

Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <http://orca.cf.ac.uk/71085/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Sakellariou, Dikaios 2015. Home modifications and ways of living well. *Medical Anthropology* 34 (5) , pp. 456-469. 10.1080/01459740.2015.1012614 file

Publishers page: <http://dx.doi.org/10.1080/01459740.2015.1012614>
<<http://dx.doi.org/10.1080/01459740.2015.1012614>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

TITLE: HOME MODIFICATIONS AND WAYS OF LIVING WELL

AUTHOR: Dikaios Sakellariou

ABSTRACT

People living with a disability or illness and health care professionals often have different perspectives on what needs to be done, and why, in order to create a life they can recognize as good. Focusing on home modifications, I explore the enactment of diverging perspectives on the desired good. I show how one couple living with the effects of motor neuron disease in Wales tried to create a way of living. Drawing from a narrative-based study, I explore what happens when there is an interaction of different perspectives of what is considered to be a desirable outcome. I argue that the construction of some expectations as needs, and others as desires, serves to subjugate people to certain technologies. These technologies are those deemed necessary, following a neo-liberal language of cost-effectiveness where desires can be seen as liabilities.

KEYWORDS: Disability, home modifications, intersubjectivity, knowledge legitimation, motor neuron disease, narratives.

MEDIA TEASER: What does it mean for people to have their wishes treated as irrelevant? How are desires and needs understood as a home is modified to adapt to disability?

RUNNING TITLE: Home modifications and ways of living well

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

BIONOTE

Dikaios Sakellariou is a lecturer at the School of Healthcare Sciences, Cardiff University, United Kingdom. He has co-authored and co-edited the volumes *A Political Practice of Occupational Therapy* and *Occupational Therapies without Borders* (with Nick Pollard and Frank Kronenberg), and *Politics of Occupation-Centred Practice* (with Nick Pollard), on the enactment and enablement of daily life and the experiences of disability and disablement.

Address correspondence to Dr Dikaios Sakellariou, School of Healthcare Sciences, Cardiff University, Ty Dewi Sant, Heath Park, Cardiff CF14 4YS, United Kingdom. Email:

sakellarioud@cardiff.ac.uk.

HOME MODIFICATIONS AND WAYS OF LIVING WELL

Dikaios Sakellariou

Advances in health care and increased life expectancy have led to an associated increased prevalence of particular disabling conditions, and the associated need for people to learn how to live with their ongoing effects (Mol 2006). However, people living with these conditions and health care professionals often need to negotiate what kind of life people want to live and what interventions might be helpful, given their different understandings about the ‘good’ expected from these interventions (Good 1994, Hunt and Mattingly 1998). Home modifications are one intervention used to enable people to continue living in their own home and restore the house as a place that fosters social relationships (Heywood 2005).

Modifications may increase independence, make the house a safer place, and reduce the need for paid care services and long term residential care (Stark 2004, Stark et al. 2009).

Modifications also provide an arena where different actors enact diverging perspectives of moral values about what is good and how to achieve it (Johansson 2013), as I illustrate in this article. By examining one couple’s experiences trying to modify their home in Wales, United Kingdom, to accommodate motor neuron disease, I show how they tried to create a way of living. Drawing on a structural, Foucauldian analysis to foreground issues of power (Foucault 1994a, 1994b, 1994c, 2010), and a phenomenological approach (Jackson 1998, 2012, 2013, Mattingly 1998, 2010) to foreground what matters to specific people, I argue that the bridging or otherwise of different notions of the good, depends on how people are positioned within these different understandings.

Motor neuron disease (MND), also known as amyotrophic lateral sclerosis or Lou Gehrig’s disease, is an incurable, neurodegenerative disease of unknown etiology. The average life expectancy after diagnosis is between three and five years. While cognitive function

usually remains intact, during its course MND can lead to complete paralysis of voluntary muscles, affecting functions such as walking, eating, talking, and breathing. People with MND often have to use alternative and augmentative communication devices, and modify their home environment to allow, for example, use of a wheelchair and access to bathing and toileting facilities (Kiernan et al. 2011).

People living with ongoing illnesses or disabilities and health care professionals often focus on different issues when considering care and management options (Frank 1995, Good 1994, Montgomery and Fahey 2001, van der Waal, Capsarie, and Lako 1996). Hunt and Mattingly (1998:267) referred to these different perspectives as “diverse rationalities” and “multiple realities,” suggesting that people living with a disease and health care professionals may use different systems of knowledge to make sense of particular diseases and the necessary actions to make things better. Such different perspectives are widely reported in relation to MND (Brown, Lattimer, and Tudball 2005, Hughes et al. 2005, Pavey, Allen-Collinson, and Pavey 2013, van Teijlingen, Friend, and Kamal 2001). Describing an instance when a professional caregiver took a decision about the initiation of assisted ventilation, without consulting with her, Verwey (2010) offered a potent account of the frustration that can be caused when one rationality dominates others. At question was neither the initiation, nor the timing of ventilation, but the disregard of the wishes of Verwey and her husband, who had MND.

