“I hate being a burden”: The patient perspective on carer burden in amyotrophic lateral sclerosis

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Abstract

Background

Research has shown that family caregivers of ALS patients encounter carer burden. Studies that have investigated the impact of caring on family in ALS have reported predominantly from the family caregiver perspective.

Methods

We undertook in-depth qualitative interviews with a diverse group of ALS patients (n=34) sampled from the Irish ALS population-based register and explored their experiences of receiving care from family members and from formal service providers. Interviews were audio recorded and transcribed and data was coded to identify psycho-social processes.

Findings

Patients perceived their care as a burden on family and had concerns about the adverse effects that caring had on family caregivers. However, participants also resisted being a burden on family and they provided emotional support to their family. Participants felt a strong sense of obligation towards family and their concern about family members shaped their expressed preferences for care. We identified that the caring process between ALS patients and their family is often bi-directional, leading in some cases to the *patient* experiencing carer burden.

Conclusions

Greater attention in ALS research and practice to patients' supportive roles in family is required to counterbalance the already strong focus on family caregiver burden.

Key words: caregiver burden, patient perspective, care giving, family care

Introduction

‘Carer burden’ or ‘caregiver burden’ has been defined as the stress and strain that caregivers experience because of the problems they encounter and the challenges they face caring for another (1). Caring for a family member can have a significant physical, social, emotional, and financial impact on those who care (1,2). Family carers in ALS encounter caregiver burden (3,4) and caregiver burden can have an adverse effect on their wellbeing (5). Caregiver burden in ALS increases with disease duration (6) and is higher among those who care for patients who have behavioural impairment (7).

ALS patients’ families can have a central role in making decisions about patient care (8,9). Indeed, best practice guidelines in ALS care emphasise the inclusion of family/significant others in patients’ care (10) and are a structural feature that incorporates families closely into the decision-making process. Expectation of reliance on family care in many welfare states enhances the centrality of family dynamics in ALS care. In many countries/systems, people with ALS become highly dependent on their family because formal services cover only a fraction of their care needs. However, ALS patients and their carers can also differ in their preferences for care (11) and in some cases families might not necessarily be attuned to ALS patients’ preferences for family involvement in their care (12).

Disparities in perceptions of distress and burden can exist between ALS patients and their carers; patients have rated carers as more burdened than carers rated themselves (13). People with ALS have also indicated that they are a burden on their informal caregivers (14). However, research on ‘carer burden’ in ALS has reported

predominantly from the family caregiver perspective (3). We knew little about how ALS patients themselves perceived ‘carer burden’ and its impact on decision making in care. Here, we report on the patient experience of receiving care from family members, and on how the caring process is often bi-directional, leading in some cases to the patient experiencing carer burden.

Methods

We undertook a qualitative study to identify key contextual factors that shape how ALS patients experience and make decisions about care, from their perspective. Methods and procedures have been described in detail elsewhere (15-17).

Briefly, we sampled 34 people from the Irish ALS population-based register (Table 1) to identify key processes that underpin their experiences and decision making in care. Consistent with our qualitative methods (18), we sampled for variation in participants’ life situations (e.g. family status, age of children) and healthcare experiences. Our overall aim had been to develop substantive theory to explain how ALS patients engage with healthcare services. We captured participants’ experiences as openly as possible and we encouraged participants to communicate at length about experiences that were salient to them (17). All but two of the participants were interviewed in their home. Duration of interviews ranged between 40 minutes and 2 hours 10 minutes and the average duration was 1 hour 20 minutes. All interviews were audio-recorded and transcribed.

Data was coded to identify psycho-social processes (18) that explain how participants engage with healthcare services and family care. Key contexts that shaped

participants' experiences and decision making in their care emerged from our analysis of the data (17). Here, we report on the primary context (i.e. family) that emerged from the data. We analyse the patient perspective on 'carer burden' in ALS and how it impacts on their decision making in relation to care.

