an individual person can be sometimes difficult to predict and this has an impact on caregivers' ability to plan and prepare for death, dying and afterwards.

> We thought the MND would go on for a few years. We thought we had time. Didn't know what she wanted for the funeral. *[Guy]*
>
> The minimum that we were given was two years… The fact that I lost her within nine months. We need a plan for what we're going to do when it comes because I thought that was in the future at the moment. *[Martin]*

Caregivers shared how they wished to understand the process and symptoms involved in dying so that they felt prepared. In addition, caregivers discussed how they do not recall being told about the bereavement support available once the person with MND had died. Some caregivers also expressed how it was difficult to remember whether support had been offered; this is understandable

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in the context of the caregiver experiencing the psychological and physical impact of grief.

Caregivers who did not feel prepared expressed how this impacted their bereavement.

> Everybody deals with bereavement in a different way and must process watching their loved ones go. And for me it was not having advanced warning or planning on how to deal with the symptoms. So, I needed professional help at that point. *[Abbie]*

Caregivers explained how they did not recall being told what bereavement support was on offer:

> I suppose we hadn't had that kind of conversation of what happens after. There wasn't a conversation between ourselves or any other services beforehand. We saw you and the district nurses but they would flit in and out. *[Katie]*
>
> It was always around, no one particularly sat me down and said this is what we can offer. I always had an idea there would be something. *[Betty]*

Other caregivers shared that they found it difficult to remember what support was offered:

> They may have offered support but I can't remember it and I wasn't in any state to accept support. *[Isobel]*
>
> I cannot remember what was offered. I was not in a good place when he was diagnosed or when he died. I think it was all swirl of emotions. I really can't remember what support was offered me when he died. *[Phoebe]*
>
> I am sorry I have forgotten. I can't remember the hospice offering anything. *[Katie]*

Despite the need to know about dying, and support for bereavement, some caregivers said that they felt that professionals were frightened about sharing what death is like:

> The MND team are frightened of telling you how it's going to happen at the end… I needed a bit of a warning. It would have been good to talk to someone so I would have been prepared. *[Guy]*

Caregivers need to access support at a time that is right for them. As previously explained, some caregivers could not recall whether they had been offered support. For some caregivers, accessing support for their bereavement early on was helpful, whereas others needed more time to process their grief before they reached out to services. Many caregivers described needing support from services once their social network, friends or family, had begun to provide less support. However, at the point of needing services, some caregivers described how too much time had passed, and they could no longer access the support they needed from services.

Lola was prepared to access support earlier at what felt like the 'right time':

> I accessed the counselling straight after losing my sister and I felt it was the right time as I had contact with the hospice whilst she was alive. *[Lola]*

Many caregivers felt that support was needed later, after their social support had begun to 'drop off':

> Family and friends helped but after a while they drop off as they move on. *[Guy]*
>
> At the beginning I was busy sorting his flat out and people rallied but then it all stops. And this is when I struggled. *[Cathy]*

However, Esther acknowledged how services are only available for a limited amount of time:

> I started to have counselling. Its's difficult. I needed it then but also needed it about a year down the line when everyone is getting on with their own lives. Your life has gone back to normal but services are only there for a limited time and then they are gone. I wouldn't have bothered them unless I really needed them. *[Esther]*
>
> I think it would have been nice for the hospice to maintain contact for longer so I could talk to someone who knows what (Husband's name) was like at the end. *[Esther]*

This theme expresses how caregivers require individualised support to feel prepared for death, dying and afterwards. Many caregivers want to understand symptoms relating to death and dying, as not having this understanding can impact the person with MND's experience of a 'good death' which can impact the caregiver's bereavement process. Caregivers also shared the difficulties with timing of bereavement support and recalling what support is on offer. Services should seek to have discussions with caregivers from diagnosis about their needs and continue these discussions about the support that is available throughout the person with MNDs care. Caregivers found it difficult to recall support available, and some wished to access support at a later stage in their bereavement, but they could not. Services should be aware of the need for caregivers to access support at the 'right' time for them, which may be long after the person with MND has died.