Cox (1992) and Brown (2003) have argued that people with MND and health and social care professionals operate from different standpoints, based on the values they adopt as legitimate. The scientific standpoint adopted by professionals often leads them to focus on functional assessments, adaptations or equipment that can render a functional outcome. People living with MND, however, often focus on what it means for them to live with MND in their local context. Discussing the mechanisms involved in the process of deciding what constitutes

valid knowledge and what does not, Lyotard (1984) described how different kinds of knowledge employ different criteria to establish legitimacy. In this article I discuss how, in the arena of home modifications, establishing and justifying ‘need’ is based on divergent perceptions of not only ‘what should be done’, but also, ‘why’, ‘when’, and ‘who knows best’.

A home in the world: Home modifications and the construction of a good life

The purpose of home modifications in the United Kingdom is to reduce physical barriers from the home environment, and to enable a disabled person to access some areas of their house (Department of Communities and Local Government 2006). Home modifications are recognized as a statutory right in the United Kingdom (Great Britain 1996), and they are carried out through the mandatory provision of disabled facilities grants (DFGs) from local government to all eligible applicants. While the initial impetus for home modifications funding came from the disability rights movement, home modifications were promoted because of their cost effectiveness in relation to other interventions, such as long term residential care (OECD 2003).

A further impetus, closely linked to cost-effectiveness, came from the emergence of what Mold (2011, 2013) called the ‘patient-consumer’ in the United Kingdom. This became visible from the 1960s and into the Thatcher administration in the 1980s. During that time, the emphasis of health and social care shifted from what was perceived to be a patronizing and paternalistic system “to the rights of individuals within increasingly marketized services” (Mold 2011:509). Patient-consumers are expected to make choices that are right for them and assume responsibility for the outcomes of their choices. This focus is reflected in national policy, where home modifications are seen as an “individualised solution to the problems of people experiencing disabling environments” (Department of Communities and Local Government 2006:6). The environment will usually be modified to enable access to a sitting

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

room, a bedroom, a bathroom and toilet, movement within the house, and access into and out of it. These modifications are funded by local governments through the use of DFGs, which are means tested for all adults; in Wales funding is available for up to GBP 36,000 (Welsh Local Government Association 2009). People are given a fixed sum to cover the costs of work approved as necessary by the local government. This emphasis on a combination of cost-effectiveness and individualization of services is reflected in the official documents that provide the regulatory framework for the provision of home modifications. Modifications must 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).

Disabled people who live in Wales and wish to adapt their living environment need to adhere to the following process. First, an application needs to be made through their local government. The next step is a home assessment, usually conducted by an occupational therapist. If the outcome of the assessment supports home modifications for the performance of essential activities, such as going to the bathroom, accessing the front door, using the kitchen, or getting into bed, the application is approved, and a course of action is decided. This usually involves a number of joint visits involving an occupational therapist, builders and other contractors, to fulfil the required modifications, and can be a protracted process. Individuals can also choose to carry out home modifications privately, self-funding the process; this can sometimes be more expeditious.

The good that home modifications aim to produce is an environment with reduced physical barriers, so enabling a disabled person to stay on in their home. All actors involved in home modifications try to achieve this good. This good, however, can be understood in different ways.

A home with reduced physical barriers enables the creation of what Jackson (2012) called a home in the world. A home in the world is a place where one can experience

intersubjective life and feel recognized as a person. Home modifications can help to create a home in the world by enabling activities, such as cooking a meal or sleeping together with one's partner. For Johansson (2013), "the home is one of the major arenas where cultural values and practices are developed, expressed, and acted" (414), and where a good life is created and enacted. A home with limited physical barriers can also contribute to the retention of the locus of care to the home, by enabling some independence. As already noted, this can be cost-effective as it can lead to a decreased need for paid home-based or residential care services (Lansley, McCreadie, and Tinker 2004).

METHODS

In this article, I draw on a narrative-based study conducted in Wales, United Kingdom, between 2011 and 2013, the aim of which was to explore how certain people make sense of living with MND in their local contexts. Participants were recruited through the Welsh branch of the Motor Neuron Disease Association (MNDA). Data collection took place through observations and multiple joint, in-depth interviews (see Sakellariou, Boniface, and Brown 2013 for a detailed discussion of data collection). Seven people in total participated in the study, which resulted in the production of unique narratives for each participant. The seven participants in the study participated in a total of 23 interviews (total time 59 hours), resulting in more than 1000 pages of data (transcribed interviews and field notes from observations).

