Control and surrender in human services interaction: The relational contexts of living with motor neurone disease

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Introduction

- Drive in healthcare research & management to design ‘care pathways’

- Care pathways conceptualised as ‘ideal’ timing and sequencing of healthcare services

- Typically cast as interventions designed to accommodate criteria-based progression (e.g., specific clinical problem, procedure or episode) (Kinsman et al. 2010)

- Rely overwhelmingly on professionals’ assumptions about care and about the patient experience of care
Introduction

- Service users’ priorities do not necessarily align with managerial concerns about optimal scheduling and resource use (Gubrium, 2016)

- The service user experience contrasts with a simplified & linear notion of disease experience (Sturmberg, 2013)

- What of the service user’s reflexive position in human services interaction (Foley & Timonen, 2016)
Background / context

- MND / ALS / Lou Gehrig’s Disease

- Terminal, multi-system and neurodegenerative disease

- 60% of people die within 1,000 days from symptom onset

- Estimated that the majority of people with MND in developed countries engage with services

- ‘Expert opinion’ – Care should be palliative and multidisciplinary from point of diagnosis (Andersen et al. 2012) where key points in the disease process trigger interventions (Bede et al. 2011)
Background / context

- Terminally-ill patients’ satisfaction with care is shaped by their interactions with service providers (Briggs, 2010)

- But in the case of MND, little was known about how service users ‘interact’ with service providers and what shapes the interaction (Foley et al. 2012)
Aims of study had been to:

- To develop substantive theory about how people with MND engage with healthcare services

- To identify key contextual factors that shape how people with MND engage with healthcare services
Methods

Inductive qualitative approach – Grounded Theory method (Corbin & Strauss 2008; Foley & Timonen 2015)

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

- Purposive sampling at the very beginning
- Followed by theoretical sampling – i.e. participants sampled based on emerging concepts in data
- Sampled for variation in participants’ life situations and healthcare experiences
- Collected and analysed data in tandem – iterative process
- Interviews (unstructured) 40mins to 2hrs10mins; average duration: 1hr 20mins. Audio recorded & transcribed
- Extensive memoing and field notes
- $n=32$ interviewed at home, $n=2$ interviewed in care facilities
Methods: Data collection & analysis

- Data coded to identify psycho-social processes – open, axial & selective coding procedures (Foley & Timonen 2015)

- Key contexts that shaped participants’ experiences of and interactions with services emerged from analysis of the data
### Table 1  Sample by age, gender and MND type. \( n = 34 \)

<table>
<thead>
<tr>
<th>Age</th>
<th>Men</th>
<th>Women</th>
<th>MND 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>

Mean age = 60 years  
Average duration disease [symptom onset]: 31 months. Range: 4 months – 13 years

\( n = 34 \) had engaged with health and social care services, to varying degrees  
\( n = 29 \) used a range of assistive devices
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>
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<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>
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<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</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>
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<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>
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<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>
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<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 partner</td>
</tr>
<tr>
<td>P#33</td>
<td>55</td>
<td>Partner (female, no children)</td>
<td>Partner</td>
<td>With spouse and grandchild</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

Living with MND constituted a life of unremitting loss

Loss of control is central to the experience of loss:

“I feel like I’ve been taken over by a sort of an alien presence and it’s, it’s in my brain and I think it’s like an alien that has nuclear weapons, that it can do all sorts of things to me and I’m combating it with bows and arrows. … So I find myself in a constant battle, day after day because this, this MND alien that has taken over my body and that I have not too much defence against. Normally in, in a war you win some battles; I’m losing all the battles and I know for a fact I’m going to lose the war. The war, the war is lost already because MND is going to take me anyhow, but I’m not winning any battles, because I feel that I don’t have, the arms that I’m provided with in no way, can in any way defeat or even hold back this alien that is taking me over.” (Martin, p#31)
Findings

People with MND exert control in their interactions with service providers to adapt to loss:

“I was in a lot of trouble [difficulty mobilising] until she [community occupational therapist] brought me the wheelchair even though I rejected it at the start ... I hid it in the shed outside for a while ... I just hated the thought of being wheeled in that (crying) but I've no bother now. It’s a process to get to that [point].” (Richard, p#8)
Findings

