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Enacting Varieties of Subjectivity Through Practices of Care; A Story of Living with Motor Neuron Disease

Dikaïos Sakellariou¹

¹ School of Healthcare Sciences, Cardiff University

Corresponding author:

Dikaïos Sakellariou, School of Healthcare Sciences, Cardiff University, Ty Dewi Sant, Heath Park Campus, Cardiff CF14 4XN, United Kingdom

Email: sakellarioud@cardiff.ac.uk

Abstract

People living with disability or chronic illness often use practices of care to construct a version of life they are satisfied with. Drawing from a narrative-based study with people living with motor neuron disease, I show how one couple tried to be recognized as active agents in their life, while oscillating between positions of less and more power. Through an examination of the practices of care that the couple enacted, I illustrate how their positioning in relation to practices of care helped them create meaning in their life. In their efforts to create a way of living they were satisfied with they engaged in negotiations between varieties of subjectivity. Their subjectivity was not static, but was constructed as they shared power to carry out everyday self-care activities. The findings also underline the importance for healthcare practices of exploring the experiential knowledge of people living with MND.

Keywords

Agency; caregivers/ caregiving; disability/ disabled persons; medical anthropology; narrative inquiry, storytelling; quality of life; Wales.

The ways people who live with chronic illness or disability position themselves in relation to practices of care, and how researchers or healthcare professionals imagine or assume they are positioned, has been the focus of much research. From a disability studies perspective, practices of care are often conceptualized as something that a more independent person gives to a less independent person (Kröger, 2009; Shakespeare, 2006; Winance, 2010). This process can create power differentials and position people as objects/ sufferers in relation to practices of care, with limited power to effect control in their life (Beckett, 2007; Hughes et al., 2005; Watson et al., 2004). Research from health care sciences often conceptualizes practices of care as a relational process, within which people are recognized predominantly through the lens of the care activities they are engaged in, holding power, albeit often limited, to act (Fine, 2007; Hecht et al., 2003; Held, 2006).

Human experience, Jackson (1998; 2012) reminds us, is intersubjective. Intersubjectivity refers to how people depend on each other to construct and to make sense of experiences (Jackson 1998; 2012). Rather than being independent, autonomous subjects with total control over their lives, people are linked to other people with emotional, biological, social, financial, and a multitude of other ties (Arendt, 1998). This network of human interconnections provides the foundations for human experience (Husserl, 1922/2002). Illness can be seen as a rift in intersubjective life (Jackson, 1998), changing the ways intersubjective processes are played out in a person's life, often through practices of care.

Drawing from a narrative-based study on living with motor neuron disease (MND), in this article I show how, through practices of care, people can try to be positioned as active agents in their life, creating meaning within it. By focusing on

practices of care, and exploring what happened when one couple tried to construct a life they were satisfied with and they could define as good, I aim to highlight how each person involved in relationships of care enacts subjectivity. Using a narrative (Mattingly, 1998; 2010; 2013), and phenomenological approach about what is at stake for people (Jackson, 2010; 2012; 2013), and Foucault's (1988; 1994a; 1994b; 2010) work on technologies of the self, in this article I illustrate how people living with MND enact varieties of subjectivity through the construction of solutions that work in the context of their lives.

Background

Motor neuron disease, also known as amyotrophic lateral sclerosis or Lou Gehrig's disease, is an incurable, neurodegenerative disease of unknown aetiology (Eisen, 2009). People with MND are "not just sick, but inexplicably sick," to use Wikan's words (2000, p. 215). The average survival expectancy after diagnosis is three to five years, which can however be up to 30 or more years depending on the type of MND (Kiernan et al., 2011). People with MND often need to learn how to combine a life lived with an incurable disease that leads to paralysis and reduced life expectancy, and a life that is worth living. Writing on the process of learning how to live with an illness, Manderson (2011, p. 242) states that:

In the face of illness, people search for a diagnosis; to name a condition is to begin to control it. The second step is to search for a cure, taking advantage of the proliferation of health services available from complementary and alternative modalities and cosmopolitan medicine.