I draw on the experiences of one participating couple, Dave and Marion, who I interviewed six times over the course of 12 months, for a total of about 11 hours. I have selected their story to illustrate my argument about the creation of a way of living, because of the richness of their account. Dave had a relatively fast-moving variant of MND, and within the course of a few months he had to use a wheelchair, so necessitating home modifications.

Over time, due to the progress of the disease, both Dave and Marion were increasingly anxious about the modifications; they felt they were in a race against time.

Using narratives in health research

People make sense of their life in different ways, finding ways to connect the past with the present, and projecting their self into the future (Ricoeur 1984). Doing so requires the construction of stories that give meaning to a person's life, so that life is experienced as a connected whole, rather than a multitude of fragments in time and space. Mattingly (2010) and Alsaker, Bongaard, and Josephsson (2009) describe narratives as enacted performances, in which people engage to create meaning and make sense out of life events.

Mattingly (1998) also views narratives as event-centered, experience-centered, and meaning-making performances, co-constructed through the interaction of different actors. Following Mattingly (2010:44), I use narratives explicitly to foreground the “unfinished, idiosyncratic, unpredictable, suspenseful qualities of life.” Dave's and Marion's accounts open up the possibility for alternative explanations and interpretations of experiences, as I illustrate below.

The combination of a phenomenological analytical approach (Jackson 1998, 2012, 2013, Mattingly 1998, 2010) with a structural, Foucauldian approach (Foucault 1994a, 1994b, 1994c, 2010) enabled me to focus on different levels of Dave's and Marion's experiences, examining both ‘what should be done’ and ‘who knows best’. In particular, the use of a phenomenological approach foregrounded what really mattered to Dave and Marion, what they hoped for, and what they tried to avoid. Foucault's work on biopolitics as an additional analytical lens enabled me to pay close attention to people and how their experiences were constructed through relations of power. Biopolitics refers to the endeavor to rationalize and control the physical body through processes such as health care. Biopolitics is concerned with

the government of living, the processes through which people and discourses interact to achieve desirable outcomes. The selected design enabled me to explore not only what Dave and Marion did to the world – their actions – but also what the world did to them, and how they interacted with the world around them (Mattingly 1998).

HOME MODIFICATIONS AND THE GOOD LIFE

Dave and Marion were in their late fifties, had been married for more than 30 years, and lived in an urban area in south Wales. At the time of the first interview, Dave had recently retired from his job as an electrician and could still walk short distances. A couple of months into data collection, he had to start using a wheelchair both indoors and outdoors, and had stopped driving. His hands and arms became progressively weaker, and a few months after he had enrolled in the study, he had only some limited movement in his right arm. When I first met them, Dave and Marion had already applied for a DFG, and had just had their needs for home modifications assessed by an occupational therapist. Although Dave and Marion, and the professionals involved in approving and carrying out the modifications, agreed that home modifications were necessary, they had different understandings of why these modifications were necessary and of what they wanted out of them, as the following examples illustrate.

First scene: What should be done

The through-floor lift

The first modification that the occupational therapist recommended was a stairlift so that Dave could access the second floor of the house, where the bedroom, the bathroom and the toilet were located. However, a stairlift requires a person to be able to get on and off a wheelchair. Before the lift had been installed, the occupational therapist reconsidered this decision because

of the progressive nature of MND, and changed the recommendation to a through-floor lift to enable Dave to get to the second floor without having to transfer out of his wheelchair.

Initially, however, the occupational therapist was reluctant to approve this procedure because of restricted space to turn the wheelchair upon exit from the lift on the first floor.

Dave and Marion, however, did not think that was a problem:

Marion: We've thought of ways of making it bigger from the other rooms, so Dave can turn the wheelchair. So, we just meet hopefully with the engineer and the surveyor from the council, whether they can talk together...

Dave: All they are whining about is six inches, which is nothing really. The engineer can find a way around it, you know.

While they waited for the lift to be installed, Dave had to remain on the ground floor of their house, with their downstairs dining room functioning as their bedroom:

Dikaios: How are you coping at the moment then...?

Dave: With the stairs? I don't go upstairs at all. We've moved the bed down in the dining room and I sleep, well, we both sleep, in there.

Marion: We sleep downstairs, yes. 'Cause he was trying, with one stick, holding on to the stairs and then one stick. His good leg is the right leg, and he was getting up the stairs, but then he was getting more and more tired.

These delays resulted in major disruptions in their daily life:

Dave: The decision has to be made where the through-floor lift goes because it depends on what room there is upstairs. If we...if it goes where I think they want it to go, they have enough room for two single beds...that would be alright, you know.

