

Abstract

Family carers of people with motor neurone disease face many challenges pre and post-bereavement, with support needs not routinely assessed and little attention focused on recognising abnormal grief responses. Our survey (n=56) sought the views of those involved in the care of this population in England on bereavement support and Prolonged Grief Disorder. Results revealed over two-thirds of respondents felt unable to predict future cases of Prolonged Grief Disorder and that an alert tool to help identify carers of people with motor neurone disease at risk would be welcomed. Implications for future research and development of support are discussed.

Introduction

Bereavement and Prolonged Grief Disorder

Each year, globally, around 56,000,000 people die (WHO, 2012), with large numbers of the general population losing a ‘significant other’ (Stroebe et al, 2007, p.1960). Although there is acknowledgement that the effects of bereavement can be profound, it is also true that most people will grieve in a *normal* manner with their grief fading into adequate coping mechanisms within six months of bereavement (Segen, 2012). However, it is estimated between 10 and 20% of bereaved people will develop Prolonged Grief Disorder (PGD) (Middleton et al, 1996; Prigerson and Jacobs, 2001). There is variation in attempts to define PGD (Stroebe and Schut, 2006); here we adopt the suggestion that it refers to instances where:

[t]he normal grief reaction lingers and becomes increasingly debilitating . . . people with PGD have intrusive thoughts and images of the deceased person and a painful

yearning for his or her presence. They may also deny their loss, feel desperately lonely, and want to die themselves (Prigerson et al, 2009, p.12)

Although commonalities exist with the experience of ‘normal’ bereavement, PGD health consequences are typically longer-lasting and more severe. Alongside ‘yearning, disbelief about the death, difficulty moving on and feeling detached, bitter and agitated about the death’ (Kristjanson et al, 2006, p.37), PGD symptoms have been associated with a range of physical and psychological health concerns and behaviours and reduced quality of life (Silverman et al, 2000; Jacobsen et al, 2006; Melhem et al, 2007; Prigerson et al, 2009; Rings et al, 2014), as well as increased health service use and absence from employment (Lannen, et al, 2008).

Motor Neurone Disease and PGD

Motor Neurone Disease (MND), a progressive terminal condition, is thought to result in the deaths of over 100,000 people, each year, worldwide (<http://www.alsmndalliance.org/>). MND has no known cure; the complex nature of the illness and rapid deterioration at end-of-life can be traumatic for carers unprepared for the final phase (Goldstein et al, 1998) and prognosis is poor, with average survival from diagnosis approximately 14 months. Carers of people living with MND (plwMND) have likened their experience of caring as akin to a series of bereavements with fragmented, poorly communicated and generally dissatisfying service provision meaning these carers are under considerable strain (Aoun et al, 2012). Additionally, the continuous losses associated with MND can be cumulative, reflecting the notion of pre-death grief recognised in dementia (Kiely et al, 2008).

MND family carers, therefore, are potentially at greater risk of grieving in an unusually intense manner beyond the period typically considered normal. There is

little published research, however, identifying particular populations of carers, such as MND family carers, who might need additional bereavement-related support (Stroebe et al, 2006). The only published study to explore PGD in MND, conducted in Australia, reported a 37.5% incidence amongst carers (Aoun et al, 2012), which is substantially higher than that reported in the general population, though the sample of 16 was small. As it is unknown what bereavement support is available, or offered, to carers of plwMND and whether their bereavement support needs are being met, we undertook a study to explore experiences of bereavement support and awareness of PGD with health and social care professionals involved in the care of plwMND in England.

Methods

The study involved the distribution of an online survey, using Survey Monkey® software, to gather the views of health and social care professionals directly involved in the care of plwMND. University Faculty research ethical approval was granted in January 2014 and National Health Service (NHS) Research and Development (R&D) permissions from 16 trusts were secured between January and July 2014.

Sampling was purposive and targeted at individuals with direct involvement with plwMND and included 20 MND Association Regional Care Development Advisors (RCDAs) in England who provide support and information to plwMND and their families, and 84 members of staff working in 16 MND Care and Research centres in England. Snowballing was encouraged with individuals prompted to share the survey link with others with experience of caring for plwMND (Procter et al, 2010).

