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Towards the Construction of a Nicer Life

Subjectivity and the Logic of Choice

Dikaios Sakellariou

ABSTRACT: In this article, I bring to the foreground the enactment of the logic of choice and focus on what happens when people are denied the interventions they choose. The specific interventions I focus on are home modifications. My aim is to show how people living with a chronic illness or disability interact with the logic of choice. Drawing from a narrative study on experiences of living with motor neurone disease, I present the narrative of one woman as she tries to enact a life that she can describe as good, or better. Using empirical evidence, I explore some of the links between subjectivity and the logic of choice, focusing on the experiential knowledge that guides decision-making. In this article, I illustrate how people living with a chronic condition can enact subjectivity by choosing interventions that can attend to their social world.

KEYWORDS: disability, experiential knowledge, home modifications, logic of choice, motor neurone disease, subjectivity, United Kingdom

In the context of healthcare, making choices can be seen, states Mol (2008: x), as 'the very act that turns a person into a subject'. Having choice about what interventions to use, what technologies to allow into their life and the kind of care they need can turn people into actors – active agents who have the power to make some changes to move a little bit closer towards the construction of a good, or better, life. People are increasingly being given the responsibility to make choices that are seen as *healthy* (Henwood et al. 2011), although it is not always clear which choices can be described as healthy and which not (see for example Department of Health 2010, for a repeated use of the word healthy without defining it).

Mol (2008) has offered a comprehensive critique of what she refers to as the 'logic of choice' as a guiding framework in healthcare. She argues that this logic has led to the construction of people as consumers of services, with not only the right, but also the responsibility to choose the services they need. In the logic of choice people are turned into what Mol called patient-consumers and the emphasis shifts 'to the rights

of individuals within increasingly marketised services' (2011: 509). People are expected to make the choices that are right for them and assume responsibility for the outcomes of their choices. Mol (2008) discusses a logic of care as a necessary complement to a logic of choice. In care, Mol argues, solutions to disease can be found only by acknowledging the intersubjectivity of life.

In this article, I want to add to the ongoing discussion about the logic of choice by exploring a different dimension of it. I am interested in what happens when people are denied the interventions they choose. The specific interventions I focus on in this article are home modifications. Drawing on a phenomenological (Jackson 1998, 2006; Mol 2006) and on a narrative (Mattingly 2010, 2008) approach to foreground what matters to specific people, my aim in this article is to show how people living with a chronic illness or disability interact with the logic of choice when they are denied choice; what effects does it bring in their lives, and how do they evaluate these effects? To do this, I focus on how one woman, Arleen, living with motor



neurone disease (MND), tried to construct a good life in her local context. In order to do this, Arleen mobilised certain practices to create a present where life was worth living and imagined a future where this would continue to be so.

Using empirical evidence from a narrative-based study on living with MND, in this article I tease out some of the links between subjectivity and the logic of choice, focusing in particular on the experiential knowledge that guides decision-making. By presenting Arleen's efforts to create a life she was satisfied with and that she felt was worth living, I also contribute to a broader discussion about the construction of subjectivity. In this article, I illustrate not only how people living with a chronic illness enact subjectivity by moving between 'what is given and what is chosen', to borrow Jackson's (1998: 21) phrase, but also by moving between what can be chosen and what cannot be chosen.

Background

The Logic of Choice in the United Kingdom

In the United Kingdom the emergence of the logic of choice is particularly evident in the ways people are expected to take responsibility for managing long-term or chronic illness and disability (Heaton 1999). This often happens through the development of relationships of care, the use of adaptive equipment and the modification of the living environment. Successive governments in the U.K. have placed emphasis on the latter, viewed home modifications as providing an 'individualised solution to the problems of people experiencing disabling environments' (Department of Communities and Local Government 2006: 6). Depending on the outcome of a needs assessment by an occupational therapist, people living with a chronic illness or disability can be given a fixed amount of money to modify their living environment to fit their needs. Choice is a guiding principle in this process, and is mentioned several times in relevant policies. In 2006, the Department of Health in the U.K. set out its vision for a 'strategic shift aimed at supporting choice and giving people more say over decisions that affect their daily lives' (Department of Health 2006: 17). Four years, and two governments later, the same government department stated in its public health strategy document, that:

all capable adults are responsible for these very personal choices. At the same time, we do not have total control over our lives or the circumstances in which we live. A wide range of factors constrain and influ-

ence what we do, both positively and negatively. (Department of Health 2010: 29)

It is interesting to note that people are still held responsible for their choices, although it is recognised that they do not always have control over these choices.