Marion: Because they did say they could make an en suite, like a shower room, so that would be fine. Uhm, but, I think Dave may need the bed quite soon...he's trying to hang on, but if it carries on too much...if Dave has the bed in there, uhm, we haven't

got enough room there and I'll have to put the other bed upstairs. Then, I will have to find...I don't know where I'll sleep, you know. Whether I'll sleep on the settee, but it's not really comfortable for me either. Because I have a back condition.

The occupational therapist working with Dave and Marion made numerous assumptions about how they would live their life, and what would be best for them. These assumptions related not only to the progression of MND, which is inherently unpredictable, but also to how Marion would live her life. Marion was worried that she might need to sleep on the sofa if the installation of the lift was further delayed, or she and Dave would need to sleep in separate rooms. For Dave and Marion, mobility meant more than moving from one place to another; it meant having access to their bedroom and being able to share a bed. This was not possible in the dining room because of space restrictions. A lift was a device that enabled them to enact an important aspect of their relationship, i.e. share a bed.

The way people make sense of their life with MND influences their needs, choice of services, and negotiation of their illness. Individuals, their families and friends, and health and social care professionals have their own ideas of how life is to be lived, what needs to be done, how, and why. They create what Kleinman (1988) called the different personal and interpersonal meanings of the disease and of life with it. These different meanings influence what different people prioritize. Functional abilities and independence, survival, personal relationships, personal growth, or comfort can all be perceived as important for people living with MND, their families, and the professionals who support them, but they cannot be organized hierarchically to privilege survival and functional abilities. As a case in point, research suggests that people living with MND sometimes choose to not have gastrostomy to facilitate nutritional intake, even though the procedure could prolong their life (Albert et al. 2001). The different perspectives that people have about living with a progressive, incurable

illness are constantly negotiated, with everybody involved trying to establish a common ground for understanding what is good and what has to be avoided (Letiche 2008).

Understanding what should be done, with what effect, and why, requires understanding the expectations and assumptions of everybody involved. This understanding is achieved little by little, through synthesizing the different voices and making sense of the different goods at stake for particular actors (Mattingly 2010). It is not always easy to combine these different goods. Dave wanted to be able to use the bathroom, which was upstairs, and sleep in the same room as his wife. Hence he wanted a lift. However, others considered Dave's and Marion's wish to sleep together to be a desire rather than a need. As Johansson (2013) said, in the context of home modifications, needs are about "performing activities on a basic standard level," while desires are associated with an "*excessive* standard level" (422, my emphasis). So, although the lift would enable access to a shared bedroom, this was not a priority from the perspective of the professionals.

Second scene: Why and when it should be done

Getting to the bathroom

The main reason the lift was approved was because it was the most cost-efficient way to provide access to the bathroom, cheaper than constructing a new bathroom on the ground floor. In other words, the lift was deemed necessary, and thus good, by the professionals, so enabling Dave to carry out, in a cost-effective way, activities such as washing himself.

Marion: Dave will be able to sit down and be able to wash himself then, rather than me...doing it between us. But it's very hard, you know....

Dave: In the kitchen.

Marion: And it's coming up to the winter now, so I'm hoping...

Dave: Hopefully it will be done then...it will be warmer.

Marion: It will be upstairs...they couldn't do it downstairs, There were too many problems with the drains and everything. Uhm, but it's better really, because everything will be out of the way and we will have a bit more room downstairs to move around and...because at the moment, with the beds there...these beds are quite long, they are longer than a normal bed, so, we've still got a table in there and I just have a chair myself and Dave needs the wheelchair..so, it's not really ideal...there is still all the other furniture there too, so it's a bit crowded. I mean, it should have been there already, but it takes time.

Dave had to strip wash in the kitchen for several months while waiting for the through-floor lift to be installed and the bathroom to be adapted. Dave and Marion had to enact a practice of care, strip washing in the kitchen, which was not ideal for either of them. The delay in getting the lift installed was partly because of the involvement of several different actors.

Marion: Well, the surveyor came to do the drawings and he has to do them on the computer. He said, he would submit that to the council. I said, "can you order the lift now?", he said "no", they have to have an official order from the council for the lift.

Dave: If they get the official order, they start the manufacture of the lift, but they will also then be coming into the house for a site meeting with the builder they are using to do the holes. Probably, when it comes to that, they will give us a definite day when to come in and do it.

Delays in home modifications can threaten possibilities for participation in daily life (Johansson, Josephsson, and Lilja 2009), leading to feelings of loss of control (Aujoulat, Luminet, and Deccache 2007). Loss of access and use of all areas of their house can be frustrating and disempowering, limiting the possibilities people have for action (Johansson et al. 2009). Dave could not access the first floor of the house where the bathroom was, and this caused a major disruption in his and Marion's life. The lack of access to space was further

complicated by a loss of control over time.

