The impact of family on decision-making in ALS care: The patient perspective

Dr. Geraldine Foley, Discipline of Occupational Therapy, School of Medicine, TCD
Prof. Virpi Timonen, School of Social Work & Social Policy, TCD
Prof. Orla Hardiman, Academic Unit of Neurology, School of Medicine, TCD
Background

Family caregivers of people with ALS encounter caregiver burden (Aoun et al. 2013; Chio et al. 2005; Pagnini et al. 2010; Weisser et al. 2015)

Best practice guidelines in ALS care emphasise the importance of including family in care (Andersen et al. 2012)

These practice guidelines are a structural feature that incorporates families closely into the decision-making process

Expectation of reliance on family care in many welfare states also enhances the centrality of family dynamics in ALS care
Background

ALS patients and their carers can differ in their preferences for care (Trail et al. 2003)

In some cases, family members might not necessarily be attuned to ALS patients’ preferences for family involvement in healthcare decision-making (Sharma et al. 2011)

Studies that have investigated the impact of caring on family in ALS care report predominantly from the family caregiver perspective

The role of family in ALS care from the patient perspective?
Objectives

How do ALS patients perceive the role of the family caregiver in ALS care?

What impact do family have on the decisions ALS patients make about their care?
Methods

Inductive qualitative approach – Grounded Theory Method (Corbin & Strauss 2008)

[Overall aim of study had been to identify key contextual factors that shape how ALS patients experience and make decisions about care]

In-depth qualitative interviews with ALS patients ($n=34$) from Irish ALS population-based register
Methods: Data collection & analysis

Theoretical sampling – participants sampled based on emerging concepts in data (Corbin & Strauss 2008)

Sampled for variation in participants’ life situations and healthcare experiences

Interviews (unstructured) comprised open-ended and probing questions - 40mins to 2hrs10mins; average duration: 1hr 20mins. Audio recorded & transcribed

n=32 interviewed at home, n=2 interviewed in care facilities
Methods: Data collection & analysis

Data coded to identify psycho-social processes that explain how participants engage with healthcare services (Foley & Timonen 2015)

Key contexts that shaped participants’ experiences and decision making in their care emerged from our analysis of the data (i.e. family) (Foley & Timonen 2015; Foley et al. 2014)

Participants encouraged to communicate at length about their experiences of care and how they perceived family impacted on their care
Sample

\(n=34\) (17 men, 17 women)

Age range: 37 years – 81 years. Mean age = 60 years

26 spinal onset, 6 bulbar onset, 2 respiratory onset

Average duration disease [symptom onset]: 31 months. Range: 4 months – 13 years)

All but \(n=2\) required assistance for activities of daily living

\(n=29\) used a range of assistive devices

\(n=30\) had received varying degrees of physical assistance from family

\(n=27\) lived with family
Table 1  Sample by age, gender and ALS type

<table>
<thead>
<tr>
<th>Age</th>
<th>Men</th>
<th>Women</th>
<th>ALS type</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-39yrs</td>
<td>1</td>
<td>1</td>
<td>spinal onset (n=2)</td>
</tr>
<tr>
<td>40-49yrs</td>
<td>3</td>
<td>2</td>
<td>spinal onset (n=5)</td>
</tr>
<tr>
<td>50-59yrs</td>
<td>2</td>
<td>6</td>
<td>spinal onset (n=8)</td>
</tr>
<tr>
<td>60-69yrs</td>
<td>6</td>
<td>6</td>
<td>spinal onset (n=6), bulbar onset (n=4), respiratory onset (n=2)</td>
</tr>
<tr>
<td>70-79yrs</td>
<td>2</td>
<td>2</td>
<td>spinal onset (n=2), bulbar onset (n=2)</td>
</tr>
<tr>
<td>80yrs&gt;</td>
<td>3</td>
<td>0</td>
<td>spinal onset (n=3)</td>
</tr>
</tbody>
</table>
## Table 2. Participants’ family status, (primary) family caregiver(s), and living arrangement

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

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

In most cases, participants depended on family to supplement the formal care (public or private care):

*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)

Some participants acknowledged that living with ALS could be more challenging in the absence of support from family:

*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)
Findings

Participants accepted, decided against and/or delayed services in order to alleviate family distress and to help family members cope with their (caregivers’) loss - even when patients differed from family in their preferences for care:

*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 .... I felt I needed to wait for him [spouse] .... 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. (Samantha, participant 22)*
Findings

Reliance on family for assistance had the potential to create conflict between patients and their family when making decisions about care – *most* evident in cases of pre-existing conflict:

*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].* (David, participant 30)
Findings

Participants expressed a desire not to be/become a burden on their family and in most cases, wished to die before they would become totally dependent on family:

*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 .... To think that he would have to do everything for me. That’s very upsetting .... I never like to be a burden on people .... I feel if my diaphragm is going to go, my speech, my hands ... just let me die.*

(Cara, participant 32)
Findings

Nonetheless, most participants still felt obliged to engage with symptomatic and/or life-sustaining interventions so that they could provide support to their family:

*My biggest problem really is you know these here [pointing to photographs of children] .... them being so young .... I just want to get them across the line .... 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.* (Terry, participant 11)
Findings

Participants shared a strong sense of duty towards their family and made decisions about care in the interest of family wellbeing:

*I have a grandson living with me ... [because] his mother has a drug addiction. We have an agreement between her and me that we [participant and spouse] are sort of guardians .... I have a son, he’s an alcoholic and he has a condition called [congenital disorder] .... So I need to be around for as long as I can be for them.* (Maureen, participant 34)
Discussion

Family exert a *central* influence on health and social care preferences of ALS patients

ALS patients’ expressed care preferences are shaped by the obligations they feel towards family

ALS patients perceive informal flows of family support and care as bi-directional – ALS patients also have care-giving roles

Family care-giving in ALS can be reciprocal: people with ALS receive care from family but also seek to reassure their family and make decisions about care in the interest of their family
Discussion

Consistent with other studies on the reciprocal nature of family caregiving in life-limiting illness [e.g. HIV, cancer, renal failure] (Heinemann 2014; Hausser et al. 2006; Uphold et al. 2012)

Terminally-ill patients can accept symptomatic and/or life-sustaining interventions out of a sense of obligation to family (Griva et al. 2013)

Intergenerational dimension of caring within families in ALS
Conclusions

ALS patients can also experience a ‘carer burden’ because they too provide emotional support to family and experience emotional strain in family care-giving.

But ‘components’ of carer burden are often closely intertwined - further research is required to map out other types of supports, and their scope.

Assisting patients to negotiate family obligation when they make decisions about care is important in ALS care.

Attention to the supportive roles that ALS patients enact in family is required to counterbalance the already strong focus on ‘caregiver’ burden in ALS research and practice.
Acknowledgments

All participants of this study

Health Research Board – Grant HPF/2011/1

Trinity College Dublin
References


References


References