Motor Neurone Disease

MND is an adult onset, incurable, progressive, neurodegenerative condition that is characterised by the wasting of voluntary muscles secondary to the destruction of motor neurons, leading gradually to partial or complete paralysis (Eisen 2009). As the disease progresses, functions such as walking, eating, talking and breathing can be affected, and people with MND often require help with activities such as eating, toileting or dressing. The average survival expectancy after diagnosis is three to five years, which can however be considerably longer, depending on the type of MND.

In the absence of a cure and with no hope for recovery, studies exploring the experience of living with MND often emphasise loss and suffering, presenting narratives of tragedy. In these stories, the central characters cannot live a good life, ever after. A good life however can refer to 'possible worlds and possible selves worth striving for' (Mattingly 2008: 95). Living with MND is after all an everyday reality for many people. The main issue then becomes, how can one live with MND combining a life lived with an incurable disease that leads to paralysis and reduced life expectancy, and a life that one can still define as good and that is worth living? In this article I discuss some of the choices that people can take in their efforts towards the construction of a good life.

Methodology

This article is based on a narrative-based study that was conducted in Wales, U.K., between 2011 and 2013. My aim was to explore how people make sense of living with MND. I developed a methodology that facilitated in-depth meaning-sharing by the participants (see also Sakellariou et al. 2013). Data collection took place through observations, e-mail and multiple, joint, in-depth interviews. Seven people in total participated in the study, which resulted in the production of unique narratives for each participant. This article reports on the findings from one of the participants. Although all participants were trying, in their own ways, to construct a good life, a life they were satisfied with and which they thought was worth liv-

ing, Arleen interacted very closely with the logic of choice throughout the eighteen months of her involvement in the study. I chose to use two specific scenes from Arleen's story to illustrate my argument about the logic of choice.

The study was approved by the research ethics committee of the School of Healthcare Sciences, Cardiff University. Some personal details of the participants and all names have been changed to protect the anonymity of the participants.

Arleen: Learning What Can Be Chosen and What Cannot Be Chosen

Arleen was in her early fifties when I met her in 2011 and had been diagnosed with a slow-moving subtype of MND for a few years. She had developed dysarthria, and therefore she spoke slowly. At Arleen's request our initial interactions took place via e-mail and when we first met in person I remember being nervous, worrying I might not be able to understand her, leading to a potentially awkward situation, especially since it was me who had suggested that meeting in person might facilitate data collection. However, Arleen's speech was entirely intelligible and over the course of her involvement in the study, I cannot recall a time when I could not understand what she was saying. In the sections below I present two scenes from Arleen's narrative, focusing on how she interacted with the logic of choice.

Scene 1: The Handrails: A Choice Denied

Arleen lived in a spacious flat, in a relatively central location, close to shops and a big park. Her front door, which was only used by her, was on the ground floor, but the living space was one flight of stairs up on the first floor. When I first met Arleen she had just received a power wheelchair and she was looking forward to going shopping again by herself. However, as she did not have any space in the entrance of her flat to store the wheelchair and it was not possible to move it up and down the stairs to the main living space, she kept it in the garage. The garage was accessed through an uneven pathway that could be quite slippery when wet and especially when there were leaves on the path. Recognising this as a problem, she wanted to have handrails installed for part of the pathway, but this was not as straightforward as she had hoped, as she described in an e-mail message:

My garage is at the front of my property & the garage occupies the ground floor, the front door is at the back & accessed via a pathway on a gradual incline consist-

ing of a number of steps some metres apart. Even though it is a public footpath it only houses 12 properties & where the steps are situated is a blind spot not overlooked by any properties or the car park/road. On dark mornings [...] I began to lose my confidence on the steps. I applied to the Council for a hand rail to be installed, I was told that the waiting list for the 'District' Physiotherapist would be anything from 3 to 6 months, & with my disease it properly would not be worth it. I was told that it would have been futile for me to go on the waiting list for a district Physiotherapist assessment for outside hand-rails as the waiting list was too long for someone with my 'condition' [...] This [is] one of many 'like' examples.