Month after month there were unexpected delays, and appointments with the social services and the contractors took a long time to arrange. Hogden and colleagues (2012) suggest that people living with MND often focus on living in the present, making decisions that have a direct impact on their daily life, whereas health professionals focus on the future, on an unpredictable future can lead to starkly different expectations of outcomes. This is complicated by the progressive nature of MND and the associated functional decline, which means that interpretations of what is a desirable outcome for one's life change constantly. Being chased by time in a very pragmatic way, Dave and Marion were in turn chasing up the services responsible for installing the lift. They knew that Dave's functional abilities would decline and they were anxious for the modifications to be in place. However, the average duration of major home modifications in Wales, from application to completion, was 386 days in 2012 (National Assembly for Wales 2012). With an average prognosis of three to five years survival after diagnosis, MND is not a condition that gives people the luxury of time.

The fact that Dave had a progressive, incurable condition, and that the professionals knew that the modifications would take a long time, was unsettling for all involved. Everybody was in agreement about what should be done, but they had different understandings of why it had to be done and how they should collaborate.

Third scene: Who knows best

“And they say ...”

I return to Dave's and Marion's wish to share a bedroom. Dave and Marion had to negotiate different priorities and positions in their daily experience of living with MND. This was challenging when they felt that their wishes on how they wanted to live with MND were sidelined. When negotiations regarding the modifications began, before the decision to apply

for the through-floor lift was taken, a health care professional suggested converting their front room downstairs into a toilet and a bedroom. Marion was concerned they would not be able to fit a double bed or two single beds in there.

Marion: And they [health and social care professionals] say, “well, Dave can sleep there because he would probably need a special bed quite soon”, and then I said “well, I would need a single bed then”, “oh, you will have to sleep somewhere else” and I said “no, that’s not possible”, because...

Dave: We want to stay together...

Marion: We want to stay together, but apart from that, he does sometimes need me in the night, so... it’s this sort of adaptability... I can’t understand.

The installation of a through-floor lift meant that parts of the second floor had to be reconfigured, to allow for an entry point for and access to the lift. Once again, this was done without much consideration to the couple’s wish to sleep together. As Marion said,

and then she [the occupational therapist] wanted upstairs to knock a hole between the middle bedroom and the front bedroom, where we would sleep. And I said, “why would you do that?”, because she is widening the doorway, and she said, “oh, so there is more room for you”. And I said, “well no, not really, because you are cutting down on where we would put the furniture, the bed.”

Dave and Marion felt that they had to constantly defend their wishes against those of the professionals with whom they were liaising. To them, a house was a “place to foster relationships” (Heywood 2005:543), and they expected modifications to respect that basic belief. However, the good they were after, sleeping together, was recognized only as a desire, not as a true need. Only essential modifications were eligible for funding assistance, and sleeping together was not understood as a good in the official discourse.

This divergence between what one couple wished for, and what the professionals decided they needed, points to different worldviews. For Jackson different worldviews can be viewed “not as theories about the world but as existential means of achieving viable ways of living in and with the world” (2012:123), or as different, and complementing ways of constructing a life one is satisfied with. The question then becomes, how can these different worldviews best inform each other to construct a good life?

NEGOTIATING A WAY OF LIVING

People living with the effects of an illness often try to produce a life that they can recognize as good. To achieve this, they try to find a balance between what they want, and what other people want for them, between what is available and what is not. In engaging with the world around them, people often focus on what is at stake for them and for other people around them (Biehl 2013, Frank 2000, Jackson 2013, Mattingly 2010). Anthropological inquiry focuses increasingly on the intersubjectivity of human life, and how this is experienced in different situations, by exploring how people interact with the world around them to achieve outcomes that can be recognized as good, and how is the subject constructed through these interactions.

The achievement of a good life requires negotiation between different expectations associated with that life. As I have illustrated, Dave and Marion tried to create possibilities for action, despite the difficult circumstances they were facing. They tried to create a *modus vivendi*, a way of living, that would bridge the discrepancy between expectations seen as desires and expectations seen as needs. Although everybody seemed to be in agreement about ‘what should be done’ (through-floor lift), there were divergent opinions on other questions, such as ‘why it should be done’. In other words, different actors expected different goods from the lift. For Dave and Marion, a through-floor lift ought to give them access to a bedroom large enough for them to share. A DFG, however, pays for modifications that are “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).