What happens after these two first steps, and when people with MND realize there is no cure available, is unique to each person with MND (see Sakellariou, Boniface, and Brown, 2013a for a review of the relevant literature). As the disease progresses, changes in daily life become necessary. People might stop working, driving, and doing their own shopping. They might require help with bathing, eating, and dressing (Talbot & Marsden, 2008). More than 80% of all people living with MND develop dysarthria, and some of them eventually lose the ability to talk (Tomik & Guiloff, 2010). As activities such as walking, writing, or eating become difficult, equipment and processes such as wheelchairs, lightwriters (1), and gastrostomy (2) can be used to mitigate the impact of the disease.

Methods

Study Design

This article is based on a narrative study that was conducted in Wales, United Kingdom, between 2011 and 2013. Some personal details of the participants, and all names, have been changed to protect the anonymity of the participants. I approached narratives from a postmodern perspective, acknowledging the existence of multiple perspectives and voices, all interconnected and equally valid. Following work by Mattingly (1998; 2010) I considered narratives to be enacted performances that people engage in to create meaning and make sense out of their life. Rather than concerning one truth, their remit is with people and with multiple interpretations of stories (Rodriguez, 2002). The construct of narrative in this study includes the “unfinished, idiosyncratic, unpredictable, suspenseful qualities of life” (Mattingly, 2010, p. 44). Narratives in this study are viewed as *opera aperta* (open works) (Eco, 1989) and open

up the possibility for alternative explanations of experiences, contributing to an understanding of what is the good that people seek to achieve through practices of care.

The study was approved by the research ethics committee of Cardiff University. Recruitment was facilitated through the care coordinator of the Motor Neuron Disease Association (MND) in Wales. Participants were seen as “subjects-who-know” (Pols, 2005, p. 204) and data collection sought to create the circumstances for extensive narration. This entailed giving up control of the interview and exercising minimal direction. The seven participants in the study, three couples and one person participating without her partner, participated in a total of 23 interviews (total time 59 hours), resulting in more than 1 thousand pages of data in total (transcribed interviews and field notes from observations). All experiences of the participants were unique, all highlighting different issues. This article draws from the experiences of two of the participants, Rhian and Gwyn. Other findings are presented elsewhere (Sakellariou 2015a; 2015b).

I chose to present Rhian and Gwyn’s story in this article because she had lived with MND for a long time. Getting to know them better I became very interested in how they constructed meaning in their life, and how they engaged with the various practices of care they participated in, as the following excerpt from my field notes illustrates.

Although what they describe could be interpreted as loss (e.g. a story about an unsuccessful transfer from the commode onto the bed which led to a fall and to Gwyn having to sit on the commode himself to lift Rhian off the floor), they do not view their life in that way. For them, it is about making the best of what one has and living and hoping, rather than experiencing loss. It would be interesting

to explore further how, and why, this attitude develops [field note, October 10, 2012].

At the time data collection commenced, Rhian had already been diagnosed with a slow variant of MND for more than 30 years, and Gwyn had been with her throughout that time. This length of time not only gave them plenty of time to establish care practices, but it also meant they had to adapt to many changes as the MND progressed and new symptoms appeared. When I met her, Rhian used the following equipment: power wheelchair, lightwriter, and nightly percutaneous endoscopic gastrostomy (PEG) feed. She had some control of the muscles in her left arm and hand, neck, and face, but used assistive equipment to communicate, transfer, and eat. She was also receiving twice-daily visits from carers, who helped with dressing in the morning and with some housework in the afternoon.

I interviewed Rhian and Gwyn six times, for a total of eight hours, over the course of 18 months. All interviews were joint, because Rhian experienced speech impairment and she wanted Gwyn to be there with her during interviews. This enabled the exploration of the intersubjective and heteroglossic nature of illness experiences (Sakellariou, Boniface, and Brown, 2013b), and was consistent with the understanding of narratives as co-constructed events. Gwyn would often help Rhian finish a sentence, would repeat what she was typing, or would offer an answer, and wait for Rhian's confirmation. Although it might appear from the excerpts below that his voice was the dominant one, they repeatedly told me that their experience was a joint one, but communicated through Gwyn because it was easier to do so. This issue has been discussed in detail elsewhere (Sakellariou, Boniface, and Brown, 2013b).

