Theorising rehabilitation: actors and parameters shaping normality, liminality and depersonalisation in a UK hospital

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Abstract

Sociological concern for rehabilitation remains limited. This paper aims to contribute to rehabilitation theory. It examines two units of a specialist rehabilitation hospital in the UK (amputee and neurological services) by focusing on the key actors involved-families, patients, staff- and the parameters shaping their relationships. The findings extend previous theoretical understandings of rehabilitation in three themes: normality, liminality, and depersonalisation. We argue, first: normality is constantly negotiated amongst the different actors. This complicates existing works' critique of rehabilitation as reproducing the ideology of normality. Second, discourses produced during acute care shape the inpatient rehabilitation experience. This calls attention to the pre-rehabilitation phase and complicates existing works' emphasis on the transition from inpatient stay to the time of discharge. Finally, inpatient rehabilitation is notable in rendering the adverse effects of depersonalisation apparent. It combines the bureaucracy of a regular hospital ward, with institutionalising aspects of long-term care. These findings have a potential to enhance practice as well as knowledge. We call for a deeper sociological attention, combining theory-building with empirical data for a better understanding of inpatient rehabilitation.

Keywords: inpatient rehabilitation, amputee and neurological services, normality, liminality, depersonalisation

Introduction

This paper aims to contribute to rehabilitation theory. It uses data collected on the role of the family in two units of a specialist rehabilitation hospital in the UK, as a window onto the more general functioning of disability-related inpatient rehabilitation.

Sociologists of health and illness have paid limited attention to the study of rehabilitation (exceptions include Papadimitriou and Stone 2011, Wiles *et al.* 2002, 2004). Sociological concerns for rehabilitation tend to derive either from rehabilitation sciences (Gibson 2016, Hammell 2006) or disability studies (Oliver 1993, Finkelstein 2004). Yet disability-related inpatient rehabilitation deserves sociological attention, because it is a distinctive process compared to other areas of medicine, which aims "to facilitate a transition to a life with a new bodily status" (Bezmez *et al.* 2019: 7, Hammell 2006).

This paper helps fill this gap by focusing on the key actors involved in rehabilitation - families, patients, staff- and the parameters shaping their relationships. Data on family role is helpful in initiating such discussion. Practically, families are integral to this process. Yet as formal agents they lie outside of the dominant, traditional models of rehabilitation (Bezmez *et al.* 2019). As they sometimes complement rehabilitation practices, and at other times challenge them, their encounters with other actors help unfold some of rehabilitation's particularities.

Our reseach extends rehabilitation theory in three ways: First, the findings complicate existing work's emphasis on rehabilitation as reproducing the ideology of normality (Oliver 1993, Hammell 2006). This paper depicts normality as being negotiated amongst the different actors. Second, the findings complicate discussions on rehabilitation as a liminal phase (Devlieger *et al.* 2007, Arntzen *et al.* 2015, Hammell 2006). Research often focuses on the transition from inpatient rehabilitation to the time after discharge (Wiles *et al.* 2004, Arntzen *et al.* 2015). Our findings draw attention to the transition from acute care to inpatient rehabilitation. Finally, we focus on the "depersonalising" character of inpatient rehabilitation.

We argue that disability-related inpatient rehabilitation is notable, for it is neither community nor acute care. This position makes the adverse effects of depersonalisation especially apparent. The two sites in this study, amputee and neurological services, contribute to these findings in different ways, depending on impairment-specific factors, and inpatient stay duration.

The focus on these two sites contributes also to the empirical literature: First, our review for this paper displayed a dearth of research analysing rehabilitation for distinct impairment groups simultaneously. Second, existing literature on amputation-related rehabilitation is relatively limited and derives mainly from medical and rehabilitation sciences (exceptions include Messinger 2009, NiMhurchadha *et al.* 2013 and Cohen 2012). Third, there is extensive research on neurological rehabilitation. Yet it largely describes the rehabilitation experience of one actor, mostly the patient-e. g of the client-centred approach (Van de Velde *et al.* 2016), of goal setting (Holliday *et al.* 2007) etc.-. Our goal is to better understand the functioning of rehabilitation as an institution, by exploring diverse actors' relationships and the parameters shaping these.