Dave’s and Marion’s expectation was that home modifications would attend to their sociality and the intersubjective nature of MND. Whether being able to share a bedroom would be understood as a need or a desire, and the implications of this, were dependent on official (professional and political) discourses on home modifications that prioritize outcomes relating to identified needs. In these discourses, a need refers to activities that the person must carry out to mitigate the effects of functional limitations. Other activities, not strictly related to this definition, are seen as relating to desires, and thus become the realm of personal wishes beyond the limits of professional responsibility. While professionals tried to accommodate Dave and Marion’s desire to share a bedroom, the main reason that the lift was recommended was to provide access to the bathroom (a need).

Dave and Marion were frustrated because of the existence of what they saw as a maze of procedures introduced by the representatives of health and social care systems. People, out of choice or not, often have to learn to navigate new environments, as Jackson has elaborated for migrants:

Perhaps the worst fate that can befall any human being is to be stripped of the power to play any part in deciding the course of his or her life, to be rendered passive before impersonal forces he or she cannot comprehend and with which he or she cannot negotiate (2013:149).

Dave and Marion had not changed physical environments. But they were recent migrants to illness, learning to live with its constraints. They had to learn to navigate a new environment, one where disability and illness were not only focal points in their life, but also domains of professional power, beyond their control (Foucault, 1994c). Within that environment, Dave and Marion tried to construct their desires of what Johansson (2013:414)

called “eligible needs.” They did this by presenting a story that foregrounded what was at stake for them.

Dave and Marion actively sought solutions that worked in the context of their life. They tried to be actors in their life, “to make certain things happen, to bring about desirable endings, to search for possibilities that lead in hopeful directions” (Mattingly 1998:47). They wanted to be able to share a bedroom, and they were tired of having to wash in the kitchen. They wanted to be able to construct a life they were satisfied with. Home modifications was the solution they were offered. However, for Dave and Marion, the desirable ending, or the good, was also dependent on an official discourse of a true need versus a desire. Needs trump desire.

The different questions that actors try to answer, about what good is desired, and why, and who can decide about it, are not really separate; one influences the other. Even though different actors might agree on a solution (such as a lift), the expectations that people have of it will shape the enactment of that solution in the context of a person’s life. These expectations are arranged hierarchically: expectations relating to a need are prioritized over expectations relating to desires. Ultimately, the construction of certain expectations as needs requires access to power, in the sense of control over the way people can live their life.

If power for Foucault (1994c) is diffused in ideologies and practices that govern daily life, then where should one look to find it? How can power be located and how can it be shared out? Dave and Marion wanted the power to act and do what they thought was best, but did not know how to get that power. They were left with no choice other than to “powerfully participate in the discourse that defines them as weak” (Holstein and Gubrium 2005:491). They felt reassured that the professionals shared their understanding of what needed to be done, but it soon became obvious that their different expectations posed a threat to Dave’s and Marion’s ability to be actors in their own life. By entrusting their hopes for the construction of

a desired good to professional knowledge, Dave and Marion felt objectified by that knowledge and dominated by its power.

Knowledge is not always a means of domination and possession of knowledge does not necessarily lead to power. The two are dynamic and inherently contextual. Knowledge and power are neither bad or good. Although power might be located anywhere, it is constructed through knowledge that is perceived as legitimate and hence 'true'. True knowledge constructs true needs. Dave and Marion could not get the modifications they wanted, the way they wanted them, unless a professional approved them. Health and social care professionals themselves, however, often operate within strict boundaries and rather than having themselves absolute decision-making power, they act as representatives of a broader system of power and knowledge.

Although they often had limited control over the world around them, Dave and Marion were actors in their story, working in interaction with other actors (Jackson 1998). Through persistent negotiations and reminding professionals what they expected from the intervention, they tried to find a balance between "what is given and what is chosen", to borrow Jackson's (1998:21) phrase. They did this through attention not only on 'what should be done', but on other relevant questions, such as why, and when. They ultimately achieved a way of living, to address not only what was seen as a need, but also what they desired. Unfortunately, this was only achieved a few weeks before Dave died.

Dave and Marion's experiences tell a larger story about how the construction of some expectations as needs, and others as desires, serves to subjugate people to certain technologies. These technologies are invariably those that are deemed to be necessary, appropriate, and reasonable, following a neo-liberal language of cost-effectiveness, where often "desire is of no value" (Biehl 2007:413). In this language, desires can be seen as liabilities. But, if desires are seen as liabilities, how does this neo-liberal language construct people who desire a good life?

CONCLUDING REMARKS

By focusing on home modifications, I have foregrounded the different expectations associated with one specific intervention. I argue that while different actors might agree about what should be done, the enactment of an outcome recognized by everybody as a good requires negotiation between the different expectations associated with that outcome. Here I wanted to explore what happens when different perspectives about the good come in contact, and need to interact with each other, and in doing this, I have highlighted the role of power in relation to the construction of needs and desires. Anthropological understandings on the enactment of the good will be enriched by the examination of more specific questions, relating to how these interactions can work toward mending intersubjective life, or cause further ruptures to it.