All our meetings took place in their house, located in an urban area in southeast Wales. Rhian In the winter we would meet in their sitting room, which was the front room of the house, facing the street. In the summer, and whenever the weather was good, we would meet in the conservatory, or sunroom, which was in an extension built at the back of the house. This was a smaller room, and we would all be sitting in our individual chair in a tight circle, often with their dog sitting there with us.

The analysis concentrated on the enactment of practices of care in everyday life, and how participants positioned themselves in relation to these practices. The focus of the analysis was to bring to the foreground this positioning, and explore how Rhian and Gwyn “imagine[d] or allow[ed] themselves to be known and understood” (Hollan, 2008, p. 487) through this process. This particular focus highlighted the centrality of Rhian and Gwyn in their narrative, and enabled an exploration of what mattered to them.

The analysis was informed by a phenomenological approach influenced by Jackson (2010; 2012; 2013) and Mattingly (1998; 2010; 2013), and by a more structural, Foucauldian approach (Foucault, 1988; 1994a; 1994b; 2010). After reading the data a number of times and identifying important events and incidents, as defined by the participants, I developed some initial, possible storylines, which were then further informed by the use of theory.

The Participants; Rhian and Gwyn

The first time I visited Rhian and Gwyn, one of the carers was just leaving. After very brief greetings, and as she was walking out of the door, after I had just entered the house, she turned around and in lieu of a goodbye told me, in a loud voice, indicating this was not confidential information, “don’t be afraid, she’s just finished eating.”

What should I be afraid of, and why? This phrase both embarrassed me (did I look like I was afraid?), and intrigued me. Whom did the carer think I saw in my encounter with Rhian?

If people only feel at-home when they are recognized for who they are as individuals, rather than as representatives of a particular group (Jackson, 2012), what does it mean for people with progressive, incurable conditions to have their experiences reduced to a discourse of burden, power, or individualistic perceptions of care? In an auto-ethnographical article about her mother, Taylor (2008, p. 333) offered a compelling account of how through a process of misrecognition people can be constructed as impersonalized objects in their lives:

Everyone becomes impaired in one way or another, unless we die first. Every human being begins life utterly reliant on kindness he can neither remember nor repay, and many of us will end our lives in a similar state. *As individuals*, every one of us is bound to fail to keep the cares together (emphasis in original).

Getting to know Rhian and Gwyn, I became interested in the way they enacted practices of care and how they positioned themselves in relation to these practices. After presenting the methodology of the study that offers the empirical data for this article, the following sections illustrate how one couple, Rhian and her husband, Gwyn, mobilized practices of care in their effort to construct a good life. In doing so, my aim is to contribute to existing knowledge by describing how people living with MND enact varieties of subjectivity through the construction of solutions that work in the context of their lives.

Findings

Rhian first started experiencing symptoms of MND in her first year at university. After raising two children and taking care of her family, she decided it was time to fulfil her long-term desire for further education. And so, in her early forties she enrolled at a university close to home. At the time, Rhian was working as a cleaner in a local factory and Gwyn, her husband, was also working in another factory. During her first year at university it became apparent that something was not quite right. Her legs would feel weak, and climbing up and down steps on local buses was sometimes difficult. One evening her daughter called, and as they were chatting she asked, “are you alright mum?” She sounded different. Living with her, Gwyn had not noticed the progression into dysarthria. The following two sections describe some instances of the care practices Rhian and Gwyn participate in.