Rehabilitation theory: quest for sociological contemplation

Our aim is not to provide an exhaustive summary of rehabilitation theory, but explore some key trends in the relevant writing from disability studies and rehabilitation sciences. Parallel to others (Gibson 2016, McPherson *et al*. 2015, Whyte 2007, Siegert *et al*. 2005), we argue that theoretical reflections on rehabilitation are limited. A heightened sociological focus, in which theory and lived experience nourish each other, could achieve a better understanding of rehabilitation as an institution.

Within disability studies, the tendency has been to criticize rehabilitation as an oppressive process, shaped by an ideology of normality (Oliver 1993; Abberley 1995, Finkelstein 2004). Such criticism highlights the biomedical assumptions underlying

rehabilitation. However it also means that disability studies' interest in the complexities of the lived experience of rehabilitation remains restricted. These include how ideology might operate in practice, and whether rights-based rehabilitation might promote disability equality (Shakespeare *et al.* 2018). Thus, in spite of the growing interest in the field (Arntzen *et al.* 2015, Crisp 2000, Bezmez 2016), the everyday functioning of rehabilitation and its theory remain under-researched.

Although there is encompassing rehabilitation sciences literature, as rehabilitation scholars pointed out (McPherson *et al.* 2015, Whyte 2007), "…[T]heory development has been undervalued in rehabilitation" (Siegert *et al*. 2005: 1493). Roughly, this literature comprises two orientations towards rehabilitation theory. The first draws on disability studies and critically analyzes rehabilitation as a process, that employs biomedical frameworks and reproduces social biases (Gibson 2016, Hammell 2006). It introduces disability scholars' critique of rehabilitation, to rehabilitation professionals, contributing to the overcoming of disciplinary boundaries, and boundaries between practice and theory. Yet, again, it presents rehabilitation as a relatively unambiguous enterprise, whose assumptions regarding normality and difference reproduce social norms and power relations.

The second orientation also highlights the insufficient attention directed at theory. Yet its rather uncritical approach focuses on theory to accomplish "'clinical' aims" (McPherson *et al.* 2015: 9). In spite of a hint about the role of the environment, enhancement of human functioning is central (Whyte 2008: 208). Development of a sounder theory is proposed for the sake of a rehabilitation science with more status, better resources and credibility, which might increase patients' adherence to rehabilitation programmes (Siegert *et al*. 2005: 1498).

In this paper, we analyse field data to complicate these discussions. Although there is some prominent empirical work with potential to contribute to rehabilitation theory (e.g. Cott *et al*. 2007, Papadimitriou and Cott 2015, Van de Velde *et al*. 2016), this potential remains

unsufficiently explored. Rehabilitation could be better understood with a rich combination of theory-building and empirical data: a deeper sociological interest would be a step towards this goal.

Methods

This paper's fieldwork was part of a project that explored how disability-related rehabilitation operated in the UK, with an emphasis on the role of the family. Two key research questions guided that project: What role do families play during inpatient rehabilitation? How do disabled people experience their involvement? The project was funded by the European Union's Horizon 2020 research programme. Ethical approval was obtained from NHS Health Research Authority.

For this paper, we used data on family role to describe the rehabilitation process in the two units. Next, this process is analysed in light of the negotiations between different actors, and the parameters shaping these. Finally, this analysis' contribution to rehabilitation theory is explored.

Data collection

Data were collected in the amputee and neurological services of a specialist rehabilitation hospital from October 2016 to February 2017. In the amputee unit, patients mostly experienced below knee amputation, usually following a long period of disease, often diabetes or circulatory problems. In the neurological services, patients had experienced brain injury or a disease that often involved fatigue, changes in the cognition, mood, and behavior and degrees of memory loss, among other impairments. Patients in the amputee unit stayed in the hospital for several weeks, whereas neurological patients could stay as long as several months.

The fieldwork comprised semi-structured in-depth interviews, focus-group discussions and participant observation. Interviews were conducted with 10 patients (6 amputee, 4 neurological services) and 8 family members (3 amputee, 5 neurological services). Interviews lasted from 7 minutes to 2 hours, depending on participants' energy level: majority lasted about an hour. Patients' ages ranged from 40 to 81, majority being in their 70s. Table 1 below summarises patient characteristics.