Dave and Marion worked toward certain desired outcomes and tried to avoid other undesirable ones, and in so doing they sought to position themselves as central characters in their story. However, while they tried to enact their expectations about the good they associated with the through-floor lift, they had to work hard in order to get these expectations recognized as needs. They were caught between two different worldviews: their own, where what mattered was to be able to sleep together, and the worldview articulated in official documentation and enacted by professionals, where what mattered was efficiency and functionality.

ACKNOWLEDGMENTS

The study that provided the empirical material for this article 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 anonymity. Different publications use different pseudonyms to refer to participants, to reduce the chance of tracking

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

down multiple quotations to a single participant. I wish to thank the editor of this journal, and the three anonymous reviewers, for very helpful comments during the review process. I also wish to thank Margaret McGrath for her critical feedback on an earlier draft of this article. I am grateful to Dave and Marion for sharing their story with me.

REFERENCES

Albert, S., P. Murphy, M. Del Bene, L. Rowland, and H. Mitsumoto

2001 Incidence and predictors of PEG placement in ALS/MND. *Journal of the Neurological Sciences* 191(1-2):115-119.

Alsaker, S., R. Bongaard, and S. Josephsson

2009 Studying narrative-in-action in women with chronic rheumatic conditions. *Qualitative Health Research* 19(8):1154-1161.

Aujoulat, I., O. Luminet, and A. Deccache

2007 The perspective of patients on their experience of powerlessness. *Qualitative Health Research* 17(6):772-785.

Biehl, J.

2007 A life: Between psychiatric drugs and social abandonment. *In* Subjectivity; Ethnographic Investigations. J. Biehl, B. Good, and A. Kleinman, eds. Pp. 397-421. Berkeley, CA: University of California Press.

_____.

2013 *Vita; Life in a Zone of Social Abandonment*. Berkeley, CA: University of California Press.

Brown, J.

2003 User, carer and professional experiences of care in motor neurone disease. *Primary Health Care Research and Development* 4:207-217.

Brown, J., V. Lattimer, and T. Tudball

2005 An investigation of patients and providers' views of services for motor neurone disease. *British Journal of Neuroscience Nursing* 1(5):249-252.

Cox, D.

1992 Perspectives of motor neurone disease. *Clinical Rehabilitation* 6:333-339.

Department of Communities and Local Government

2006 *Delivering Housing Adaptations for Disabled People: A Good Practice Guide*. London: Department of Communities and Local Government.

Foucault, M.

1994a Technologies of the self. *In Ethics; Essential Works of Foucault 1954-1984*. P. Rabinow, ed. Pp. 223-251. Transl. R. Hurley et al. London: Penguin Books.

1994b The ethics of the concern of the self as a practice of freedom. *In Ethics; Essential works of Foucault 1954-1984*. P. Rabinow, ed. Pp. 281-301. Transl. R. Hurley et al. London: Penguin Books.

1994c The subject and power. *In Power; Essential Works of Foucault 1954-1984*. J. Faubion, ed. Pp. 326-348. Transl. R. Hurley et al. London: Penguin Books.

_____.

2010 *The Government of Self and Others; Lectures at the College de France*.

Transl. G. Burchell. Basingstoke, UK: Palgrave Macmillan.

Frank, A.

1995 *The Wounded Storyteller; Body, Illness and Ethics*. Chicago, IL: The University of Chicago Press.

Frank, G.

2000 *Venus on Wheels; Two Decades of Dialogue on Disability, Biography, and Being Female in America*. Berkeley, CA: University of California Press.

Good, B.

1994 *Medicine, Rationality and Experience*. Cambridge, UK: Cambridge University Press.

Great Britain

1996 *Housing Grants, Construction and Regeneration Act 1996*. London: The Stationery Office.

Heywood, F.

2005 *Adaptation: Altering the house to restore the home*. *Housing Studies* 20(4):531-547.

Hogden, A., D. Greenfield, P. Nugus, and M. Kiernan

2012 *What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives*. *Patient Preference and Adherence* 6:829-838.

Holstein, J. and J. Gubrium

2005 *Interpretive practice and social action*. In *Handbook of Qualitative*

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

Research. 3rd ed. N. Denzin, Y. Lincoln, eds. Pp. 483-506. Thousand Oaks, CA: SAGE Publications, Inc.

Hughes, R., A. Sinha, I. Higginson, K. Down, and N. Leigh

2005 Living with motor neurone disease: Lives, experiences of services and suggestions for change. *Health and Social Care in the Community* 13(1):64-74.

