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Exploring the impact on young people who are caring and grieving for a parent with motor neurone disease

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Abstract

Background: Motor Neurone Disease (MND) is a terminal neurological disease. Little attention has been paid in the literature to investigating the experiences of children and young people who provide care for a parent with the disease.

Aim: To explore how providing care for a parent with MND impacts upon a young person's life.

Sample: A purposive sample of seven young people who were bereaved or currently providing care for a parent with MND.

Methods: A qualitative methodology with informal semi-structured interviews.

Analysis: Verbatim transcripts were created before carrying out a thematic analysis.

Findings: Five key themes were identified; initial MND diagnosis, changing family roles, implications upon education, implications upon social life and positive outcomes.

Conclusion: Our study suggests that young carers for a parent with MND experience substantial challenges in addition to some positive outcomes.

Keywords: Motor Neurone Disease (MND); Amyotrophic Lateral Sclerosis (ALS); Young Carers; End of Life; Qualitative Methods.

Background

A young carer is defined as "[…] *children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances…* (The Children's Society, 2013, p.6). This distinct population of young people are noted to experience a number of negative consequences from their caring role such as social isolation, depression, anxiety and educational difficulties (Simon and Slatcher, 2011; The Children's Society, 2013; Kavanaugh et al., 2014). As many as 47,000 young carers are thought to be providing care for a family member with a terminal illness at any one time in the UK (Gandy et al., 2012). Yet, there is currently a dearth of research concerning this distinct population of young carers.

Motor Neurone Disease (MND), also known as Amyotrophic Lateral Sclerosis (ALS), Lou Gehrig's disease or Charcot's disease is a rapidly progressive neurodegenerative disease with no known cure. Symptoms vary greatly between individuals, but 50% of those diagnosed will die within three years of symptom onset (Mitchell and Borasio, 2007). MND is aggressive resulting in a loss of physical abilities whilst cognitive facilities often remain intact (O'Brien, 2011). Due to constant disease progression and physical decline, people living with MND will have increasingly challenging caring needs. Assistance will usually be required in a variety of contexts; feeding, toileting, dressing, mobility, communicating and translating, amongst many more daily tasks that will, in time, become impossible for the person to complete. This often requires a shift in household roles from spouse or child, into full-time carer (Aoun et al., 2011).

Research to date has tended to investigate the experiences of the patient or the spousal caregiver. Some of this literature has suggested that providing care for a person with MND can create significant psychological distress (Aoun et al, 2011) and have a detrimental impact upon a caregiver's quality-of-life and wellbeing (Kristjanson et al., 2006) which worsens over time (Gauthier et al., 2007).

Consequently, a diagnosis of MND is often considered a 'family disease' as a substantial impact is felt by all members of a family affected by the condition (Gauthier et al., 2007). However, little research has focussed on the unique experiences and needs of children and young people who are affected when a parent is diagnosed with the disease (Quinn, 2010). To date, only one study (Calvo et al. 2015) has researched young carers of a parent with MND focussing on the psychological impact. Calvo et al. (2015) carried out a variety of assessments on 23 children who had a parent with a confirmed diagnosis of MND. The children's responses were compared to a control group of children who had healthy parents. The findings suggested that children who have a parent with MND displayed significant internalising of problems along with symptoms of anxiety and depression. A key limitation of this study is the adoption of a quantitative methodology in using self-administered questionnaires to collect the data which clearly lacks depth and potential explanation from the children.

We therefore suggest that a qualitative exploration of the experiences of children and young people who provide care to a parent who has MND is missing from the literature.

Method

Participants

The participants self-selected through response to an advert in the quarterly MND Association member's magazine 'Thumbprint'. The main inclusion criterion was that the young person was in fulltime education when their parent was living with a confirmed diagnosis of MND.

Ethical Considerations

As the research was conducted by the first author as part of an educational qualification, ethical approval was granted by the relevant University research ethics committee. Due to the sensitive nature of the research, it was necessary to ensure participants were provided with emotional support if required. Consequently all participants were informed of the MND Association Connect helpline which could be contacted if required. Each participant received a brief information sheet with details of the study which also outlined the voluntary and confidential nature of their participation. Formal consent was verbally obtained and audio-recorded before the interview began.