According to the Welsh government, all people are entitled to a grant for modifications that are deemed to be 'necessary and appropriate for the needs of the disabled person, and reasonable and practicable in relation to the property' (Welsh Local Government Association 2009: 32). However, Arleen was not able to choose the modifications she wanted; not because the requested modifications did not meet the necessary criteria, but because Arleen herself was not a good candidate for such a modification, due to the perceived quick progression of MND.

In Arleen's story, someone with *her* condition is recognised as someone who has a few months to live and services cannot help her. Arleen was sad and frustrated for being misrecognised not as Arleen but as someone with MND, having her individuality and personal needs ignored in favour of a group identity. This led to an important decision concerning her everyday life, the installation of handrails, being taken mainly on the basis of a pathological entity without regard to the specificities of the context and the person.

Arleen tried to fulfil her responsibilities as a patient-consumer by making a choice that could contribute to the construction of a good, or better, life. Handrails would enable her to get to her car and to her wheelchair independently, and she could then go into town to meet friends, or to the nearby park. However, she was confronted with the fact that people do 'not have total control over our lives or the circumstances in which we live' (Department of Health 2010: 29).

During our first couple of interviews, Arleen would state how lucky she felt for knowing how the health and social care systems work. Gradually, through sharing stories about her interactions with these systems she came to a different conclusion, as illustrated through the following e-mail excerpt:

I realise that the system is under a considerable financial strain, but my frustration & concern is that even

Social & Health Professionals only see MND as a disease with a rapid progression & a short lifespan.

According to Fraser (2000: 113):

What requires recognition is not group-specific identity but the status of individual group members as full partners in social interaction. Misrecognition, accordingly, does not mean the depreciation and deformation of group identity, but social subordination – in the sense of being prevented from participating as a peer in social life.

Being constructed as just another case of MND, Arleen was given a group identity that had little to do with either her needs or with how she viewed herself. Rather than an abstract sense of exclusion, Arleen felt she was denied choices and consequently her chance to participate on a very practical level, by being told it is futile to apply for modifications, although it was of course her right to proceed with the application and she was aware of this. She had to follow a logic of choice, but she could not choose what she wanted. Rather than feeling that she was helped, she felt like she was treated as another representative case of MND. But who is to blame for this situation? The professional who advised Arleen against having the handrails installed might have in fact be trying to be helpful by giving her a realistic estimate of how long the modifications would take to be carried out (advice which is sometimes needed, as illustrated in Sakellariou in press). His or her intention might have been to help Arleen make an informed decision as to whether she wanted to wait for six months for an assessment, given the average life expectancy of a person with MND. Furthermore, professionals themselves are restricted by the logic of choice in what they can allow patients-consumers to choose and what not.

Scene 2: The Flat Entrance: Buying Solutions

With no accessible route to her garage, Arleen was disabled. She was disabled by an interaction between a body affected by MND, a physical terrain and a service that was too slow to respond to her needs. A change in any of these elements could eliminate the disability that Arleen experienced; while changing the body was not an option, changing the physical terrain, either through a publicly funded service or privately, would enable her to access the garage again. So, Arleen took action:

I was then transferred back to the Council switchboard, who asked which department I wanted, where I explained my predicament again, & was given the number of a company which specialized in erecting rails for people with mobility problems, the

work was completed with the costs paid for by me. (E-mail excerpt)

If in the logic of choice, people are transformed into consumers, then this means that they can buy interventions. This possibility for action through buying comes with two conditions: people need to know what they need, and they need to be able to afford it.

Some time after the incident with the handrails, Arleen again contacted the social services. This time her request was about a door-control system. The following excerpt is from an e-mail she sent me:

Once again I contacted Social Services, for a door entry system, as by the time I could safely go downstairs, any callers would have left, they accessed [assessed] that as I had no falls on the stairs at this time they could not help, but if my circumstances/condition changed. (I can only assume they meant break my neck while rushing to answer the door) I paid for my own.