Complex *mediation* between control and surrender in terms of how people with MND engage with service providers

Exerting control in their interactions with service providers includes the possibility to relinquish control on their own terms:

“I know that near the end I’ll need the hospice ... Sometimes it’d be nice to meet them [hospice] ... even just to say look, this is us, this is what we do ... [but] I mean hopefully I’m a long way off the hospice. ... I’m not inclined to jump the gun and go forward down the road too far. ... I am not going there [planning end-of-life care] fully yet because that is something mentally very hard to deal with. ... Right now I don’t want to see myself like that [dying], imagine myself like that.” (Helen, p#12)
Findings

Being in control of care included the right to accept, decline and/or delay services

The ultimate form of control—the right to decide how to live, and how and when to die:

“When you get to a stage where the only thing you can move is your eyelid you wonder whether you are kind of just existing. I know your brain is alert and you feel, you know you’ve got your sense of touch ...[but] if I got to the stage where I was just existing I would be leaning towards going to Switzerland [for assisted suicide].” (Pascal, p#23)
Findings

Age, life stage, family and parenthood exert central influence over how people with MND approach death and end-of-life care

‘Older age’- resignation and a more acceptable stage of life for having MND:

“I’d love to wake up in the morning with my toes permanently up. ... I don’t mind death but I feel sorry for people that would get it young, you know. God, I would hate to have it younger. ... I’m lucky to reach [eighties] and happy with what I’ve done” (Paul, p#13)
Findings

Interactions with services heavily influenced by obligation to family:

“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.” (Vincent, p#5)

Informal flows of care and support perceived as bidirectional:

“I have a grandson living with me, he is twelve and his mam [mother] has a drug addiction. We have an agreement between her and me that we [Maureen and spouse] are sort of guardians [for the grandson]. ... I have a son, he’s an alcoholic and he has a condition called [congenital disorder]. ... He [pointing to spouse] tells me that he wants to hold onto me. ... So I need to be around for as long as I can for them.” (Maureen, p#24)
Findings

*Struggle* between desire to live on and the desire to die – related to perceived responsibilities as parents (or freedom from such responsibilities):

“[I] just want to get them across the line. . . . I’ve three of them. My eldest is [late teens], my youngest is, he’s nearly [childhood], there’s a bit of rearing on him left to be done. . . . [But] I also know I don’t want them being so young seeing me quite ill . . . so it would be peace of mind for me to think that when this thing goes so far that it’ll be stopped.” (Terry, p#11)

“I thought if I am so bad, obviously if I can’t swallow, I can’t walk, who wants to go on? . . . . So I mean it’s tough but there are a lot of worse things. I don’t have young children. It would be quite different for someone with young children.” (Jennifer, p#25)
Discussion

- Losing control and fighting to remain in control - central to interaction with service providers

- Negotiated loss via engaging with services on their own terms

- MND service users more likely to accept assistance from healthcare services when they perceive assistance to be on their own terms (Foley et al. 2014a)
Discussion

- Participants did not decide on palliative or life-sustaining interventions in the context of their prognosis

- Engaged with services in line with their own life-course trajectories & family relations (Foley et al. 2014b)

- Family roles that people with MND enact shape their response to MND and healthcare providers (Foley et al. 2016)
Conclusions

- So much of what shapes how MND service users engage with services exists outside services

- Interactions with human services are intertwined with other complex interactions (in particular, family relations)

- *Human service relationship* - shaped **not only** by recognisable service needs **but also** by needs that are embedded in the everyday relational context of illness (Foley & Timonen, 2016)
Conclusions

- The MND service user experience is mediated by ‘experiential’ tension between control and surrender (Foley & Timonen 2016; Foley et al. 2014a,c)

- Contrasts with the rationalisation of experience that underpins the idea of pathways

- Care pathways are futile if simply understood and deployed as formulas for service provision that expeditiously ‘manage’ the experiences of users

- Soften the predictive stance inherent in care pathways - recognise the experientially contingent course of terminal illness
References


References


Kinsman, L., Rotter, T., James, E., et al. (2010). What is a clinical pathway? Development of a definition to inform the debate. *BMC Medicine, 8*:31