“I Know Best”; Choosing Practices of Care

Rhian and Gwyn need to decide what kind of practices of care they want to engage in, and how these fit in with their life. These decisions are rarely straightforward and often involve a negotiation between which outcome is the best or most desired one (Struhkamp, Mol, & Swierstra, 2009). Rhian, for example, does not want Gwyn to brush her teeth for her in the morning, although it would save them both energy and time. Brushing her teeth however is one of the few self-care activities Rhian can perform and she is intent to keep doing it, despite the effort. For Rhian and Gwyn, practices of care involve experimentations, trying to find out what works.

Gwyn (G): Yes, different problems come up all the time, like . . . if I don’t know what to do, Rhian might say, “let’s try it this way,” like. We are trying

this way, and, “no, I can’t do that.” Like I, I got to lift her from this way, I can’t do it from that way. I don’t know why, but I can’t.

The experimentations that Rhian and Gwyn have to do are also those of an ageing couple (both were in their mid-seventies when data collection commenced). They both worry what the future will be like. In the following excerpt Gwyn admits that helping transfer Rhian is getting more and more difficult.

G: Thing is, I’m getting older, she is getting older. She is getting weaker in her legs so I got to hold her more than I used to before . . . it gets harder for me, like. The trouble with Rhian, she is so short, that she can’t put her feet on the floor, like that. So, when we get her on the commode upstairs, her feet are off the floor. So, when I take her off it, to put her up, like, she drops onto her feet . . . But, because she is so short, if I am not careful, her feet will start sliding, like we did last Friday. . . . Get her out of the bath, her feet sled on the floor. I don’t have no bare hands, so she drops on the floor. Now, she is sitting on the floor now, she is, and I’m thinking, “how can I pick her up?” like. Because, you can’t get between her arms to lift her, so we seem to be in a quandary.

Rhian and Gwyn find themselves in a quandary, when an established practice of care does not seem to be as effective as it used to be in the past. Rhian is sitting on the floor, and Gwyn knows he cannot leave her there, waiting for the paramedics to come and lift her back on to the bed, but does not know how to lift her up himself. “Is there an alternative?”, I asked.

G: The only other thing is a hoist, you see. We don’t want a hoist, picking up a lump of meat with a hoist. Seen one on TV, it’s horrible, like. We don’t want to go through that. . . . They [occupational therapists] came and assessed . . . ,

“you shouldn’t be doing what you are doing, anyway.” I shouldn’t be moving her. . . . What else can you do, like? They came here, looked at it, that’s it, “I can’t do anything for you, but you shouldn’t be doing what you are doing.” So, what else are we going to do then?

MND happens within a life, or between lives. Because Rhian has a slow progressing variant of the disease, she and Gwyn find themselves growing old with MND. They are both getting weaker, but the solution offered, a hoist, is not only not good enough, but something they want to avoid. “It’s horrible,” Gwyn says. “It’s horrible,” that people have to use hoists, which turn people into “a lump of meat,” but health care professionals have already told Rhian and Gwyn that their current arrangements, whereby Gwyn transfers Rhian between wheelchair and other locations, is not a good one. Lifting Rhian himself, or doing that using a hoist; although they both achieve the same outcome, these are two very different care practices. The one practice, lifting manually, is the one they hope they can continue to perform, but it is getting difficult to do. The other, which is using the hoist, is one they try to avoid, but fear they might not be able to avoid forever.

Both Rhian and Gwyn want to remain active agents in their lives, constantly moving between what they need to address the effects of MND and ageing, and what they desire for their life. As Jackson (2010, p. 137) reminds us, “one can only be one’s own person to the extent that one belongs to a wider context than the self”. For Rhian and Gwyn that context is provided through a relationship they have constructed over the years they have been together, and this relationship helps them enact some of the practices of care they desire.

Rhian and Gwyn want to choose those practices of care that are suitable for them; those practices of care that will lead to the construction of a self they envisage for themselves. In one of our interviews Rhian stated, “I know best.” She knows best what she needs and what works for her. Rhian wants assistance for a lived body, not for a body-as-a-tool. In effect, she wants to be able to engage in a process of caring for herself where she will be able to make the decisions that are right for her. She wants to be able to manage how her body will be cared for, assuming control of the process. Rhian and Gwyn move between positions where they have control over elements of their life and positions where they have to accept loss of control.

