

Understanding how people with MND engage with healthcare services

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Background

- Service users have different perspectives on healthcare services compared to service providers
- Care outcomes influenced by service user perspective on illness and healthcare services
- Systematic review (Foley et al. 2012a) – we knew little about key processes that underpin how people with MND engage with services
- What are real life concerns facing people with MND and are they consonant with outcomes that ordinarily measure effectiveness / value of healthcare intervention in MND care (Foley et al. 2012b)?


Aims

- To identify key parameters of healthcare experiences among people with MND from their perspective
- Build substantive theory that explains about how and why people with MND engage with services so to enable comparison between contexts and further development of theory in relevant substantive areas

Objectives

- To identify key variables that shape how people with ALS engage with healthcare services
- To unearth key psycho-social processes which explain how and why people with MND engage with services.


In other words.....



What are the things that *really* matter to pwMND in healthcare?
 Why do they engage with healthcare services?
 What conditions impact on how they engage?
 What shapes how they make decisions about care?


Method: Grounded Theory

.... *What is Grounded Theory?*



- A systematic research approach that builds theory from qualitative data (Corbin & Strauss, 2008; Charmaz, 2006) - primarily inductive
- Concerned with psycho-social processes of behaviour (i.e. how and why people behave in certain ways)
- Conditions / context (micro & macro) which result in action
- Variation of experience - variation in 'action' / behaviour arises from different and similar contexts

GT 'conditional-consequential matrix' in MND care



Adapted from Corbin J, Strauss A (2008). Basics of Qualitative Research (3rd edition)

Data collection



- In-depth qualitative interviews with people with MND (n=34)



- Sampled from Irish MND population-based register [Sept 2011 - Aug 2012 ca 265]
- Purposeful sampling initially to capture variation in participant experience
- Theoretical sampling – participants sampled based on emerging concepts in data i.e. theory building
- Questions open-ended, probing, prompting, verifying
- Interviews between 40mins and 2hrs10; average duration 1hr 20

Data analysis

- Interviews transcribed verbatim
- Sampling and data analysis occur **in tandem**
- Data coded for concepts → categories [subcategories, primary categories]
- Data coded for 'process' (being / doing in different & similar contexts)
- Relationships between categories (variables) build theory
- Data 'co-constructed' by researcher (reflexive & theoretical memos)

Sample

- N=34 (17 men, 17 women)
- Dublin (6), North East (7), West (3), South West (2), Mid-West (3), South East (5), South (5), Midlands (2), North West (1)
- 26 spinal onset, 6 bulbar onset, 2 respiratory onset
- N=2 anarthric N=6 severely dysarthric
- Average duration disease [symptom onset] 31 months. Range (4 months – 13 years)
- Age range 37 years – 81 years
- All but n=2 required assistance for activities of daily living
- N=29 using a range of assistive devices

Some key findings : Loss and exerting control in healthcare to adapt to loss (Foley et al., forthcoming *Social Science & Medicine*)

- **Participants equated living with MND to a life of unremitting and insurmountable loss:**
"I get very emotional when I think about what I have lost ... When I was diagnosed I was walking with a limp but no aids. Within six months I was needing to use a frame because I kept falling over. Within nine months I needed people to walk with me. Within a year I could hardly do two steps... the future is so grim because of all the loss." (Samantha)
- **Physical loss engendered unremitting loss in other domains:**
"What was important to me was always the family, then food, drink, and conversation ... I can't do any of it now ... huge, unbelievable loss." (Morris)
- **Loss of control was central to the experiences of loss:**
"I find myself in a constant battle day after day because [of] this MND alien that has taken over my body and that I have not too much defence against. Normally 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 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 defeat or even hold back this alien that is taking me over." (Martin)

Participants exerted control in healthcare in response to loss of control in their lives