Description of participants

The majority of participants ($n = 27$) lived with family. The primary caregiver was in most cases the spouse/partner. At the time of interview, most participants ($n = 30$) had received assistance from family for activities of daily living, to varying degrees. This included participants who lived alone and those who had lived at home before they moved to care facilities. Twenty-six participants were parents, of whom 17 were also grandparents. Four participants were widowed, each of whom had adult children. Those who had never married and/or who were not in a relationship ($n = 6$), either lived alone, in a care facility or with a sibling. Table 2 outlines participants' family status, their living arrangements and their primary family caregiver(s). All participant names in the findings that follow are pseudonyms.

Ethics

Ethical approval to conduct this study was obtained from Beaumont Hospital Ethics (Medical Research) Committee, Dublin, Ireland (REC ref. no. 10/59) and from the Research Ethics Committee at the School of Social Work and Social Policy, Trinity College Dublin, Ireland (REC ref. no. 298).

Findings

Becoming dependent on family and feeling a burden on family

Although the majority of the community-dwelling participants were in receipt of some home care services, they depended on family to supplement the formal care. Some participants acknowledged that living with ALS would be more challenging in the absence of physical and emotional support from family:

I am grateful to my sister [But] I am very conscious of the cut backs [in services]. I have two carers that come in the morning, helping me out of bed and to shower but I depend on my sister ... who helps me get to bed at night before I wait till somebody gets me up the following morning. (Danielle, participant #9)

It's [ALS] going to progress and it's degenerative I'm very, very limited what I'm doing now but I have a wonderful wife and wonderful [family] support around me I could probably see where you could die quickly without it. I'm blessed with the support I have from my wife. I'm blessed. (Tim, participant #16)

Participants were resigned to become dependent on their family and some participants felt that they were a burden on their family. Participants perceived that burden of care experienced by family caregivers had physical *and* psychological dimensions, and they were sensitive to the emotional strain encountered by their caregivers. Cara (participant #32) felt that ALS took a heavier toll on her husband than on her i.e. that the carer's burden was higher than her own burden of disease:

Obviously he [spouse] would worry, probably more than I would. I always think it's the other person who has to put up with an ill person, goes through more I feel that he's going through so much more than I am.

Nonetheless, having family who were willing to provide physical and emotional care reassured participants. All participants were cognisant of the terminal nature of ALS and many had thought about the final stages of ALS and what that might entail. Participants themselves relied on family to reassure them about their future care. Edward (participant #14) who was in the latter stages of ALS disclosed:

I accept that we must all die. I have to accept what is coming I prefer to be at home and to have someone near me at night, my family, [spouse], my son and daughters I don't want to be alone.

Indeed, most participants were keen to involve family in decision making about care and some relied heavily on family caregivers to obtain services for them. The debilitating effects of the disease rendered some participants less able to co-ordinate their care and in these cases, family caregivers liaised with services and co-ordinated participants' care. Cathal (participant #28) explained:

If I've a problem, myself and [sister] will sit down and we'll decide what's best I'm not able to make decisions properly now at all. [Swears] I can't remember what happened yesterday you know.

In some cases, we found that participants felt they had no choice but to rely on family to supplement their care even though they thought that this imposed a burden on family. In the Republic of Ireland, home care services provided by the public healthcare sector are very limited and the private health insurance coverage for home care services is minimal. Mary (participant #18) explained that she had become dependent (reluctantly) on her sister because she could not obtain sufficient levels of formal homecare services:

She [sister] is doing a lot of things for me She said she'll end up now in a [nursing] home [need care herself] because she's so worried about me [So] I'd prefer for somebody [home care services] that would come, someone else to help me and just do things I can't do [but] I don't think they [home care providers] can come in and live with me.

Participants also struggled with the notion of becoming a burden on their family and in some cases, resisted assistance from family. Sally's (participant #20) preference was to limit burden on her spouse and she hoped that she would "slip away quickly" before she would become completely dependent on him:

I just hope that I can keep going, keep going as long as I can without being a big problem to people ... a burden I suppose My husband there, he is great like, he does everything but I feel in myself I hate being a burden on him So I'd love just to slip away [die] quickly I'd hate to become too dependent.