Table 1: Patient characteristics

Patients	**Unit**	**Gender**	**Age**
P1	Neurology	Male	70s
P2	Neurology	Female	40s
P3	Amputee	Female	70s
P4	Amputee	Female	70s
P5	Amputee	Female	70s
P6	Amputee	Female	70s
P7	Amputee	Male	60s
P8	Neurology	Female	50s
P9	Amputee	Male	80s
P10	Neurology	Male	70s

Three focus-group discussions included doctors (n=4), nurses (n=5), and therapists (2 physiotherapists, 4 occupational therapists), and lasted around 90 minutes. All doctors were consultants in rehabilitation medicine. One had retired. Most health professionals were serving in both units. Participant observation was undertaken with 5 visiting families (2 amputee, 3 neurological services). 5 interviews were conducted with academics. Purposive sampling technique was used. A staff member initiated first contact with participants, who could speak

and consent; then the researcher met patients and families. Participants were asked about two leading themes: First, their views regarding their and other actors' participation in rehabilitation were explored. Second, their thoughts on how this participation shaped the rehabilitation process were discussed. Families and patients were also asked about their future plans. Preliminary findings were discussed with academics.

Data analysis

All interviews were recorded and transcribed. Patients were anonymised as P, families as F, doctors as D, therapists as T and nurses as N. We performed thematic analysis and followed Braun and Clarke's (2006) six steps: After multiple rereading, we coded the data to find key patterns of family role and classified these in three categories: roles to bring the patient back to her old self, to personalise rehabilitation and to increase patient autonomy. Next, we undertook a second round of analysis of each role and focused on how and in light of which parameters these were discussed among key actors. This analysis highlighted actors' ambivalences regarding recovery, their negotiations reflecting this ambivalence and multiple parameters shaping these. A reevaluation of this analysis demonstrated that activities performed by families to bring the patient's old self back and to personalise rehabilitation could be discussed together as different phases of the actors' negotiations surrounding normality. Our findings on patient autonomy did not substantially contribute to existing literature, where issues of autonomy have been discussed widely. Thus, even though data on patient autonomy is still there, we prioritised aspects of rehabilitation that extend prior knowledge. Next, these findings were refined to analyse their contribution to rehabilitation theory, highlighting three key themes: normality, liminality and depersonalisation. The paper's structure reflects these rounds of analyses.

Challenges

The key challenge related to conducting research with neurological patients. Even though the inclusion criteria ensured that patients had capacity to consent and speak, field experience exposed the difficulties of such encounters. Patients were quickly tired; appointments were rescheduled, interviews were cancelled or kept very brief. Consequently, greater weight was put on to interviews with patients with amputations, families, focus group discussions, and participant observation.

Findings

Families take on multiple tasks during inpatient rehabilitation. A significant proportion of these are oriented towards getting the patient's "old self" back.

The following is a descriptive account of the two units in light of families', patients' and staff's negotiations surrounding such family efforts.

Getting the patient's old self back: amputee unit

Most patients in this unit had had surgery only recently (P4 18 days, P5 17 days prior to the interview). Following a 4-day stay in acute care, they had been transferred to the rehabilitation hospital. On the interview date, the majority had been in rehabilitation for 10 to 14 days, which may be about the total inpatient time spent following surgery. Thus, the specific aspects of the process of getting back to the old self discussed here happen soon after surgery, during the first couple of weeks of inpatient rehabilitation, often followed by discharge.

Although families were at the very early stages of the limb loss experience, interviews revealed that following the initial impact of facing impairment, they often had a relatively clear idea about amputation's meaning and what was expected to happen next. Two discourses were noticable: First, it was emphasised that this was a physical change in the body and not

personality. A sense of relief was brought by an understanding of change happening at the surface, with the deeper aspects of self remaining untouched.

> P3: (Talking about her husband's response) "He said, 'You only had your leg off…You're still the same person'"

Second, there was a relatively clear understanding of how one could bring back the look and the physical functioning of the body with the use of a prosthesis. P4's son F4a commented:

> …I did a lot of research online…Mum's going to be disabled but not in a way that some people are...I was trying to encourage her…to get her prosthetic leg…and then I said, 'you're not going to be disabled anymore'.