DISCUSSION

Main findings

This study explored the experiences of bereavement care from the perspectives of bereaved caregivers of people with MND. Four overarching themes were identified and the main findings of each are summarised below.

Types of support accessed

The findings highlighted how important a caregivers' social network, including friends, family and pets, is in supporting a bereaved caregiver. Other types of support accessed included counselling, typically provided by

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hospice provisions, and finding comfort in personal displays of support, such as cards from the MND team. Caregivers appreciated spaces where they could be with other caregivers of people with MND. Even if caregivers did not want to access support, they would still like to be offered this, as it shows caregivers that they are not alone. Some caregivers accessed other types of support such as doing artwork or fundraising for MND charities.

The importance of people who understand

The findings illustrate how important it is for caregivers to access bereavement support from people who understand MND. This includes having opportunities to meet other bereaved caregivers of people with MND, access to counsellors who have knowledge of MND, access to healthcare professionals who can discuss symptoms and dying, as well as opportunities to be with friends and family who helped them through their journey of caregiving.

Barriers to accessing support

Caregivers need a comprehensive range of support including psychological, practical and financial assistance. This study identified barriers that caregivers face in accessing support, including the inadequate availability of support being offered. In addition, caregivers experienced a lack of face-to-face support due to the COVID-19 pandemic. Caregivers also discussed perceiving others as too busy, or unable to cope with a caregivers' bereavement, as well as difficulties asking for support or finding the right support for a caregivers' individual needs.

Being (un)prepared for death, dying and afterwards

Bereavement starts from diagnosis of a person with MND. There is a need for, and an opportunity to, prepare caregivers for the emotional, practical and financial difficulties that they will experience from the day the person with MND receives a diagnosis. Some caregivers desire support to help them prepare for the symptoms and dying process. Caregivers also want to feel prepared for the bereavement support post death. Caregivers need to be able to access support at a time that is right for them, which may be early on after the death of a person with MND, or a long time afterwards, when services are sometimes no longer accessible.

What this study adds

Positive social support can decrease caregiver burden.[39–41] Social prescribing is an approach that helps people access activities, and local community groups, to address their social and emotional needs, thereby enhancing their well-being.[42] This study adds to the literature supporting the value of social support and social prescribing for bereaved caregivers. In addition, it highlights that social bereavement support can include non-human companions such as dogs. The literature recognises dogs as a form of social support.[43] Counselling was accessed by many caregivers within this study. Although counselling interventions have previously been suggested in the literature, this study highlights the need for counsellors who understand the impact of MND.[44] In addition, the findings indicate a need for some caregivers to access professionals with a clinical understanding of MND, to help them process the death of the person with MND. The difficulty of finding counsellors and other clinicians who have knowledge of a disease has also been noted in other neurodegenerative disorders, such as Huntington's disease.[45]

Caregivers reported a lack of any financial support and limited signposting from primary care services. Caregivers are likely to experience financial strain because of caregiving and death of the person with MND; in one study, 35% of caregivers experienced a devastating or near devasting financial impact of MND.[44 46 47] Providing or signposting to bereavement services is regularly recommended to support caregivers, and these findings highlight the need for professionals to be aware of the local services available to signpost to.[48 49]

Bereavement support for many caregivers in this study was impacted by the COVID-19 pandemic and many were not able to access in-person support. Despite online support being useful, there are limitations in terms of time or practicalities, and this study highlights the importance of having the option of in-person support, which is more common in the UK, as discussed in the introduction.[30 50]