Data Collection

Semi-structured interviews were carried out between December 2011 and January 2012 lasting between 20-60 minutes. An interview schedule was generated from existing young carers' literature. Seven participants were recruited and six interviews were carried out with two sisters wishing to be interviewed together. All participants had been affected by paternal MND. Two interviews occurred face-to-face in the participants' home whilst the remaining four occurred via Skype, due to participants living in widespread geographical locations in England. Educational experiences reflected multiple tiers of education with participant details being summarised in *Table 1.*

Analysis

Computer assisted qualitative data analysis software was considered, however, given the small sample size and the desire to remain close to the data which is not always possible with computer assisted analysis, a manual approach was adopted (St John and Johnson, 2004). All interviews were audio-recorded and transcribed verbatim. This aided with familiarisation and immersion of data before undertaking 6-stage thematic analysis as advocated by Braun and Clarke (2006). Following familiarisation with the data, initial codes regarding any poignant or key features were made. These codes were then collated to provide an outline of overarching themes before reviewing the relevance of these themes across the dataset. Finally, these themes were defined and refined in order to better represent the underlying essence of the theme before writing up the final report. Each stage of analysis was manually recorded to provide an audit trail which was checked with an external researcher to promote rigour. In adherence with ethical research practices, all identifiable information has been removed from the supporting quotations and a pseudonym has been allocated by the researcher to promote confidentiality. Five key themes emerged from the data, '*being diagnosed with MND', 'changing family roles', 'the implications upon education', 'the implications upon social life'* and '*positive outcomes'*.

Pseudonym	**Gender**	**Age at interview**	**Status at interview**	**Age when diagnosis occurred**	**Educational tier whilst caring**	**Siblings**	**Location**

Table 1. Participant demographic information

Barney	Male	31	Bereaved	18	Further Education	1 older brother, 2 younger brothers	South West
Lily	Female	29	Bereaved	17	Sixth Form/University	1 younger brother	South
Loretta	Female	21	Caring	11	Secondary School/Sixth Form/University	1 younger brother, 4 older sisters	South
Nora	Female	21	Bereaved	11	Secondary School	1 older brother	South
Robin	Female	21	Bereaved	9	Primary/Secondary School	1 younger sister	South
Stella	Female	20	Bereaved	8	Primary/Secondary School	1 older sister	South
Ted	Male	20	Caring	18	University	1 older brother, 1 older sister	North West

Results

Being diagnosed with MND

A common finding amongst those interviewed was a sense of confusion and a lack of understanding as to an MND diagnosis actually meant. In many cases the young people were unaware that the diagnosis was terminal and that their parent would deteriorate over time.

> *It was a bit vague. We knew that something was wrong and they told us about it very briefly but we didn't know that there was, um, that it*

> *was life limiting or anything like that at first. And we didn't really know anything about it until he died.*
>
> *Robin*

Participants mentioned how parents withheld information in an attempt to "*shelter and protect*" *(Lily)* the young people from the disease progression until symptom progression meant it could no longer be hidden.

> *I think I was 9 when he first got diagnosed, but he didn't tell us until I was 11. He sort of kept it from us. He only sort of told us when he needed um, like a walking stick, and before that, we didn't really know anything.*
>
> *Loretta*

Changing family roles

The young people indicated that their caring role was very important to themselves and that it developed gradually alongside the deterioration of their parent.

> *….it was very gradual and it didn't really, it just seemed a very natural process and that was the way it was and why would we think any differently?*
>
> *Robin*

It was clear that the care requirements for a person with MND were complex, but the participants explained that they also provided a form of socialisation for their parent.

> *He'd just sit there and listen all day just to what I've been doing, even if it was just a 'standard day'*
>
> *Ted*

The young people would also frequently undertake more household tasks to alleviate the cumulative burden and support their healthy parent whilst they cared.

> *…just washing up and stuff like, she'd [Mum] usually do after meals, just to give her a break 'cos she's up super early just to dress my Dad […] I do a little bit like, all that, just to help out.*
>
> *Ted*

Participants who had younger siblings adopted a parental role for their brothers and sisters as the disease progressed and increasing care needs put more of a demand on the healthy parent.

> *It was more school runs, you know, speaking to teachers, just basic, probably would be deemed as parental activities with my younger brothers.*
>
> *Barney*

One participant discussed how she would actively ensure her younger brother had limited caring responsibilities in an attempt to shelter him.