“What do you Want to Have Sludge for? It’s Bloody Horrible, Like”; Enacting Subjectivity Through Practices of Care

In the following excerpts Rhian and Gwyn discuss about gastrostomy (a PEG), which is a procedure often recommended by health care professionals for people with MND. PEG was introduced into clinical practice in 1980 and is now fairly common practice in MND (Miller et al., 2009), although this does not mean that all people with MND view it in a positive way, as the following excerpt illustrates.

G: No, Rhian didn’t want it, no.

Dikaios (D): Why not?

G: Because it is another step down the road, you see. Each step you lose, you going further down under . . . [Rhian starts synthesizing answer]. She didn’t want that, she wanted to stay as she was. I felt that she didn’t need it, I said “don’t do it, she don’t need it. She is okay as she is, right.” He says [the doctor], he insisted that she should have it. Because, when she was in the hospital for a couple of days, she didn’t have anything to eat, because it wasn’t

mashed or anything, and of course they weren't feeding her either. . . . So the doctor said, "well, she will starve to death, you got to have a PEG," like. For she blamed me for having had the PEG put in, but it wasn't my fault, I didn't want it in the first place. But best thing that ever happened to her.

Rhian (R): I felt it was too life-changing.

To care for oneself requires close attention to the kind of self one needs and wants to care for, and to the technologies of the self that a person can mobilize. Rhian and Gwyn have their own ideas of what disease and illness mean, how they want to relate to people around them, and ultimately how they want to live their life. They take care of themselves in small or bigger ways, and they continuously modify their perceptions of what they need to do to construct a good life. They choose some ways to live, engaging in what Mol, Moser and Pols (2010) described as 'tinkering', or exercising control when and where they can to experiment with what is possible and what is desirable. In other words, in choosing different technologies of the self, Rhian and Gwyn engage in truth games about who they are and who they want to become.

A PEG is one of these processes that produce a "fusion of the technological and organic" (Manderson, 2011, p. 58), leading to the reclaiming of lost function (nutrition in the case of the PEG), but can also act to highlight "the departure of the individual from normatively able bodies" (Manderson, 2011, p. 86). A PEG signifies a radical change of what bodies are supposed to look like, and can make people feel subjected to medical technology. As the excerpt above illustrates, however, these ideas change over time. Partly, this is because a PEG *tastes* better than the alternative. In our second meeting they told me that Rhian had started eating from the mouth again, and she was advised by the nutritionists to use thickening agents for water and other liquids.

G: For years she never drank nothing so you couldn't give her milk and you couldn't give her water, because the water was going down too quick. So, we went Tuesday, they got a thickener, but it looks like paste to paint the wall with. It is thicker but looks sludge-like, you know, we don't want that, like. What do you want to have sludge for? It's bloody horrible, like.

R: Yuck, it's yuck. [Rhian and Gwyn laugh].

G: Like slime in your mouth. Like trying to eat wallpaper paste. [All laugh].

From a procedure that had to be avoided, PEG became a way to avoid another dreaded possibility, that of having to eat "wallpaper paste," which is "yuck." As Gwyn exclaimed, "what do you want to have sludge for?" So, as long as there is an alternative, Rhian and Gwyn will avoid using these liquid thickeners.

A PEG however, can still present challenges. Just before they enrolled in the study, Rhian had a new PEG tube inserted, using a less invasive technique than the one she went through several years earlier. Although they saw this as a positive development, Rhian and Gwyn were not satisfied with the end connector of the outside lead of the PEG. Because this was made by a hard plastic component placed inside a softer tube, any pressure change caused, for example, by gas, would cause the inside part to be dislocated and food to drip out. When they communicated this problem to their community nurse, she said that nobody else had complained and the tube was fine. But as Gwyn said, "I am the one who has to clean up the mess, not her. I am the one who lies down thinking, 'what's happening, will I find a mess in the morning?', and Rhian getting all soiled. And it smells too." Rhian agreed, "it's smelly, glue-like." Instead of waiting for a solution that was not forthcoming, they decided to experiment.