Overall, participants were grateful to their family for support but they also felt a burden on their family. Due to the paucity of State-funded formal supports in Ireland (and the very high cost of privately-purchased home care), some participants had no choice but to rely heavily on family to provide care despite having concerns about being a burden on their family.

Supporting family and feeling obligated to family

Notwithstanding participants' accounts of the practical and emotional support they received from family caregivers, we found that participants were also rendering support to their family. Indeed, in some cases, participants had been primary providers of emotional support to family. Helen (participant #12) and Pascal (participant #23) described how they provided support to their family in an attempt to alleviate distress encountered by their family:

My husband died [of cancer] a year after I was diagnosed He was on the chemo[therapy] and he said to me "I can't put a comprehensive thought together." So his mind was obviously swirling with his condition and my condition [But] there could be no real talk about me because [I was] just hoping that he would keep well. (Helen)

When I got out into the car park [following diagnosis] and my wife was in floods of tears and that you kind of get this, I don't know, feeling of determination and resolution. As I say you got to be strong. Not so much for yourself but for the people and family around you. (Pascal)

Some participants' anxieties about end-of-life care were heightened by concerns about the impact of end-of-life care on their families. Indeed, a number of participants felt obliged to "live on" for the sake of family *and* worried about the effects the latter stages of ALS would have on their family. Such anxieties were most evident among participants who were parents of young and adolescent children. Terry's (participant #11) preference was to die before the final stages of ALS and avoid palliative interventions. However, he also felt obliged to stay alive for the sake of his children:

My biggest problem really is you know these here [pointing to photographs of children] The impact it's [end-of-life care] going to have on them ... them being so young If I had a choice when this thing [ALS] would go so far I think it'd be great to say right, let's have a little party, I'll pop a little pill [reference to euthanasia] at the end of the party and say goodbye.... [But] you stay there [stay alive] for them [children], simple as that.

We found that participants accepted and declined services at the request of their family even when they differed from family caregivers in their preferences for care. Participants' attention to the wellbeing of their caregivers meant that many felt obliged to go along with what their caregivers deemed appropriate. Samantha (participant #22) recalled how in an effort to help her spouse adjust to his loss on his terms, she agreed to delaying home care services even though she felt she needed them:

I thought how the hell are we going to manage because I knew I'd need more and more help? The palliative care nurse obviously looking at the carer's

needs had been pushing it [home help] and [spouse] said “No” to her Because we had always done it [household chores] together you see It’s [living with ALS] hard on him, we never imagined this, it would ever happen to us and it is hard for him.

Indeed, many participants felt obliged to engage with symptomatic and/or life-sustaining interventions because they recognised that family caregivers were frightened about the prognosis in ALS without such interventions. Andrew (participant #6) who had respiratory onset ALS explained one of the main reasons why he wanted to use non-invasive ventilation:

I know the consequence of it [ALS] and I can handle the news [prognosis] alright but I don't know whether [spouse] can. [Spouse] can get very excited [distressed] So if you can get a few years longer out of it [non-invasive ventilation], that’s what I’d say, that you’d like that.

Nonetheless, participants indicated that dependence on family had the potential to create conflict between them and their family when they differed in their preferences for care. Indeed, reliance on family to agree on care sometimes exacerbated pre-existing conflict. Conflict between participants and their caregivers was also a burden felt by participants. David (participant #30) spoke about how conflict between him and his spouse constrained him in the decisions he wished to make about his care:

My wife doesn’t seem to have any sympathy for me, empathy I’m thinking if we had [build] a [accessible] bedroom ... I’ll have my own little bit of

independence That's trouble now at the minute ... The decision will have to be made this week but I have a problem with my wife. The relationship isn't great and it's [relationship] been a problem for years and years and now it's coming to a head over this [swears] thing [making home accessible].