Once again, Arleen took action to modify the environment around her. While it is not possible to know the actual response of the social services, or their rationale for their response, Arleen felt her needs were not recognised. While before she was too unhealthy to get the handrails, in this case she was too healthy to get the door-control system. Something happened in that interaction she had with the services that made her feel she was seen as someone who could not be helped. In a way, the speed of her progressing condition was not in match with the services offered: too quick for the handrails, too slow for the door-control system.

Still, with her new handrails and the door-control system, both of them paid for by herself, her living environment was still not quite appropriate for her changing needs. The main problem was that a small segment at the beginning of the path to her garage was directly in front of another person's property and handrails could not be fitted there. Arleen still needed someone to help her from her front door to the start of the handrails so that she could get to the garage and on to the wheelchair. Her solution to that was to move into a bungalow, in order to be able to use the wheelchair without help and not to depend on someone being there when she wants to go out. Moving into a bungalow means having her own entrance and space to park her car right in front of her door, with the wheelchair being stored in an accessible location.

Dikaios: And then you also said buying a house is a necessity to make your life easier, and that's coming out as an important theme as well, to make life easier. How do you mean life is easier, or what makes life easier for you?

Arleen: So, I will be able to get to the car on my own, and drive around. It won't just be easier, it will be nicer, it will be more pleasurable. I will have a garden to sit in. And [now] everytime the post comes, I've got to go up and down the stairs.

Although the location of the flat she lived in was very convenient, giving her easy access into town or to the nearby park, she decided that moving into a bungalow would lead to a nicer life. A nicer life for Arleen would be a life in which she would be able, among other activities, to (1) get the post without having to go up and down stairs, and (2) get to her car or the power wheelchair even if she is by herself. In other words, a nicer life is a life where the environment is modified in order to eliminate obstacles, such as stairs and slippery pathways, so that she can carry out the activities she wants to. To move a little bit closer towards the construction of this nicer life, Arleen had to devise, and pay for, her own solutions. In some ways she was given the freedom to choose, but this freedom came together with the responsibility to know about available solutions, and the need to be able to pay for them.

Developing an Understanding of the Choices Leading to a Good, or Better, Life

The two scenes above illustrate one of the many scenarios that can be performed when people are denied the interventions they choose. Arleen sought to enact subjectivity by moving between what could be chosen and what could not be chosen. 'It's got to be me first and my illness second', said Arleen in one of our interviews. What was at stake for her was the maintenance of an identity that while it included MND was not dominated by it. She tried to enact her identity through the modifications she chose.

Illness, Jackson (1998) argues, can be seen as a rift in intersubjective life. In their efforts to construct a good life *with* an illness, people seek out interventions to attend to their social world. Many of these interventions, or practices, do not happen in a clinic or hospital but in people's homes (Mol et al. 2010). Having a door-entry system would allow Arleen to answer the door to her friends; having handrails installed would enable her to get to her power wheelchair or to her car, and go into town to meet friends. These modifications would lead to the creation of a home in the world, which is a place 'where one can experience intersubjective life and feel recognised as a person' (Sakellariou in press).

The enactment of the logic of choice in the context of home modifications is often based on a neoliberal language of cost-effectiveness, where 'desire is of no

value' (Biehl 2007: 413), and 'desires can be seen as liabilities' (Sakellariou in press). Choices are hierarchised according to their value, and those deemed to pertain to a desire, rather than a need, are downgraded in priority. Johansson (2013) and Sakellariou (in press) have shown how in asking for home modifications, people try to frame their wishes as eligible needs, rather than as desires, because the latter are likely to be rejected.

De Certeau (1988) argues that people implement different strategies and tactics 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. Autonomy itself can be seen as something that people practice in their everyday life, in order to achieve some goals they desire (Struhkamp 2005). Strategies for de Certeau (1988: 36) refer to:

the calculation (or manipulation) of power relationships that becomes possible as soon as a subject with will and power [...] can be isolated. It postulates a place that can be delimited as its own and serve as a base from which relations with an exteriority [...] can be managed.