G: Look at this [showing the PEG tube]. . . . You see that flap there was on top of there, but it was leaking all the time. Not now, we taped it up, put a hairclip on it, tied it on there with the cord. Before it was falling out. The feed was still going, it messed on the floor, all over Rhian, everywhere, like. When the nurse saw that, she said that's the only one we got. Well, it's rubbish, absolutely crap. They couldn't change it. So I had to adapt that now. So, the idea of this [hair]clip is hers [Rhian's], and the idea of the cord is mine [both laughing]. . . . It works. The other one, it doesn't work. . . . And you tell these people, "it's not working, it's making a mess everywhere." Now, it's working perfectly fine, we got no problem at all.

"We got no problem at all" means that they found a solution that works for them and there is no more food dripping out of the tube. They enact what Pols (2011, p. 203) called "patient knowledge," which is developed through the everyday experience of living with an illness. For Gwyn and Rhian food dripping was bad because it smelled bad and it was hard to clean from the carpet and it soiled Rhian's clothes in the middle of the night. So, the solution was to find a way to stop food from dripping out of the tube so they could both have an uninterrupted night's sleep. Many strategies for managing some of the impairments of the disease have been developed, several of them based on high technology, such as gaze control systems for computers, text to speech machines, ventilation machines, and power wheelchairs. However, sometimes people need to develop their own solutions, based on technologies of the self. Foucauldian technologies of the self:

Permit individuals to effect...a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being. So as to transform

themselves in order to attain a certain state of happiness, purity...perfection.

(Foucault, 1994a, p. 225)

Rhian and Gwyn chose those practices of care that could facilitate the construction of a life where Rhian does not have to eat “wallpaper paste,” and where they can wake up in clean bed linen.

“Trying out all the Time, Try This, Try That”; Trying to Construct a Good Life

Despite, or perhaps because of, the ambiguity they were experiencing, Rhian and Gwyn wanted to live a good life. The good they were working toward could not be defined a priori but only within the ever-changing context of their life. Life might be subjunctive, with uncertain endings to different stories, but Rhian and Gwyn were trying out different means to different endings. Rhian and Gwyn tried to create that good through actions that can be viewed as experiments. Like all experiments, some were successful, and some were not. In these experiments, Rhian and Gwyn were subjecting themselves to different practices and measuring the outcomes against their notion of the good they were trying to achieve. The outcome was never certain. Will the hairclip hold the PEG tube in place, or will Rhian and Gwyn face another morning trying to clean food spilled on the bed linen and carpet? Or perhaps, will their actions jeopardize their relationships with health care professionals? In their own ways, Rhian and Gwyn sought to create their own versions of Campbell’s (1968) ‘hero’, and take a central role on how they enacted their notion of what their life should look like.

Rhian and Gwyn often did not plan these experiments in advance, but engaged in them when particular problems arose. When Rhian and Gwyn realized their new PEG connector did not work like it was supposed to, leaking food on the beddings and

on to the carpet, they were not sure what to do to fix this problem. What they did know, however, was that this was a problem and it needed fixing. Their first reaction was to seek advice from a health care professional that had expertise in dealing with issues, such as the one they were facing. When a solution was not forthcoming, they decided to see if they could address the problem by themselves. They had no way of knowing how the story would turn out. A few months later they decided to try out something different.

D: So what happened with the tube, the leak?

G: That, that was a bad connection, we sorted that out. . . . We put the [feed] tube into the PEG tube, so a soft tube going into a soft tube, so it holds it alright like, working properly.

D: So, how did you decide to sort it out that way?

G: I don't really know, really. We just experimented. . . . You see this? [showing me the PEG tube]. I got to open this, open that, shut that, put that back in, put that tube in there, and I've forgotten to open this, right? Push the thing out, you see. . . . As long as it doesn't block it there, it will keep going in, like. So, we sorted that one out. Trying out all the time, try this, try that.