In addition to participants' concern for their children, we found that older participants also had anxieties about the wellbeing of their grandchildren. In some cases, participants strove to limit their dependence on their adult children who they perceived had foremost responsibility to their own children. Some participants also felt that they had a sense of duty towards their grandchildren who relied on them. Maureen (participant #34) who had already encountered respiratory problems described how she provided support to her grandchild:

I have a grandson living with me [because] his mother has a drug addiction He [grandson] is starting secondary school and he has a bit of an emotional problem – anger So I bring him to anger management classes.

Overall, participants shared a strong sense of duty towards their family and they provided psychological and emotional support to their family. Participants' sense of obligation to family meant that they made decisions about care in accordance with their understanding of best interests of family.

Discussion

Participants' perception of being a burden on family, in our study, is shared by patients with other terminal illnesses (19-21) and is consistent with a previous study

on carer burden in ALS (14). Reliance on family for care has also been reported by patients with other neurodegenerative conditions including multiple sclerosis, Parkinson's disease, and Huntington's disease (22). However, we also found that people with ALS are reassured by family care and support even when they feel a burden on family. We know that in many countries/systems, people with ALS consider health and social care services inadequate to meet their needs (23). In our study, participants had concerns about the Irish healthcare system's ability to deliver sufficient levels of home-based services to them. In the Republic of Ireland, access to community-based health and social care services is means-tested. In addition, home care services are fragmented and poorly regulated (24). In some cases/care systems, ALS patients may have no choice but to rely on family to provide care regardless of their (patients') preference for family involvement in care.

We discovered that people with ALS also resist being and/or becoming a burden on family caregivers and strive where possible to limit the strain that living with ALS imposes on their family. Research has already shown that terminally-ill patients are often more concerned about the problems encountered by their family caregivers than by the challenges they face themselves (25). In our study, we found that participants were very much attuned to the losses and limitations encountered by their caregivers. Importantly, we identified that in some cases, ALS patients agree to family caregivers' preferences for care in order to help family caregivers adjust to loss. To our knowledge, this has not previously been reported in the ALS field.

Our study sheds light on how patients' perceived responsibilities towards family impact on how patients make decisions about care. Similar to reports from

people with other life-limiting illnesses (26,27), we found that ALS patients accepted symptomatic and/or life-sustaining interventions out of a sense of obligation to family. In our study, participants had already endured profound loss (28) and had anxieties about the prospect of future suffering (15). However, they also felt obliged to “be there” for family and engaged with healthcare services for the sake of family. Moreover, some participants felt burdened by having to negotiate care preferences with family when they had conflict with family.

The findings of our study reveal that informal flows of family support in ALS are bi-directional: ALS patients receive support from family caregivers *and* give support to family. People with ALS also have care-giving roles within family. Studies of family support in life-limiting illness have traditionally neglected the reciprocal nature of care-giving in families (29). Our findings resonate with those from other studies on family care-giving in life-limiting illness (e.g. HIV, multiple sclerosis) (30,31) where patients receive support from *and* provide support to family. Indeed, our study highlights the intergenerational dimension of family care-giving in ALS. Research has already reported that people with ALS have a desire to live on in order to see their children and grandchildren grow up (32). We have identified that people with ALS maintain a strong sense of obligation towards and worry about the wellbeing of their children and grandchildren.

Limitations

Our study is qualitative in design and so our findings might not be representative of all ALS populations. Participants’ experiences of care are contextualised within the Irish healthcare system. Well developed homecare services in other healthcare

systems/countries might ease ALS patients' reliance on family. We did not screen participants for cognitive and/or behavioural impairment. We knew in advance of this study (or in some cases suspected in the course of interviewing) that a small minority of the sample had cognitive and/or behavioural impairment (16). Cognitive screening of participants could have provided useful contextual information i.e. another dimension to our understanding of the data had we known 'for sure' that other sample members had cognitive and behavioural impairment.