Thus, the aftermath of amputation surgery is filled with the hope of prosthesis, the return of physical outlook and functioning, along with the emphasis on the patient being the same person, despite the limb loss.

The patients' responses to this hope were ambiguous, combining excitement with doubt. P4 comments on her family's response:

> …They started to talk about legs and…prosthesis…it was reassuring in a way, cos I hadn't even thought about the future, just thought about being a cripple.

Later, when P4 was asked about *her* expectations regarding the time after discharge, she sounded more concerned and humble:

> Well, I'm hoping that I can get back to some form of normality, I know I might not be able to do what I did before quite, but I feel that if we can get some sort of life together as it was….

P6's account had a similar cautious tone. There was hope: "… they have to take your measurement in and send away for the leg. I hope I get it." Yet P6 knew that the prospects of a new leg were not certain:

> Not everybody gets a leg… that chap…he couldn't get no leg. He was too fat…and other people can't get it because their other leg is bad, yes and if the wound doesn't heal up you won't get a leg…

Thus, patients' attitudes towards the promise of the prosthesis combined hope and excitement with doubt and fear.

From staff's perspective, the discourse surrounding prosthesis was a challenge to cope with. D1 and D2 explain how prosthesis might not be appropriate for a patient for reasons including the level of amputation, the refashioning of the stump, patient's ability and willingness and previous health conditions. One therapist talks about a relevant experience:

> …We got one guy up and he…couldn't breath…and his wife was shouting at him "Can you just try a bit harder dear?" and I'm like, "I think you better sit down at this moment"… It was because she wanted to go, be able to go out and do things and she wanted him to be able to drive …actually he doesn't need a leg…to do all these things.

Thus, interviews with staff demonstrated that the drive to return to the normality that existed prior to the amputation, did not originate from medical staff and was perceived as a challenge.

However, staff approach this challenge with ambiguity. The same therapist explains a preference not to overtly communicate that a prosthesis might not work for the patient:

> It's not my job to tell them this… I want them to try and resolve it themselves. Because…if I say: "You're not going to manage a leg", the wife is then going to say: "It's your fault; you wouldn't give him one". So, it's trying to get everybody to talk and listen to what everybody has to say…

Hence, the coming to terms with the possible unsuitableness of a prosthesis is partially postponed to the time after discharge.

Getting the patient's old self back: neurological services

In neurological services, the duration of inpatient rehabilitation is longer. Commonly patients stay for 3 to 6 months (N1). Some patients stayed for even 2 or 3 years (N3). This longer duration makes it possible to observe key actors' negotiations of normality over time. .

Similar to the amputation unit, at the outset, families' quest for getting the patient's old self back prevails. T2 refers to families' expectations:

> … families often want patients to walk and they come here with such … severe problems.

F7a talks about their initial expectations from rehabilitation when they were first transferred from acute care:

> …well our expectations of the (hospital) were very high because when P7 was in intensive care … they were only concentrating on her actual medical conditions… we felt that they weren't addressing the actual rehabilitation of the (condition)…you know more intensive physiotherapy so… we had assumed that when she got here that it would be full-on intensive…

Yet, soon after the initial transfer (e.g. two weeks in P7's case), high-set expectations are replaced by disappointment. Families witness that they are introduced to a "slow" process that is about "bowels, bladders, skin care, having a bath…" (D3). F7a explains:

> I think she'd been here nearly two weeks and there was nothing on her sheet in her room…and so we've been a little bit disappointed.

At this stage, the disappointment in rehabilitation results in the transfer of the responsibility for recovery from staff's shoulders onto the patient. F7a explains how she tried to motivate P7 when their expectations from rehabilitation were undermined. She said to her:

> …You know P7, you're probably the only one that can change what they're saying…You know how you motivate yourself…they can only do so much.

F1 comments on how she motivated P1 at the earlier stages of rehabilitation in another hospital. She said to him: "We need to do this…It's going to be painful, but you only get out of it, what you put into it".