> *When my brother was little, I didn't want him doing anything... because he's younger you know? I think it's the protective, older sister role really.*
>
> *Loretta*

The implications upon education

All participants discussed that education provided a sense of escapism from their caring duties and responsibilities. This finding was applicable to all educational stages from those who were at primary school, to those who were at University during their parent's illness. It was described as a time to be normal with their peers.

> *It was quite nice that you could just, sort of, pretend to be a sort of 'normal' 11 year old girl, you know.*
>
> *Nora*

It was also clear that the young people had the opportunity to spend more one-to-one time with their ill parent as the disease progressed and employment had stopped. Often the ill parent would support learning and help with homework when the young person returned home after school.

> *I can remember that the day he died [Dad], my friend came over and I had my SATS […] she came round and gave me all this work to do over the holidays, and I thought 'well I can't possibly do that 'cos there's nobody to help me with it now!'*
>
> *Stella*

We identified a drive amongst the young carers to achieve educational success both during the time of caring, and after their parent had died.

> *…it made me go "right, I've got to make him proud now…I can't disappoint him", so it sort of pushed me to do better"*
>
> *Robin*

Having a parent with MND was noted to be a crucial reason why many participants chose their course at University and future career.

> *I wouldn't have done medicine if hadn't of been for Dad*
>
> *Nora*

Interestingly, only one participant explained that formal support was offered by their educational organisation in the form of counselling. More commonly, the young people indicated that their institutes had a lack of awareness and understanding of the effects of being a long-term young carer, and the potential implications this would have on their education.

The implications upon social life

We noted that friends and peer relationships were important to young carers to provide emotional support, guidance, escapism and offer time to be *'a typical teenager' (Lily).*

It was clear that challenges were faced when it came to balancing their social lives with caring for their parent. Participants spoke about feeling restricted as a result of caring.

> *That [caring] becomes a priority, you say, "well, no, I can't go out because I've, you know, got to do that [caring]" and that's not something you can necessarily walk away from.*
>
> *Lily*

This was also reflected in the accounts of bereaved participants who were still facing certain challenges in social situations.

> *…every time we see family, that [MND] was all that was talked about. Whereas, when I was away, I was like "no, I don't, I'm done talking", there's only so much talking I could do… still now you get it, "oo, that's the daughter of [Dad's name], the dead one"…and I'm like, "my name's [Lily], I'm not just a dead man's daughter!"*
>
> *Lily*

Positive Outcomes

Stronger family relationships, and maternal admiration, was mentioned as a positive result of caring and grieving for a person with MND.

> *Without a doubt, I'm definitely closer to my family, probably than a lot of other families are.*
>
> *Barney*

> *[Regarding his Mother] She's the one that keeps everything together.*
>
> *Ted*

A perceived growth in maturity was identified. This was often when participants compared themselves to their peers and occasionally becoming frustrated by passing comments or actions made by their friends.

> *[…] you have to mature quickly, you know. You kind of miss out on those few years, um, and so, yeah, I suppose I sometimes got a bit annoyed with my friends though, and they'd worry about really trivial things…*
>
> *Nora*

Finally, empathy was highlighted as a positive outcome from caring and grieving a parent with MND. The young people frequently mentioned that they felt more understanding and better able to appreciate other ill people, carers and bereaved individuals.

> *A lot of people say that empathy is one of my biggest qualities and that I am very empathetic towards other people.*
>
> *Loretta*

Discussion

Only one study to date has explicitly investigated the unique experiences of caring for a parent with MND (Calvo et al., 2015). Our research however, is the first qualitative study to investigate the experiences of caring for a parent with MND.

Regarding the initial diagnosis of MND, the participants felt that they lacked an understanding of the disease, and what was likely to happen to their parent. This meant that the deterioration of their parent was confusing. Often this was done purposefully by their parents in an attempt to shelter the young person and reduce fear of the long-term challenges ahead. This sheltering has been noted in previous research investigating the experiences of young people who provide end-of-life care for family members (Gandy et al, 2012). In support of this study (ibid), our findings identified that young people felt isolated and appreciated being given accurate and honest information regarding their parent's prognosis. This is an area in need of future research and should be considered by practitioners to ensure that young carers are provided with appropriate information regarding their parent's terminal diagnosis. Resources are increasingly available with organisations such as the MND Association providing downloadable workbooks and leaflets on their website to support parents when informing their children about the condition.