Conclusion

We have reported, from the ALS patient perspective, on carer burden in ALS. We have revealed that family care-giving in ALS is reciprocal: people with ALS receive care from family but they also give support to family and make decisions about care in the interest of family wellbeing. In most cases, this support is emotional, but further research is required to map out other types of supports, and their scope. 'Components' of carer burden are often closely intertwined and need to be seen relative to the health status of the person experiencing the burden. Physical disabilities arising from ALS ordinarily limit patients' ability to provide physical care to family.

ALS patients can also experience a 'carer burden' because they too experience emotional strain in family care-giving. Moreover, their expressed preferences for care are shaped by the obligation they feel towards family. Our findings point to the need for service providers to support ALS patients when patients themselves provide support to their family. Assisting patients to negotiate family obligation when they make decisions about care is of central importance. We believe that increased attention to the supportive roles that people with ALS enact in family is now required

to counterbalance the already strong focus on caregiver burden in ALS research and practice.

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Table 1. Age, gender, ALS type and disease duration

Age	Male	Female	ALS type
20-39 years	1	1	spinal (n=2)
40-49 years	3	2	spinal (n=5)
50-59 years	2	6	spinal (n=8)
60-69 years	6	6	spinal (n=6), bulbar (n=4), respiratory (n=2)
70-79 years	2	2	spinal (n=2), bulbar (n=2)
≥ 80 years	3	0	spinal (n=3)

Disease duration: range 4 months – 169 months. Average disease duration: 31 months

Table 2. **Participants' family status, (primary) family caregiver(s), and living arrangement**

Participant	Age (years)	Family status	Primary family-caregiver(s)	Living arrangements
P#1	50	Spouse, mother	Spouse	With spouse and children
P#2	68	Widow, mother, grandparent	Son(s)	Living alone
P#3	67	Spouse, father	Spouse	With spouse
P#4	69	Spouse, father, grandparent	Spouse	With spouse
P#5	62	Spouse, father, grandparent	Spouse	With spouse
P#6	64	Spouse, father, grandparent	Spouse	With spouse
P#7	45	Spouse, mother	Spouse	With spouse and children
P#8	52	Single (male, no children)	Sister	Living alone
P#9	45	Single (female, no children)	Sister	With sister and sister's family
P#10	67	Spouse, father, grandparent	Spouse	With spouse
P#11	45	Spouse, father	Spouse	With spouse and children
P#12	56	Widow, mother	Daughter	Living alone
P#13	80	Spouse, father, grandparent	Daughter	With spouse and daughter
P#14	81	Spouse, father, grandparent	Spouse	With spouse
P#15	74	Spouse, father, grandparent	Spouse	With spouse
P#16	47	Spouse, father	Spouse	With spouse and children
P#17	81	Widower, father, grandparent	*	Nursing home
P#18	57	Single (female, no children)	Sister	Living alone
P#19	51	Spouse, mother	Spouse	With spouse and children
P#20	62	Spouse, mother, grandparent	Spouse	With spouse
P#21	39	Single (female, no children)	*	Hospice
P#22	58	Spouse, mother, grandparent	Spouse	With spouse
P#23	41	Spouse (male, no children)	Spouse	With spouse
P#24	67	Spouse, mother, grandparent	Spouse	With spouse
P#25	73	Single (female, no children)	Nephew	Living alone
P#26	61	Spouse, father	Spouse	With spouse and children
P#27	77	Widow, mother, grandparent	Daughter-in-law	With son and daughter-in-law
P#28	37	Single (male, no children)	Sister	With sister and sister's family
P#29	60	Spouse, mother, grandparent	Spouse	With spouse
P#30	51	Spouse, father	Spouse	With spouse and children
P#31	73	Spouse, father, grandparent	Daughter(s)	With spouse
P#32	64	Spouse, mother, grandparent	Spouse	With spouse
P#33	55	Partner (female, no children)	Partner	With partner
P#34	62	Spouse, mother, grandparent	Spouse	With spouse and grandchild

*P#17 and P#21 resided in care facilities