From patients' perspective, rehabilitation is more about the potential of returning home than physical recovery. When P1 was asked about how rehabilitation was going for him, he mentioned that it was not going quick enough. When asked whether he wanted to see improvement faster, he replied: "…to be able to go back home…". On several occasions he made clear this was his main motive: "I need to [do alright] Otherwise I can't get home". Similarly, when P2 was asked about her plans for after discharge, she replied: "to go and have some fun with my family". Hence, patients accommodate families' expectations in the hope for returning home. N2 argued that patients had a better insight about what they could achieve:

> …I think the patients, it depends on their … cognition and stuff … but they have more insight into what is going to be achievable I think…

> …a lot of the time I think they [patients] feel pressure from the family to over achieve or set these … goals…I guess to… reassure them…

As opposed to the amputee unit, in neurological services staff cannot construct the formation of a new normality as something that families and patients must negotiate amongst themselves. They must engage with this process more actively. Yet, this engagement is not straightforward and contains conflicting approaches. At the earlier stages, staff exert special effort to involve families in the planning of the process to manage their expectations. D3 explains:

> We use the goal setting process here, where the key worker is with the family and the patient to look at setting goals and then trying to make that more realistic…

This joint goal-setting process helps families feel better. F7a refers to their meeting with staff:

> …we had the big meeting with all…the physiotherapist, occupational therapist, psychologists even and felt a bit better…, because we could see that there was a kind of a plan…

Families start imagining new ways of being with the patient:

> …I suppose our expectations now are that we would like her to be able to be independent in as much as not relying on people for everything. So, I mean if she doesn't walk again… she could still lead a fairly normal life…(F7a)

Yet, as with the amputee unit, ambiguity prevails in how staff manages this situation.

Along with the emphasis on "joint goal setting", some staff members highlight the significance of "optimistic realism" (D3), refering to how they manage families' expectations without diminishing hope for recovery:

> …Often one of the key things people want is to walk and if you really think people are not going to walk you might have to say that to be honest…but I would say to people: "Prove me wrong! … and if you can come back and walk in, then I'll, no one will be happier. (D4)

In time, families' approach to rehabilitation changes, shifting from high-set expectations for recovery, to the transformation of everyday life during the inpatient stay. The focus lies on the reproduction of the patient's everyday life before hospitalisation. First, families try to reintroduce patients' former routines. Examples include bringing in food or drinks (F7a), reading newspapers (F1), playing games (F2), watching TV (F2), putting on make-up (F7a), taking the patient out for a cup of coffee (F2). Second, families try to personalise the patients' environment by decorating/rearranging their room. Rooms are embellished with photos from family and friends (P2, P7); F2 rearranged P2's room by moving the wardrobe that blocked the window; and F1 talked with P1 about the new decoration for the upcoming Christmas. Food appeared as specifically important. When the researcher asked P8, who did not have family visiting, whether he needed anything, P8 was explicit: KitKat, Crisps, and blackcurrant juice. At this stage of everyday life reproduction, families confront rehabilitation's biomedical, bureaucratic face, aiming at risk aversion. F2 states:

> …If you're confident in taking the person…for a walk up the corridor or out in the wheelchair, you can. But if you think… you couldn't manage it…then don't… because obviously if you mess up, that's them that's going to get hurt…

Some staff are critical about this risk averse approach. D3 states:

> … I'm getting really frightened about the whole situation now, people feeling frightened of taking their loved one out because if they have a fall you have to fill in so many internal reports.…The thing is how do we… overcome the fear

> to say, their loved one is a person; they're now in a wheelchair yes, but they're still your partner or your son or daughter… take them out…We have to go through so many risk assessments round it"

D4 adds: "That's not healthy at all… Life is a risky business and most people are reasonable folk".

Yet, other staff members bolster this risk averse approach. N3 complains:

> …We've had patients here…started their rehabilitation and when they've been up in wheelchairs, their relatives have taken them outside and given them a cigarette.

Thus, inside the rehabilitation hospital, there is little room for "life as a risky business", as D4 put it.

Discussion

This section analyses these findings in two categories: The first one focuses on key actors' negotiations surrounding normality and the parameters shaping them. The second category explores this discussion's contribution to rehabilitation theory.