Hunt, L. and C. Mattingly

1998 Diverse rationalities and multiple realities in illness and healing. *Medical Anthropology Quarterly* 12(3):267-272.

Jackson, M.

1998 *Minima Ethnographica; Intersubjectivity and the Anthropological Project*. Chicago, IL: University of Chicago Press.

_____.

2012 *Between One and One Another*. Berkeley, CA: University of California Press.

_____.

2013 *Lifeworlds; Essays in Existential Anthropology*. Chicago, IL: University of Chicago Press.

Johansson, K.

2013 Have they done what they should? Moral reasoning in the context of translating older person's everyday problems into eligible needs for home modification services. *Medical Anthropology Quarterly* 27(3):414-433.

Johansson, K., S. Josephsson, and M. Lilja

2009 Creating possibilities for action in the presence of environmental barriers in the process of 'ageing in place'. *Ageing and Society* 29(1):49-70.

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

Kiernan, M., S. Vucic, B. Cheah, M. Turner, A. Eisen, O. Hardiman, J. Burrell, and M. Zoing

2011 Amyotrophic lateral sclerosis. *The Lancet* 377(9769):942-955.

Kleinman, A.

1988 *The Illness Narratives*. New York: Basic Books.

Lansley, P., C. McCreadie, and A. Tinker

2004 Can adapting the homes of older people and providing assistive technology pay its way? *Age and Ageing* 33:571-576.

Letiche, H.

2008 *Making Healthcare Care*. Charlotte, NC: IAP.

Lyotard, J. F.

1984 *The Postmodern Condition: A Report on Knowledge*. Transl. G.

Bennington, B. Massumi. Manchester, UK: Manchester University Press.

Mattingly, C.

1998 *Healing Dramas and Clinical Plots*. Cambridge, UK: Cambridge University Press.

_____.

2010 *The Paradox of Hope; Journeys through a Clinical Borderland*. Berkeley, CA: University of California Press.

Mol, A.

2006 Proving or improving; On healthcare research as a form of self-reflection. *Qualitative Health Research* 16(3):405-414.

Mold, A.

2011 Making the patient-consumer in Margaret Thatcher's Britain. *The Historical Journal* 54(2):509-528.

-
- 2013 Repositioning the patient; Patient organizations, consumerism, and autonomy in Britain during the 1960s and 1970s. *Bulletin of the History of Medicine* 87(2):225-249.
- Montgomery, A. and T. Fahey
- 2001 How do patients' treatment preferences compare with those of clinicians? *Quality in Health Care* 10(Suppl 1):i39-i43.
- National Assembly for Wales
- 2012 *Housing for Disabled Children and Families*. Cardiff, UK: National Assembly for Wales
- Organisation for Economic Development and Cooperation (OECD).
- 2003 *Ageing, Housing, and Urban Development*. Paris, France: Organisation for Economic Cooperation and Development.
- Pavey, A., J. Allen-Collinson, and T. Pavey
- 2013 The lived experience of diagnosis delivery in motor neurone disease: A sociological-phenomenological study. *Sociological Research Online* 18(2). <http://www.socresonline.org.uk/18/2/11.html>
- Ricoeur, P.
- 1984 *Time and Narrative*, volume 1. K. Transl. McLaughlin, D. Pellauer. Chicago, IL: University of Chicago Press.
- Sakellariou, D., G. Boniface, and P. Brown
- 2013 Using joint interviews in a narrative-based study on illness experiences. *Qualitative Health Research* 23(11):1563-1570.
- Stark, S.
- 2004 Removing environmental barriers in the homes of older people with

Sakellariou, D. Home modifications and ways of living well. *Medical Anthropology*. In press. <http://dx.doi.org/10.1080/01459740.2015.1012614>

disabilities improves occupational performance. *Occupational Therapy Journal of Research; Occupation, Participation and Health* 24:32-39.

Stark, S., A. Landsbaum, J.L. Palmer, E.K. Somerville, and J.C. Morris

2009 Client-centered home modifications improve daily activity performance of older people. *Canadian Journal of Occupational Therapy* 76:235-244.

Van der Waal, M., A. Capsarie, and C. Lako

1996 Quality of care: A comparison of preferences between medical specialists and patients with chronic diseases. *Social Science & Medicine* 42(5):643-649.

Van Teijlingen, E., E. Friend, and A. Kamal

2001 Service use and needs of people with motor neurone disease and their carers in Scotland. *Health and Social Care in the Community* 9(6):397-403.

Verwey, M.

2010 Proximity and distance in palliative care from the perspective of primary caregiver. *Medische Anthropologie* 22(1):31-46.

Welsh Local Government Association

2009 *Housing Adaptations for People with Disabilities*. Cardiff, UK: Welsh Local Government Association.