Recruitment of respondents was via e-mail containing an embedded link to information about the study and access to the online survey. The survey was available between February and July 2014 (access was necessarily staggered due to the varying dates on which trusts granted NHS permissions). A single e-mail reminder was sent to all potential participants two weeks after the initial contact (Oppenheim, 1992). In total, the survey comprised 12 items, and included both closed and open-ended questions on areas including opinion and experience of bereavement support (pre and post-bereavement), experience of PGD, ability to predict PGD and suggestions for improving bereavement support.

Analysis

Closed question responses were analysed using simple descriptive statistics such as frequencies and percentages. Open text comments were analysed thematically (Braun and Clarke, 2006). Comments were read a number of times and initial codes applied. These codes were subsequently grouped into themes reflecting the participants' opinions on MND family carers' bereavement needs. To increase rigour, inter-rater techniques were adopted (Low, 2007) by which two members of the team initially conducted the thematic analysis independently before coming together to agree on emergent themes.

Results

The survey was intentionally distributed to 104 people and was completed by 56 individuals: 12 (21%) respondents were MND Association RCDAs and 31 (55%) were staff working in MND Care and Research centres. An additional 10 respondents (18%) comprised of occupational therapists, physiotherapists, advanced neurology

nurses, and MND Association volunteer visitors; three respondents (5%) did not specify their role. These figures indicate response rates of 60% for MND Association RCDA's and 37% for MND Care and Research Centre staff. Results from the closed response questions are presented in graph form to indicate the overall opinion of respondents. Open text responses presented are regarded as exemplars indicative of the emergent themes and presented with anonymised identification codes assigned during analysis.

Opinions of bereavement support

Pre-bereavement support

Participants were asked their views on bereavement-related support provided to MND family carers *prior* to bereavement. The majority rated support as average or worse, with less than a fifth (18%, n= 10) rating it as good or excellent (Figure 1). Respondents commented that difficulties in the provision of support occurred as a result of a lack of formal guidelines on available services:

'There are no formal guidelines about what we do/don't offer.' R29

Similarly, uncertainty was apparent regarding the extent of available support services:

'The 'whole' range is not commonly known or knowledge of the range is not kept and coordinated in one central place.' R28

Whilst support was accessed, *'alongside their loved one during the pre-bereavement process'* (R13), respondents were unclear how much emphasis on preparation for

bereavement was provided. It was felt that the provision of pre-death assessment could potentially identify those who might experience difficulties with their grief:

‘The people who really struggle, however, are not always recognised prior to the death and may well flounder. Some pre-death assessment would help.’ R27

[Insert Figure.1.]

Post bereavement support

When asked their opinion of post-bereavement support for MND family carers a majority (80%, n=45) rated it as average or worse (Figure 2.). Respondents also believed that problems with accessing services, and waiting times experienced, needed to be addressed. Furthermore, it was apparent that most organisations were only providing minimal support:

‘Most organisations seem to be offering minimal support following the death, often just a letter or telephone call, which leaves the bereaved person totally alone after being surrounded by professionals prior to the death.’ R27

Whereas prior to bereavement many health/social care professionals are frequently present, carers are often left on their own following the death of a loved one. The effect of this sudden cessation of support was emphasised by a number of respondents:

‘We look after the ‘team’ i.e. patients and carers and then when one dies we drop the other with little support at the most difficult time.’ R21

The support available from different organisations was regarded as too disjointed:

‘Support is too fragmented so you are often unaware of who is doing what. Hospices don’t often tell a health professional what they are doing with regard to bereavement support.’ R26

A further problem was related to the way in which the needs of individuals are recorded. In some cases services might be offered by one organisation and declined as it was not the particular type of support that the carer was looking for. However, this can lead to it being recorded that no bereavement services are required at all - and consequently no further alternative support offered - rather than the carer being informed of the range of bereavement services available to them. It was apparent from responses received that the bereavement needs of carers vary widely:

‘Everyone grieves in different ways and therefore require different forms of bereavement support.’ R28

With this in mind, respondents highlighted that variability in the type and amount of support provided was necessary, as was guidance on what to include:

‘There is no “one size fits all”, although it would be useful to have some standards/guidelines about what should be offered at different stages.’ R14

Respondents underlined that due to the ongoing nature of losses in MND, bereavement can be experienced over time as the disease progresses, often necessitating ongoing support for carers:

‘Bereavement is not only related to the death of a patient and it should be recognised and highlighted that for many carers and family members bereavement begins quite often at the time a patient is diagnosed or even before this. We hear so often families and carers express they lost their family member way before the death - this is when we should be supporting these people.’ R28

It was clear from the respondents’ comments that patient involvement with specialist palliative care services/hospices should equate to better bereavement support for carers:

‘If patients access specialist palliative care services there is often much more support available for their family after death.’ R19

In situations where the patient has not received specialist palliative care/hospice involvement, or has chosen not to access it, there was less likelihood that the family would be supported post-bereavement:

‘With hospice support these [family bereavement needs] are usually well managed, where this is not available, this is less likely.’ R11

[Insert Figure 2.]

Experience of PGD

To understand the possible extent of PGD amongst MND family carers, participants were questioned about their awareness of the condition. Forty-five per cent (n=24) felt they had encountered a family carer experiencing PGD (Figure 3):

[Insert Figure3.]

A majority (70%, n=37) felt unable to accurately predict future occurrences of PGD (Figure 4) and 70% (n=37) believed that there was a need for a specific alert tool to help predict MND family carers at risk of developing PGD (Figure 5.):

[Insert Figure 4.] [Insert Figure5.]

Open text comments indicated that training in recognition of the symptoms of PGD is required to empower and educate health and social care professionals:

‘Training on early identification, support strategies and minimising risk of PGD occurring.’ R34

It was also felt that up-to-date information on bereavement and PGD-related research studies should be distributed to health and social care professionals alongside the provision of information regarding available support for MND carers in respective localities:

‘Inform multidisciplinary team members of the availability of services so they can be more efficiently signposted to ensure uptake from family post-bereavement.’ R20

Additionally, one respondent suggested that *‘a one page sheet with tick boxes for predictive factor’* (R19) would be beneficial.

As it is not currently possible to diagnose PGD until a minimum of six months post-bereavement we were keen to know the duration of any post-bereavement support

made available to MND family carers. Many respondents (41%, n=23) were unaware of how long support was provided following a death and only 9% (n=5) reported it lasting more than six months. As one respondent noted:

‘I have little or no knowledge of what is offered post death.’ R21

Discussion

The provision of bereavement support for carers should be seen as an essential component of palliative care (Sepúlveda et al, 2002). Recent reports underline the increased attention being focussed upon addressing issues around bereavement support in the UK, including notions of how intense and long-lasting grief can best be assessed and treated (PeolcPSP, 2015); this is further emphasised in work conducted not only in wider Europe (Schut and Stroebe, 2005) but globally (Aranda and Milne, 2000; Shear et al, 2011; He et al, 2014). This study sought to examine such matters to provide a picture of current viewpoints and experiences, regarding bereavement support, of professionals in England involved in the care of people with MND.

Results mirror those in other studies in suggesting that health and social care professionals hold mixed views on available bereavement support (Office for National Statistics, 2012). Large numbers view both pre and post-bereavement support as below average though some (albeit a smaller proportion) did believe it to be good; this is again comparable with findings from other studies (Macmillan Cancer Support, 2012).

Our respondents generally reported being unfamiliar with the extent of bereavement services available, which resonates with previous research indicating deficiencies in professionals’ knowledge of the organisation of services, including counselling and

emotional support, for people affected by MND (Brown et al, 2005). There is clearly variability in the type and amount of support required, with carer needs being dependent on individual circumstances. Services for people affected by MND are often disjointed and vary considerably both in the UK and internationally (Down et al, 2005; Aoun et al, 2012; Franklin, 2014) – an inconsistency that potentially fosters widely differing carer experiences. This reinforces the view that a range of support services should be provided from which MND carers can draw upon (O'Brien et al, 2012), with greater attention focused on developing clear and targeted bereavement support (Aoun et al, 2012).