Actors, negotiations and parameters

Actors' ambiguous approaches In both units, key actors have an ambiguous relationship with normality. Actors can relate to normality ambiguously at a certain point in time (mainly in the amputee unit), or they can change their approach over the course of the inpatient stay (mainly in neurological services). In the amputee unit, the family might emerge as *the* key representative of this ideology as it sets hope on the use of a prosthesis. Simultaneously, families' emphases on the patient remaining the same person, facilitates the imagery of a transformed life together.

The patient might embrace the promise of a prosthesis in order not to be a "cripple" (P4); simultaneously the lived experience of rehabilitation generates doubts about this promise. Thus, space for new forms of normality is created. Staff emerge as *the* most passionate contestants of the excitement surrounding prosthesis; yet this does not necessarily translate into an effort to manage the process. The table below summarises these ambivalent positions.

Table 2: Actors and Approaches in the Amputee Unit

Family	Discourse about the patient being the same person
	Hoping for prosthesis and the return of physical functioning
Patient	Hoping for prosthesis and the return of physical functioning
	Doubts about prosthesis, imagining a new normality
Staff	Challenging normality discursively
	Letting family relationships deal with normality

In neurological services, the long duration of inpatient stay makes it possible to observe these actors' approaches to normality over time. The table below divides this time into three phases (early, intermediate, late).

Table 3: Actors and Approaches in Neurological Services

	Families	Patients	Staff
Early	Want the patient's old self back, expectations set on rehabilitation	Focus on going back home (accommodating families' approach)	Try to lower families' expectations through rehabilitation as a "slow" process
Intermediate	Want the patient's old self back, expectations set on the patient	Focus on going back home (accomodating families' approach)	• Lower families' expectations through joint goal setting • Raise families' expectations through the discourse on "optimistic realism"
Late	Imagine a new normal, personalising the everyday life	Focus on going back home (in harmony with families' approach)	Complicate the transition to a new normality through the enforcement of hospital regulations

In practice, this categorisation is not as clear-cut, since the actors' approaches diffuse across timespans. Nevertheless, the table is useful for analytical purposes. Analysed vertically, the table demonstrates that throughout the phases, the patients' approaches to normality remain relatively consistent, whereas families' and staff's approaches change. From the early to the late phase, families move towards a more flexible understanding of what their new "normal" might look like. At the late phase they start imagining a new life without full recovery, which becomes visible in their efforts to rebuild a new everyday life inside the hospital. For staff, the early phase comprises an effort to deconstruct the normality ideology; whereas the late phase serves to undermine these early efforts. Through the enforcement of health and safety related hospital regulations, it hampers the possibility of translating the aspiration for a new normal into practice. The intermediate phase illustrates staff's ambivalence towards normality most vividly. As joint goal setting serves to deconstruct the dominant ideology of normality, the discourse on "optimistic realism" serves a counteracting function.

Normality negotiated In light of these diverse approaches, in both units key actors negotiate normality. In the amputee unit, families and patients emerge as *the* most vocal actors of this negotiation. Staff on the other hand, although contesting the excitement surrounding prosthesis discursively, remain in the background practically. Thus, families and patients emerge as the key drivers of the reproduction of normality, and staff's lack of involvement contributes to it indirectly. Following the 10 to 14 days inpatient stay, the ambivalence regarding normality prevails, possibly to be grappled with after discharge.

In the neurological services, negotiations are different to the amputee unit in the sense that families and staff emerge as the key actors and patients slip into the background. As opposed to the amputee unit, where the two most vocal actors' ambivalent approaches to normality appeared to be in relative harmony, in neurological services, in each phase of the inpatient stay, families' and staff's relationships are prone to tension. Furthermore, the characteristics of this tension transform throughout these phases.

Analysed horizontally, table 2 above, helps identify these tensions. The tension during the early phase contributes to the questioning of the normality ideology. The tension during the late phase undermines the prior efforts to construct a new "normal". The intermediate phase is an in-between stage, containing both trends. Ultimately, neurological inpatient rehabilitation cannot facilitate the exercise of a new "normal" practically, even though its participants agree on its prominence discursively. Similarities and differences between the two units can be understood better considering the key parameters shaping such negotiations.

Parameters The table below summarises the parameters shaping inpatient rehabilitation in both units. These derive from the field findings and have been abstracted to form five headings. They are interrelated and can influence the process in similar or unit-specific ways.