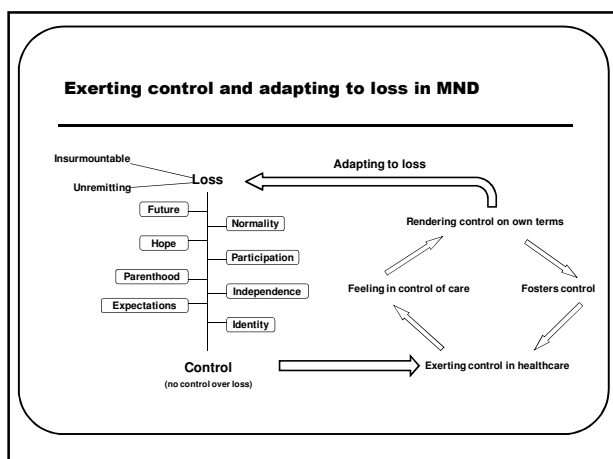
- Expressed a strong desire to follow through with their own preferences for care – acceptance of services more likely if perceived to be on their terms
- Exerted control over **when** to engage with services - needed time to process the life-altering impact of MND before willingly accepting assistance from healthcare services:
"During this summer just gone by I didn't want to be making calls to physio, occupational therapy, district nurse ... I'm processing it, I know it's there and when I'm ready I'll have no problem with it." (Eva)
- Exerting control also included the freedom to relinquish control on their own terms:

"I could probably go on indefinitely and not go back to the [MND] clinic ... I'm going to avoid doing that for as long as I can ... at some point I actually do need to go back ... [but] that is my choice." (Danielle)

Exerting control in care to adapt to loss

- Overall, exerted control in care in order 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)



Some key findings : Impact of life-course

(Foley et al. In press, *Qualitative Health Research*)

- **Age, life stage, family and parenthood** were the primary contexts to how participants responded to MND and engaged with services
- Sought to reassure family and sought reassurance from family:

"I want to be here for as long as I can yeah."
 G: "So then @@Maureen## you might choose them [life-sustaining interventions] to help you stay alive?"
 "Oh yeah but without being too much of a burden on @@Fred## [spouse]."
 G: "So is it nearly a balance then. You want to continue to live on with MND but you also don't want to be a burden on your family. I'm just trying to figure out, I suppose my question is what is the point where you think it becomes too much of a burden?"
 "Well I say this to @@Fred## but at the moment he tells me that he wants to hold onto me! (humour)" (Maureen)

"My biggest fear you know [is] around being totally debilitated. . . . I constantly crave to be, to be told by the people that matter most to me that you won't be left like this for years and years. . . . I suppose I'm talking euthanasia stuff like that." (Terry)

Life-course

- Participants in later life were more accepting of impending death and wished to die soon. Having children "done for" fostered feelings of acceptance:

"It's going to get worse unless now, unless something else takes you in the mean time which would be a god send! . . . I'd love to wake up in the morning with my toes permanently up, that is dead! . . . Wouldn't it be lovely just lying in this chair and I woke up dead you know to see what you are going to go through, I mean I know what I'm going to go through . . . I don't mind death at all but I feel sorry for people that would get it young you know, god I would hate to have it younger. I've my kids raised and everything." (Paul, age 80)

Life-course Context of parenthood at different life-stages

- Participants' decisions about care were shaped by the meaning they attached to parenthood (n=26 parents)
- Majority of young and middle-aged participants struggled between fighting and accepting MND to "be there" for adolescent and adult children **BUT** considered the impact life-sustaining and supportive interventions would have on their adolescent and adult children:

"[I] just want to get them [children] 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, age 45)

Some key findings :

The micro-level vs macro-level of healthcare experiences

(Foley et al. In press, *Palliative Medicine*)

- Participants felt "disconnected" from the HSE. HSE is an "uncertain" place:

"Well I think probably the biggest thing is not knowing what I need and what I'm entitled to . . . to be able to fully understand what you are going to need at what stage because obviously without things like the medical card you can't get anything . . . Even the application process, em having to get the forms, going to get the forms, trying to find information out . . . and you are going I'm still no clearer, you know still no clearer on what I actually need to do." (Pascal)

- Uncertain about the future of healthcare services in Ireland:

"It's [recession] definitely going to affect it [services] and I'm going to need home help and definitely the State is gone. Obviously the country is broke, we're living away as we always did, people are saying fuck the banks, we're not going to pay off the banks, but we have to, like somebody has to pay otherwise we're going to go broke." (David)

Frustrated with inequity in Irish healthcare services – Access to healthcare is a universal right:

"I think, philosophically I think we should have the best public health system. I don't think we should need a private system. I think we should all be public, and I don't mind paying taxes for that, so philosophically I think everybody should be treated equally. When you are sick it doesn't matter." (Danielle)

"We've run every test we could think of and the results show that you're out of money."

