Social Science & Medicine 101 (2014) 113–119

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Exerting control and adapting to loss in amyotrophic lateral sclerosis

Geraldine Foley [a,*], Virpi Timonen [a], Orla Hardiman [b,c]

[a] School of Social Work and Social Policy, Room 3063, Arts Building, Trinity College Dublin, Dublin 2, Ireland
[b] Academic Unit of Neurology, Trinity Biomedical Sciences Institute, 152-160 Pearse Street, Trinity College Dublin, Dublin 2, Ireland
[c] Department of Neurology, National Neuroscience Centre, Beaumont Hospital, Dublin 9, Ireland

ARTICLE INFO

Article history:
Available online 18 November 2013

Keywords:
Ireland
Amyotrophic lateral sclerosis
Motor neurone disease
Healthcare experiences
Decision-making
Exerting control
Adapting to loss
End-of-life care

ABSTRACT

People with amyotrophic lateral sclerosis (ALS) engage with a broad range of health care services from symptom onset to end-of-life care. We undertook a grounded theory study to identify processes that underpin how and why people with ALS engage with health care services. Using theoretical sampling procedures, we sampled 34 people from the Irish ALS population-based register during September 2011 to August 2012. We conducted in-depth interviews with participants about their experiences of health care services. Our study yielded new insights into how people with ALS engage with services and adapt to loss. People with ALS live with insurmountable loss and never regain what they have already lost. Loss for people with ALS is multidimensional and includes loss of control. The experience of loss of control prompts people with ALS to search for control over health care services but exerting control in health care services can also include rendering control to service providers. People with ALS negotiate loss by exerting control over and rendering control to health care services. Our findings are important for future research that is attuned to how people with terminal illness exert control in health care services and make decisions about care in the context of mounting loss.

Introduction

Amyotrophic lateral sclerosis (ALS), also known as motor neurone disease or Lou Gehrig's disease, is a systemic and terminal disorder of the central nervous system which causes paralysis of limb, respiratory and bulbar (swallowing and articulation) muscles and in some cases results in frontotemporal dementia (Hardiman, van den Berg, & Kiernan, 2011). The life time risk of developing the condition is 1:400. ALS is hastily progressive and life expectancy from onset of symptoms is on average two to four years. The care approach in ALS is palliative from point of diagnosis. International standards for best practice focus on multidisciplinary management of symptoms and preservation of quality of life (Andersen et al., 2012; Miller et al., 2009a, 2009b).

People with ALS can encounter a broad range of health care professionals as they advance in the disease and make decisions about care that extend from life-sustaining treatments to supportive care (Oliver, Borasio, & Walsh, 2006). Researchers have reported on experiences of health care services in ALS (e.g. Hughes, Sinha, Higginson, Down, & Leigh, 2005) and investigated treatment choices among people with ALS in specific domains of care (e.g. Albert, Murphy, Del Bene, & Rowland, 1999). Multidisciplinary ALS care has achieved positive outcomes in survival (e.g. Traynor, Alexander, Corr, Frost, & Hardiman, 2003) and cost (e.g. Chio, Bottacchi, Buffa, Mutani, & Mora, 2006). However, we identified disparity between positive outcomes in ALS care (as measured by service providers) and service users' generally low satisfaction with services (Foley, Timonen, & Hardiman, 2012). Rodriguez and Young (2006) found that the views of people with terminal illness regarding their care differ from the views of health care professionals. Entwistle, Firnigi, Ryan, Francis, and Kinghorn (2012) have argued that what matters most to the users of health care is grounded in personal experience. We knew little about how people with ALS construe their experiences as they engage with health care services. We therefore set out to understand and explain how and why people with ALS engage with health care services.

In a recent systematic review of qualitative research in ALS, Sakellariou, Boniface, and Brown (2013) called for further exploration of how people with ALS make decisions as they lose control over ALS and attempt to exert control in their lives. Sakellariou et al. (2013) identified that people with ALS feel they do not have any control over the disease but exert control by making choices in life and in health care. Biographical and narrative-based research in ALS (Brown & Addington-Hall, 2008; Locock, Ziebland, & Dumelow,

* Corresponding author. Fax: +353 1 671 2262.
E-mail addresses: foleyg3@tcd.ie, geraldinefoley63@gmail.com (G. Foley), virpi.timonen@tcd.ie (V. Timonen), orla@hardiman.net (O. Hardiman).

0277-9536/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.socscimed.2013.11.003

2009) has revealed that people with ALS encounter change in their biographical trajectories. Brown and Addington-Hall (2008) found instances of 'fracturing' but also of 'preserving', 'sustaining', and 'enduring' in the narratives of people with ALS. Locock et al. (2009) found that life with ALS is characterised by 'disruption' and 'abruption' (life ending) but also by 'repair' and 'continuity' when people seek to regain control and restore normality in their lives.