Feeling prepared may enable a caregiver to have fewer negative bereavement outcomes.[26] In one study, researchers found feeling prepared for death better helped caregivers' to grieve; their study highlighted how the bereavement process can be negatively impacted if a caregiver does not feel prepared for death or progressive symptoms of MND.[51] Our findings are consistent with the literature that shares how caregivers wish to feel prepared for their loved one's end-of-life care, and their own role within that.[51–53] Studies mainly focus on palliative care from the perspective of the last few days of life; however, this research highlighted the importance of having access to bereavement support from diagnosis, and for services to remain available post death, for when caregivers feel 'ready' to access them.[31]

Implications for policies, practice and future research

Lack of adequate support from healthcare professionals has been found to be a risk factor for prolonged grief; some caregivers in the present study reported how professionals seemed frightened to discuss death with them; this may be due to a lack of confidence or awareness in discussing these issues.[50 54] Professionals may benefit from training on discussing death and bereavement support which may include discussions around symptoms of MND and preparation for death.[55–57] Opening up conversations for discussions around death, and what happens afterwards can support both the person with MND and the caregivers' psychological well-being.

MND caregiver bereavement support needs clearer policies and guidelines on who provides which parts of bereavement support. MND caregivers should be able to access financial advice relating to their caregiving role

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and bereavement. Professionals may also need training on where to signpost for their local area, and dependent on the bereavement care provided, may require training to understand MND and the unique challenges that caregivers experience.

Future research should evaluate training programmes to enhance professionals' understanding of bereavement care and MND, and assess its impact on professionals' knowledge, skills and confidence, as well as caregiver bereavement outcomes.

Strengths and limitations

This study highlighted various challenges in provision of tailored bereavement support in MND. Gaining insight into those challenges is essential for the development of strategies to support professionals in navigating and overcoming them. Our data overlap with the height of the COVID-19 pandemic, and therefore this is likely to impact the participants' responses. Caregivers were interviewed by MND specialist team which may produce conscious or unconscious bias within their answers, due to factors such as social desirability. However, it is important to consider that the sensitivity of the topic warrants someone who is knowledgeable in MND care to support bereaved caregivers in these discussions. Another limitation of the study is the purposive sampling methodology, and that caregivers self-selected to participate in the study. Hence, it is possible that those recruited represent a specific group of caregivers who are particularly inclined to participate in initiatives of this nature. It is also important to acknowledge that there were many bereaved caregivers who did not participate in this study, and exploring their perspectives on bereavement support since the loss of their loved one would provide useful insights.

Despite these limitations, our study provides a unique understanding of bereavement care from the perspective of caregivers who have experienced the loss of a loved one with MND. It highlighted the support that caregivers accessed, barriers to accessing such support, and suggests actionable improvements, along with directions for future research to best assist MND caregivers.

CONCLUSION

This study highlights the importance of preparing caregivers for the emotional, practical and financial difficulties that they will encounter, spanning from the time of initial diagnosis of a person with MND to a long time after their death. It is important for bereaved caregivers to access support from counsellors, healthcare professionals and other caregivers who are aware of MND and a caregivers' unique needs. This study also highlights barriers to accessing the necessary support including the impact of COVID-19 and the lack of support offered to caregivers. MND caregiver bereavement support needs clearer policies and guidelines on who provides which elements of support. Professionals may benefit from training on discussing death and bereavement support. Additionally, MND caregivers should be able to access a wide variety of support, which may include social prescribing and financial advice, all of which should be tailored to meet the unique needs of each caregiver.

Author affiliations
[1]The School of Psychology and Humanities, Universtiy of Central Lancashire, Preston, UK
[2]NIHR Lancashire Clinical Research Facility, Lancashire Teaching Hospitals NHS Foundation Trust, Preston, UK
[3]Maggie's Oldham, The Sir Norman Stoller Building, Royal Oldham Hospital, Oldham, UK
[4]Lancashire and South Cumbria MND Care and Research Centre, Lancashire Teaching Hospitals NHS Foundation Trust, Preston, UK

X Belinda F Bradley @bfhornby@uclan.ac.uk

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ORCID iD

Liberty Braben http://orcid.org/0009-0007-1391-6519

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