'Trust' and 'reassurance' in the midst of uncertainty

- Open to engaging with healthcare professionals who they trusted and who reassured them about their care:

"It's just the way she [consultant neurologist] kind of explained about the motor neurone disease and everything and what'll happen further down the line ... I said "how sure are you" and she said "we're a hundred percent" so at least she was straight up ... I found her very easy to talk to ... after a few minutes you'd kind of open up ... I'd be trusting her." (Cathal)

"I've a very good friend and she happens to be in the hospice, she's actually in her final stages of cancer ... I went to visit her ... and it was a very good experience from my point of view knowing down the line that I will be using this service and it was good for me to experience people who are in a caring role looking after the patients that were there." (Eva)

Some key findings : 'Life sustaining' and 'life ending'

(Foley et al. In press, *Palliative Medicine*)

- Many participants questioned the role of life-sustaining interventions in MND in context of rapid disease progression and imminent death:

"I do wonder a lot, I'm saying why are they [healthcare professionals] keeping me alive for longer, why don't they just let me fade away, you know the end is going to be the same when it comes, so why prolong the suffering?" (Cara)

"I suppose I just feel let me get on with it ... [but] I mean there are days when I don't feel like living ... hopefully there won't be too much future [left] ..."

G: "Do you have any particular feelings about life-sustaining treatment?"

"Dragging it out, Well I don't see the point ... I think people might incorrectly believe that a life-sustaining treatment might lead to a general improvement ... the feeling of having something [like this] dragging on and on. I don't want that." (Melanie, end-stage MND)

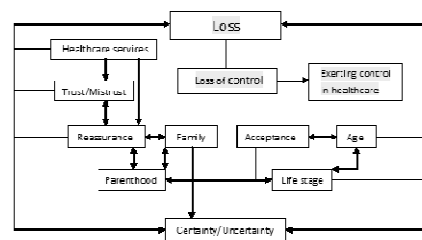
'Life sustaining' and 'life ending'

- Engaging with treatments that had the potential to prolong duration of distress was unacceptable to most
- Most participants suggested that life-sustaining interventions had the potential to prolong "suffering"
- Participants perceived noninvasive ventilation and gastrostomy as life-sustaining interventions:

"I felt I was rushed into it [gastrostomy], I would have liked more time to have thought about it ... when you get to that stage, what's the point ... It's just a life line for the medics to put in food and drugs ... to sustain life beyond what it should be." (Morris)

Coming to terms with loss

Coming to terms with loss



Conclusions: Some key conceptual & theoretical contributions


- Healthcare experiences in MND shaped by how service users construct their family roles and trajectories at different stages of their lives
- Construct later life as a period of resignation and acceptance
- Parenthood is context
- Insurmountable physical loss engenders insurmountable loss in non-physical domains
- Adapt to loss without "regaining" – finding control in healthcare is about adapting to loss – not regaining control over life
- Exerting control in healthcare includes rendering control on own terms
- Adverse to sustaining life in MND for sake of longevity alone
- Construe palliative care as intervention to alleviate suffering but construe palliative interventions (e.g. RIG, NIPPI) as having potential to prolong suffering

Conclusions: Implications for practice



- Disease progression is NOT primary context to how and why people with MND engage with healthcare services
- 'Family care burden' has traditionally focused exclusively on family carers – people with MND also seek to reassure their family
- Losing control and fighting to remain in control – shape the clinical encounter
- Healthcare services – only place where participants found control!
- Positive experiences at the micro-level can alleviate concerns about the healthcare **system**


... Cont'd



- Engage with people when they are ready to engage
- Enable people with MND to be in control of their care
- Offer choices about care
- Be honest and reassure
- Be attune to and respect people's preferences - living on with MND or choosing not to live on – some people with MND prefer to die prior to palliative intervention
- Existential support is important to people with MND

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