Arleen tried to achieve this by contacting different services, numerous times, and explaining her situation. When this strategy was unsuccessful, she could still draw upon other means of power – information about what she needed, and the necessary monetary resources. Access to power, whether in the form of social, cultural health (Dubbin et al. 2013), knowledge or financial capital was a central feature in Arleen's story and influenced her construction as a subject, namely a bearer of knowledge/power. Arleen was oscillating between being a subject and being an object and between exercising power and being the locus where power was exercised; she was at the same time both actor and sufferer (Arendt 1998). When she was denied some choices, she mobilised other practices to help her construct a home in the world and attend to the impact of MND on her sociality.

Subjectivity was not a given but it was actively constructed through enactment of her own version of a good life. Arleen wanted to construct a life that she felt was worth living, a life within which she could take decisions leading to what Ferzacca called 'a tolerable present or an ideal future' (2000: 30). The outcome of these decisions was never certain, but having the power to take these decisions maintained her position as an active agent in her life, and affirmed the importance of certain practices over others.

Mol (2006) illustrates how an illness can be enacted through many practices, in many different settings. It involves a body, and a society in dialogue between them (Shakespeare 2006). But at the same time it all comes together in the life of a specific person and all the seemingly heterogeneous practices become part of this life, in all their inconsistencies. Divides such as those between bodily manifestations of a disease and phenomenological meaning of an illness, or between choice and no-choice, only become relevant and gain meaning within the context of a particular life, within a local context (Mol 2006).

Questions about what a good life is, or what to do when health or function cannot be restored or maintained, for example, 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. MND, being an incurable and progressive disease, demands a health and social-care system that understands the specific challenges faced by people who live with this disease.

Several medical anthropologists discuss how people living with chronic illness or disability and healthcare professionals often have different perspectives regarding care and treatment options (see for example Frank 1995; Good 1994). Research suggests this is true in the case of MND as well (Hughes et al. 2005; Pavey et al. 2013). This can be problematic when people are asked to make their own choices about interventions. It is important that a common ground for understanding is established so that health professionals and people living with an illness refer to the same thing when they talk about right decisions regarding care or improving quality of life. Healthcare can be viewed as a:

knowledge-based system. It draws on different types of knowledge – scientific knowledge about biological processes, epidemiological knowledge about patterns of disease and risk factors, and clinical knowledge about how to treat a medical problem. (Ziebland and Coulter 2013: 1)

As several authors have demonstrated, however (for example Kleinman 1988; Mattingly 2010), there is also a fourth type of knowledge, which concerns how people experience illness. This type of knowledge refers to the knowledge developed through living with an illness. Healthcare professionals can access this knowledge only through getting to know how people 'care and repair', as Criado and Callén (2013: 1) put it. This includes studying how people deal with problems as they arise in their daily life, and how, and why, they choose some interventions over some oth-

ers. In other words, it is important to explore the values that guide decisions.

Understanding how people care and repair requires a constant negotiation between the experiential knowledge of the person whose body is changing and the more standardised, generalised scientific knowledge that can present facts and offer possibilities that guide choices. It is not a logic of choice that is called for but one based on constant negotiation. In a logic of choice different perspectives about the desired good remain separate; they might interact, but responsibility for choosing remains firmly within specific actors. A starting point towards the construction of a logic based on negotiation would be to let go of divides such as illness and disease, actor and object, choice and no choice, or choice and care, and instead focus on how people work towards the construction of the elusive good life, incorporating all these different elements.

Concluding Remarks

The story told in this article was about how one person interacted with the logic of choice in her efforts to construct her own version of a good life. I highlighted some of the problems of adopting a logic-of-choice approach in the management of illness and disability. While the logic of choice can give more power to people to choose from a variety of available services, sometimes people want someone to care for them and construct these choices collaboratively. This can be because they are too preoccupied with the process of adapting to an everyday life complicated by the effects of illness, or because they do not feel competent enough to make these choices (Mol 2008).

And yet some other times, although people might be both prepared and happy to choose the services they need, their choice has to be approved by a professional, who acts as a gate keeper. This is especially true when these choices involve funding, and thus need to be established as both necessary and cost-effective. When she was denied the interventions she wanted, Arleen mobilised practices to create her version of a nicer life, where she came first and her illness second.

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