Loss is a universal concept (Murray, 2001) and is closely associated with the experience of illness (e.g. Edmonds, Vivat, Burman, Silber, & Higginson, 2007). Explanatory models of adjustment to loss in terminal illness have been described (e.g. Knight & Emanuel, 2007) and perceptions of loss (including loss of control) are common among people with terminal illness (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999). The terms 'perceived control' and 'locus of control' in illness are well documented in social psychology and have already been investigated in ALS (e.g. Goldstein, Atkins, & Leigh, 2003; Plahuta et al., 2002). However, there is a dearth of literature in social science fields that illuminate *how* people with ALS perceive control or indeed *why* they feel they lose control.

People with ALS equate dignity in dying with being in control and have a strong desire for self determination in end-of-life care (Cooney, Lewando Hundt, Goodall, & Weaver, 2012). Albert et al. (1999) demonstrated that people with ALS make choices about their care and follow up with choices consistent with their preferences for care. People with ALS also have a strong desire for information (Chio et al., 2008; Wicks & Frost, 2008) and become less reliant on health care professionals in decision-making as they advance in the disease (Sulmasy et al., 2007). O'Brien, Whitehead, Murphy, Mitchell, and Jack (2012) reported that people with ALS delayed use of services in their effort to maintain control and normality in their lives.

Researchers have described how people with life threatening illness seek to re-establish control in response to loss (Anderson & Asnani, 2013) and investigated control preferences in end-of-life care (Volker & Wu, 2011), but our search did not yield any studies that explored the relationship between losing control in illness and exerting control in health care services. The focus of this article is to further our understanding of what loss means to people with ALS and how people with ALS exert control in their care in response to loss. We demonstrate that exerting control in care is an adaptive response to loss in ALS. We discuss our findings in light of how people with life-limiting illness (including ALS) adapt to loss.

Methods

We used grounded theory method (Corbin & Strauss, 2008) for this study. Grounded theory is a systematic research approach which builds concepts and theory from qualitative data. The focus in grounded theory is on basic processes of behaviour (i.e. how and why people behave in certain ways) and our aim was to unearth key processes that underpin how people with ALS engage with services. We also aimed to build substantive theory in order to enable comparisons between contexts and further development of theory in relevant substantive areas.

Participants

Thirty-four people on the Irish ALS population-based register (ca $n = 265$) participated in the study between September 2011 and August 2012. The sample comprised 17 men and 17 women. Age of participants ranged between 37 years and 81 years. All but two participants required assistance for everyday activities. Duration since onset of symptoms among participants ranged between four months and 13 years and the average duration of disease for the sample was 31 months. Nearly a third of the sample ($n = 10$) was deceased when we sampled the 34th participant. The majority of participants ($n = 27$) lived with family. The remaining participants either lived alone or in a care facility. All participants had accessed health care services and eight participants had already engaged with life-sustaining treatments (noninvasive ventilation and/or gastrostomy feeding). All participants were sampled from the national register without any selection by geographical area. This resulted in sampling participants from across the country. Participants varied across socio-economic status. Table 1 provides additional data on the age profile of the sample.

Data collection and analysis

As per grounded theory method, we collected and analysed data in tandem, and compared data with data (otherwise known as constant comparison) in order to generate concepts for further sampling (Corbin & Strauss, 2008). We purposively selected participants during the preliminary stages of sampling to capture diversity of experience (Morse, 2007). We then sampled for concepts in the data as we made theoretical comparisons between data.

Of those who we asked to participate, ten people declined to participate and three people who had agreed to participate were unable to do so due to rapid deterioration in their condition. We provided each individual who expressed interest in participating with a participant information leaflet and gained full informed consent from each participant. Location for the interview was at the discretion of each participant. All participants who lived at home ($n = 32$) chose their residence as the interview setting. The remaining participants were interviewed in a hospice ($n = 1$) and in an extended care facility ($n = 1$).

We conceptualised and theorised from the ground up (Corbin & Strauss, 2008). We opened interviews by asking participants about their experiences of health care services since "MND [ALS] came into their lives" and we integrated questions to explore themes from earlier interviews in subsequent interviews. Interviews contained a mixture of open-ended, probing, prompting, clarifying and verifying questions. Interviews lasted between 40 min and 2 h 10 min; the average duration was 1 h and 20 min. Participants' significant others were present during nine interviews. Anarthric ($n = 2$) participants used high-tech switch activated ($n = 1$) and touch-screen ($n = 1$) alternative and assistive communication (AAC) devices to communicate their responses. All but one of the participants with severe dysarthria ($n = 6$) used low-tech AAC devices (e.g. writing pads) to supplement their responses. Variation in participants' physical abilities impacted on how interviews were conducted. Interviewing severely dysarthric and anarthric participants often meant that the interviewer spoke more because she had to verify more (paraphrase what she understood the participant to be articulating, and seek confirmation/correction to her understanding). This strategy inevitably shaped how these interviews were conducted but did not diminish participants' desire to share and expand on their viewpoint.

We digitally audio-recorded all interviews and had them professionally transcribed. The first author conducted the interviews

Table 1
Age profile of participants.

Age	Men	Women	Total
20–39 years	1	1	2
40–49 years	3	2	5
50–59 years	2	6	8
60–69 years	6	6	12
70–79 years	2	2	4
≥80 years	3	0	3
Total	17	17	34