It is known that patients with MND and their carers, are more receptive to a palliative approach to care than those affected by the vast majority of other neurological conditions (Kristjanson et al, 2006). However, the findings from this study again reflect other studies in reporting difficulties in accessing palliative care services (O'Brien et al, 2012) and limited and/or inconsistent palliative care involvement in end stage MND (Kristjanson et al, 2006). Our data suggest where patients are in receipt of specialist palliative care that bereavement support for carers is more likely to be offered. Nevertheless, more than half of those expected to die will not receive specialist palliative care and consequently their carers are unlikely to be offered timely bereavement support (Hudson and Payne, 2011).

The literature points to a general PGD prevalence of between 10-20% (Prigerson and Jacobs, 2001); a suggestion of a higher incidence (37.5%) amongst MND family carers (Aoun et al, 2012) is supported by our data indicating that carers of plwMND may indeed be at greater risk of developing PGD than the general population. It is all the more concerning, then, that an overwhelming majority of our respondents felt unable to accurately predict future cases of PGD.

Those people likely to experience more severe and lasting consequences of bereavement need to be identified so that support can be targeted towards them (Stroebe et al, 2006) but our findings suggest that health and social care professionals require assistance in determining who may be at risk (Kristjanson et al., 2006). To date, many of the tools for measuring PGD have been used for the purposes of diagnosis only, assessing whether people meet the criteria for PGD, or specific adverse health outcomes, at a given point in time, usually six months following the death of the cared for person. When such criteria are met, it is recommended that a more formal assessment is then sought for the bereaved individual. It is perhaps surprising, however, that little attention has been directed towards pre-death examination of complications with grief amongst carers (Tomarken et al, 2008).

Having the capacity to accurately anticipate those most likely to experience PGD would clearly be of great value. The importance of health and social care professionals having access to reliable and valid instruments is imperative if accurate assessment of the needs of family carers is to occur (Hudson et al, 2010). Our data indicates a need for a quick and easy-to-use alert tool to help professionals identify those potentially at risk of PGD.

The effective use of an alert tool would enable the identification of those most likely to benefit from any available support and the signposting of individuals to the most appropriate intervention. Thus assessing for risk of PGD prior to bereavement might allow professionals to protect bereaved individuals from any future impairment (Guldin et al, 2011). Furthermore, the identification of individuals at risk of developing PGD could be helpful, in combination with a formal clinical assessment, when allocating resources and provision of targeted support to the bereaved (Guldin

et al, 2011; Guldin et al, 2012). As such, the potential utilisation of such a tool is the focus of current work by the authors.

Nonetheless, the findings presented here must be considered in light of several limitations, the first of which is linked to the sampling strategy which, due to constraints within the regulatory system, required to obtain NHS permissions at the time, meant that some recruitment was via gatekeepers; it is not known whether the survey link was distributed as fully as hoped. Secondly, as survey responses were anonymised we were not able to analyse responses according to geographical location. It is possible, however, that views of services differed according to place of employment, reflecting variability in available bereavement services nationwide; this would be interesting to target in future research studies. Future studies might also consider a more in-depth exploration of the services as experienced by current and former carers including reasons for not accessing available services.

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Conflicts of interests

The authors have no conflict of interest to declare.

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KEY POINTS

- The complex nature of MND and rapid deterioration at end-of-life can be traumatic for family carers who liken their experiences as akin to a series of bereavements. Generally, between 10-20% of bereaved people will develop Prolonged Grief Disorder, but one study estimated the prevalence amongst MND family carers to be 37.5%. It is important to assess and meet this population's needs in bereavement, but routine assessment of these carers does not take place in practice.
- The incidence of PGD amongst MND family carers appears to be at higher level than in the general population. Health/social care professionals working with people with MND are uncertain of the most appropriate course of action to pursue to support carers in their bereavement and struggle to accurately predict MND family carers at risk of developing PGD.
- The study highlights the importance of identifying MND family carers at risk of developing PGD so that targeted support can be initiated in a timely manner. There is a need for a simple to use alert tool to help health/social care professionals to detect MND family carers at risk of developing PGD.