All of the participants had increased responsibility with domestic tasks indicating a change in family roles. A crucial aspect for participants who had younger siblings was the adoption of a parental role. This included responsibility for school runs, advising their siblings and taking them away from the home to provide respite. This finding has previously been documented in young carer's literature with adolescents adopting a parental-type role in their family to alleviate the burden for their healthy parent (Pakenham et al., 2007; Williams et al., 2009).

Our research noted that the young people tended to provide care for their parent through socialisation. This would include discussing their school day with their parent, watching television or completing homework together. These caring duties were considered mutually beneficial with the parent gaining escapism hearing about their child's day, the child having assistance with homework, and both parent and child nurturing their relationship. Furthermore, three participants indicated that having their parent's support and guidance with school work, when they returned home, actually aided their education in comparison to the support they received prior to the diagnosis of MND. Participants also discussed that the illness fuelled their education and instilled a motivation to achieve academic success. This is a unique finding to our study and somewhat conflicting with existing literature which predominantly indicates that education and schooling is adversely affected for young carers (Barnardo’s, 2006; The Children’s Society, 2013). Consistent with existing research is our finding of education providing escapism from caring duties and responsibilities at home (Lackey and Gates, 2001; Martin, 2006).

Participants emphasised a substantial lack of understanding and support from the educational settings they attended in addition to insensitivity regarding educational content or deadlines. The support offered by educational settings for young carers and bereaved young people is an area for future research and a vital consideration for practitioners.

The impact of caring was also felt in the young persons’ social life. Participants identified their friends as providing valuable respite from responsibilities at home and offered a time to be a ‘normal’ teenager. Yet feelings of guilt were commonly felt when with peers. Often this was associated with concern for their ill parent’s health and wellbeing which would consequently result in the young person refusing to attend social activities with their friends. This finding has been documented in previous young carer’s literature (O’Dell et al., 2010; Kavanaugh, 2014). Yet a somewhat unique finding from our research identified that occasionally young carers’ social lives actually increased. We noted that some young carers were introduced to new hobbies and activities by their peers which created additional forms of escapism. The adoption of such passions has previously been identified as being important to maintain wellbeing for young carers (Brewer and Sparkes, 2011).

Overall, the participants noted that closer family relations were a positive outcome from caring for a parent with MND. The young people remarked on having an appreciation and admiration of both their parents, whether healthy, ill or deceased. This is in accordance with previous research which suggests that families affected by MND show high levels of cohesion (Tramonti et al., 2014).

Participants also discussed a sense of increased maturity when compared to their peers. Occasionally this would surface after friends made passing-comments regarding their own parents. We also identified that individuals feel better equipped than their peers in rationalising everyday concerns as an outcome of their self-reported maturity, a common finding in young carer's literature (Heyman and Heyman, 2013). More specifically, one participant felt better able, than her peers, to cope with not meeting educational targets, by simply acknowledging *'there are more important things in life to worry about' (Nora).*

Lastly, our findings are in line with published research suggesting that young carers and bereaved individuals feel better able to empathise with people and perceive this to be a positive outcome of caring (Becker and Becker, 2008). Empathy was a skill that the participants highly valued, yet something that seemed to naturally develop and be of significant benefit to them. Such perceived benefits of being a young carer are infrequently mentioned in the literature but have been noted in previously (Lackey and Gates, 2001; Aldridge and Becker, 2003; Fruhauf et al., 2006).

Our study presents a preliminary understanding of how caring and grieving a parent with MND can impact upon a young person, but its findings should be viewed in light of some limitations. Importantly, the sample was not representative of all young carers with a parent with MND and only investigated the experiences of caring for a father with the disease. Consideration should also be directed towards the retrospective nature of the interviews with some participants recalling memories and experiences that occurred over 10 years previously. Our findings are therefore tentative and replication with a larger, more representative sample would be required before the conclusions can be applied with confidence.

Despite this, we conclude that caring for a parent with MND can have a broad and significant impact on a young person's life. To our knowledge, this study is the first qualitative exploration of young carers of a parent with MND which suggests that amongst various challenges, they may experience some positive outcomes from caring and grieving.

Key Findings

1. Young people were often confused and lacked an understanding of what MND was when their parent was diagnosed.
2. The young carers tended to provide socialisation for their parent as part of their caring role.
3. Education was positively affected by having a parent with MND.
4. Young carers faced challenges in balancing their social life with caring for their parent.
5. The participants felt they gained positive outcomes such as empathy, maturity and closer family relationships.

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