Rhian and Gwyn try out different solutions all the time, carrying out experiments, with the ultimate goal to develop the practices of care that are best suited in their life. Experiments often take place in a laboratory. For Latour and Woolgar (1986), the laboratory is a space where scientific facts are constructed, through many mechanisms, including the production of artefacts, such as articles, social interactions, and the manipulation of objects. The types of construction that were of interest to Rhian and Gwyn did not take place in a science laboratory. Mattingly (2013) introduced the metaphor of a moral laboratory as an imaginary illustrating how people

try to create a good life for themselves and for those they care about. In their own laboratory, Rhian and Gwyn sought to develop practices of care that would correspond to their notion of who they wanted to become in their life.

Discussion: Practices of Care; Positions and Recognitions

In this article, I tried to tell a story about “people learning to live, living on, not learning to accept death, resisting death in all possible forms” (Biehl, 2013, p. 394), a story about two people who were facing “impossible choices” and kept “desiring and trying, against all odds, to make things otherwise” (Biehl, 2013, p. 394), often through practices of care. The use of a phenomenological approach enabled a nuanced understanding of the practices of care the participants engaged in, what they hoped to achieve through them, and how they created meaning out of them. In other words, this approach enabled attention to what was at stake for Gwyn and Rhian; what they hoped for, and also what they were afraid of. A Foucauldian viewing of power as dispersed and elusive, and operating through different apparatuses, brought to the foreground issues of power in practices of care. The combined use of these different approaches offered a vantage point from which to explore the varieties of subjectivity of the participants, and consider what was at stake for them, as they moved between positions of more and less power.

Whether it was about avoiding food that is “yuck,” or not being handled like a “lump of meat” by a hoist, Rhian and Gwyn tried to engage, together, in practices of care that not only enabled them to achieve some desired outcomes, but that they (the practices of care) were themselves acceptable in the context of their life. Sakellariou illustrated how to be able to achieve a desirable life, people often “try to find a balance between what they want, and what other people want for them, between what is

available and what is not” (2015a, p. 16). In their efforts to create a way of living they were satisfied with, Rhian and Gwyn engaged in negotiations not only between different expectations associated with that life, but also between varieties of subjectivity.

Rhian and Gwyn experimented with everyday activities and sometimes modified them. Echoing Mattingly’s (2013, p. 322) discussion of the moral laboratory, these experimentations did not happen somewhere out of everyday life but rather “they were accomplished as the expected or the normative, becomes subject to experiment.” It was a notion of the good, not defined by illness, but shaped by everyday life and all its exigencies with which participants in this study experimented and tried to work toward. Their experiments were about being able to go for a walk, eat, participate in social gatherings, or be able to share a bed with one’s partner.

Whether that good referred to being able to go the gym every morning or use the PEG without food leaking out, Rhian and Gwyn mobilized those practices that were available to them to try to achieve it or justify its unattainability. Often, their perceptions of what they desired and what they wanted to avoid changed. Rhian and Gwyn had to work toward that good while also getting used to continuous changes brought about by MND, age, learning to navigate new environments, such as health and social services, and the use of devices such as lightwriters, PEG feeds, and power wheelchairs. Their experiments involved constant negotiations between what was good for MND and what was good for living with MND. Through engaging in certain technologies, Rhian and Gwyn worked toward the construction of a desired version of themselves and in the process positioned themselves as active agents in their life.

In this article I show how Rhian and Gwyn shared power “in an ongoing

struggle to negotiate, reconcile, balance, or mediate these antithetical potentialities of being, such as that no one person [...] ever arrogates agency so completely and permanently to itself that another is reduced to the status of a mere thing” (Jackson, 2002, p. 13). Rhian and Gwyn were oscillating between exercising power and being the locus where power was exercised. The boundaries between being a subject and being an object were fluid. Rhian and Gwyn negotiated these boundaries through small, everyday actions.