Table 4: Parameters shaping both units

1. Inpatient stay duration
2. Impairment-specific factors
3. Discourses produced in acute care
4. Biomedical assumptions
5. Lived experience of rehabilitation

Inpatient stay duration: In both units, the inpatient stay duration influences the extent to which staff participate in these negotitations. In the amputee unit, the relatively short duration allows staff to refrain from a potentially charged conversation about the use of prosthesis. Whereas in neurological services, the long duration of inpatient stay makes the avoidance of such conversation impossible. Thus, staff become more active participants of the negotiation.

The difference in the inpatient stay duration also shapes actors' approaches to normality. In neurological services, families are consistently exposed to a myriad of encounters with staff and patients, and they modify their approach. In the amputee unit, the actors' negotiations and positions resemble more a snapshot taken from an inpatient rehabilitation hospital. For a careful observer this snapshot would become more discernable in its relation to the pre- and post-rehabilitation phases.

Impairment-specific factors: Methodological challenges encountered while interviewing participants in neurological services, demonstrate that cognitive/behavioural changes, memory loss and fatigue can influence the prospects of the patients' voices to be heard. In several occasions patients displayed readiness for families to take on a more active role that they themselves possibly felt too tired to assume. For instance P1 stated that health professionals

should inform families better, so that these could then pass on that information to the patient. In the amputee unit, patients are more at the forefront of the relationships inside the hospital.

Impairment-specific factors can also impact these actors' approaches to normality. For instance in the amputee unit, the special meanings attached to limb loss influence families' and patients' approaches to a new life with impairment. The physical manifestations of bodily change in limb loss are perceived as self-evident. D4 comments:

> …I think that's quite a clear disability, isn't it, you haven't got a leg anymore…

Also, reference points in popular culture give clues about it. T1, mentions the influence of paralympic games:

> …Paralympics have made my [life] really quite difficult…the number of people that come in, two weeks after Rio and say: 'Can I have a blade?'… a lot of it is about being normal …

Another impairment-specific factor regarding amputation in this hospital, relates to it having occurred following a chronic condition rather than a sudden accident. Some patients had a period of chronic pain and a prior amputation of a toe (P5); others had had a leg bypass (P3). Thus, although the initial hearing of an amputation generated "shock" (P4) and "devastation" (F4a), nevertheless there was earlier anticipation of a future amputation. Thus, patients and families had time to be exposed to and contemplate on the cultural connotations of amputation, and the promise of a prosthesis. P5 commented on her family's response to the news:

> Well I think they had anticipated because I think they… knew that there wasn't a lot more pain I could take.

Neurological impairment is different in several ways. First, often there are no obvious external manifestations of physical change. Thus popular disability discourses are not useful to make sense of what has happened. One therapist commented:

> …some of our maybe higher functioning patients, …they look as if there's nothing wrong with them, have difficulties, because family often don't understand the full implication of a brain injury.

Second, there might be alterations in the patient's personality, which makes it difficult for families to search for the "same" person underneath. N2 stated:

> …if we had like somebody recover but not recover the same…we have had families say: "they're not my husband anymore."

Nevertheless, families' high expectations from rehabilitation to bring the patient's old self back, persist. Instead of disability-related reference points in popular culture and a "self-evident" impairment, here, the uncertainty regarding the path to recovery is central. D4 refers to this uncertainty:

> I think the longer one spends (time) in medicine, the more times you know that you don't know … People have done things that I've never thought would happen.

Similarly, during acute care many families had felt that the patient might die (F8, F9, F2) and yet they could transfer to a rehabilitation hospital. This created hope for further recovery. D4 comments on his encounter with the father of one of the patients:

> …I had a patient not so long ago where the Dad said: Well we were told he was going to die, he didn't… we've actually cheated death…so therefore … we're going to carry on improving to a significant acceptable level"

Thus, the uncertainty regarding neurological recovery, reinforces the hope to return to normality. In the amputee unit, the "self-evident" nature of limb loss, opened space for the formulation of a new normality ("you're still the same person") from the very beginning. In neurological services, the imagery of a normal can appear over the longer course of the inpatient stay.