What was at stake for Rhian and Gwyn was the creation of a life that they could still define as good, despite the presence of MND. They sought to achieve that life through practices of care, such as manual handling. Yes, in this process sometimes Rhian, and also Gwyn, could have recognized themselves as being disempowered, as when Rhian fell on the floor. And some other times, Gwyn perhaps felt that the practices of care were getting too difficult for him, a man in his mid-seventies. However, what is unique about Rhian and Gwyn’s narrative, is that what mattered in these practices was not the exact positioning of Rhian and Gwyn in relation to each other (i.e. who had more power, and more control of the situation), but how they interacted to create meaning through these experiences, ultimately leading to the production of a good recognizable by both. The stories presented in this article illustrate the different varieties of subjectivity that Rhian and Gwyn enacted through practices of care. De Certeau (1988) argues that people implement different strategies in their efforts to ‘make do’, or enact everyday life. What is at stake for people is, de Certeau (1988) argues, their autonomy and power to engage in those practices that they deem to be desirable, or needed.

If illness is seen as a rift in intersubjective life, what effect does that have on

how people are recognized by other people? For Jackson (1998, p. 17) what is at stake are “relationships between persons as well as relationships between persons and the things that have ultimate value for them.” Could the reason for the casualness the carer uttered, “don’t be afraid,” in my first encounter with Rhian and Gwyn be this rift?

Rhian was not recognized as one of *us* (people somehow recognized as healthy) and thus *we* could be scared by an encounter with the difference she represented. As Rhian and Gwyn’s story illustrates, practices of care can sometimes be as much about addressing the effects of illness on the physical body, as they are about addressing its effects on the lifeworld of the people affected by that illness. Like the African American mothers Jacobs, Lawlor and Mattingly (2011) wrote about, Rhian and Gwyn tried to create an I/We story within which they could be not only positioned, but also recognized as active agents.

Rhian and Gwyn’s story has important implications for healthcare practices. The intention to effect some change that can be recognised as good lies at the heart of healthcare practices. This good can pertain to a quick discharge, a speedy rehabilitation process, a higher score in a certain assessment or the prolongation of life. People enter the healthcare process with a story about a particular complaint and how it affects their life, often leading to isolation of the problem, diagnosis, and treatment of the specific condition (Latimer, 2008). This presents several challenges, as Mol (2006) discussed. Questions such as, what is a good life, or what to do when health or function cannot be restored or maintained, do not have a definitive answer. The *good* desired by people living with an illness cannot be defined a priori, but only within the context of their life. People living with MND need a healthcare that understands the specific challenges faced by people who live with this disease and works towards a notion of good,

keeping in mind Mol's (2006) question "which good should we strive after, if health is beyond the horizon?" (p.406).

Concluding Remarks

The use of narratives in this study foregrounded the varieties of subjectivity Rhian and Gwyn moved between, and the potential impact of these varieties on their life. Will Rhian and Gwyn continue to be satisfied with the PEG, and if not, what will they do? What will happen if the nurse finds out they modified the way they use the PEG? What will happen when Gwyn cannot lift Rhian any longer? By highlighting the practices of care Rhian and Gwyn engaged in, the data presented in this article introduce new questions about the 'what might be', and how their positioning in relation to practices of care helped them create meaning in their life.

Perhaps, Rhian and Gwyn will just keep on experimenting, understanding themselves as active agents in their life, hoping that they will be able to sort things out, one way or another.

G: Can't go, aw, aw, aw, can't do it. What am I gonna do, like? Try this, it doesn't work, trying that, it doesn't work, but something has got to work anyway.

R: ateed.

G: Attitude? We have a positive attitude. Hard word to spell that one, attitude.

R: ateedude. [laughter].

G: Yeah, we laugh, don't we?

Notes

1. Text-to-speech device that synthesizes voice from text input.
2. An opening through the abdominal wall and into the stomach, through which people can receive food, water, and medication.

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Bio

Dikaios Sakellariou, PhD, is a lecturer at the School of Healthcare Sciences, Cardiff University, United Kingdom.