Discourses produced in acute care: In both units, discourses produced in acute care work to reproduce the ideology of normality. In the amputee unit, this reproduction shapes families' and patients' approaches to prostheses; in neurological services, it influences families' high-set hopes for recovery. The latter is particularly effective at the early stage of the inpatient stay, because subsequent rehabilitation experience transforms family attitudes.

Regarding amputation, the aforementioned popular discourses surrounding limb loss and prosthesis seem to shape the attitudes of acute care staff. One therapist commented:

> I think sometimes the problem with surgery is that…when they finish with having a leg off, the only thing the surgeon has got left to say is 'you can have a leg', because there isn't any more consolation prize…

Similarly, rehabilitation staff (D4, D3, T2, N4) also complain about discourses produced in neurological acute care. D4 comments:

> …People I think in other places want to offer hope and sometimes the notion of coming to a specialist rehab centre is built up with great expectation that we are going to be able to work some form of miracle.

N4 comments:

> …I think that often comes from the acute doesn't it, from like the neurosurgeon…

Thus, in neurological conditions, even though changes in the mindset make it difficult to find the "same" person, acute care discourses continue offering hope to return to normality. This combines with families' confidence in the patient, who has "cheated death" and creates "a glimmer that their loved one is going to come back" (N5).

Biomedical assumptions: Staff's biomedical assumptions shape the inpatient rehabilitation process in both units. However, in the cases explored for this paper, these biomedical assumptions did not become visible in the pursuit of restoring physical functioning. They manifested themselves in more subtle ways, specifically in staff's perceptions about what rehabilitation *is not*. For instance, in the amputee unit, they appeared in staff's perception that their involvement in a charged conversation with family and patients regarding prosthesis is "*not* their job". In the neurological services, the same tendency emerged in some staff's perception of rehabilitation as *not* an arena to bolster the introduction of the patient's everyday life routines, but as a process where any potential physical harm resulting from such an introduction should be prevented. In both examples, in indirect and subtle ways rehabilitation is drawn onto the medical sphere.

Yet even here, a careful reading of staff statements, raises doubts about the extent to which these practices derive from their biomedical assumptions and not pragmatic concerns. When the therapist justifies her lack of involvement by stating: "Because…if I say: 'You're not going to manage a leg', the wife is then going to say: 'It's your fault; you wouldn't give him one'", she expresses a pragmatic concern about becoming the family's scapegoat. Similarly, in neurological services, staff's pragmatic concerns shape their risk averse approach to

rehabilitation. For instance, D3 and D4 refer to staff's "fear of being sued" in case something might go wrong (D4). D4 states: "It's the Americanisation, you know it's that…is there medical negligence and all this sort of stuff".

Thus, biomedical assumptions do play a role in inpatient rehabilitation, but in indirect and subtle ways that are also prompted by staff's pragmatic concerns. This does not suggest that subtle workings of biomedical assumptions are insignificant or less impactful. This suggests that the workings of biomedical assumptions deserve a nuanced exploration.

Finally, in both units, patients' lived experience of rehabilitation emerges as the sole consistent factor to promote a new normal. Yet, its impact in this study is less noticeable, due to the short duration of inpatient stay in the amputee unit, and impairment-specific factors that lower patients' voices in neurological services.

Contemplating rehabilitation

The above discussion compels us to refine existing rehabilitation theory in three themes: normality, liminality and depersonalisation.

Normality Critical literature drawing on disability studies (Oliver 1993) and rehabilitation sciences (Gibson 2016, Hammell 2006), recognise rehabilitation as a process, shaped by power relationships and an ideology of normality. Accordingly, power relationships are oppressive, with the direction of the oppression flowing from the rehabilitation enterprise towards the disabled person. Furthermore normality is understood to be shaped by biomedical assumptions prioritising physiological functioning over remaining aspects of life.

This study's findings complicate these arguments in several respects: First, they show that normality, rather than being imposed by one actor over another, is constantly negotiated

amongst diverse actors. Second, these actors' relationships to normality are ambiguous. Sometimes they can contribute to the deconstruction of normality and other times reproduce it. They can relate to normality ambiguously at a certain point in time or change their approach throughout the process. Third, biomedical assumptions emerge as one among many other factors to shape negotiations surrounding normality. Furthermore, when these do play a role, this can become visible in indirect and subtle ways. Fourth, actors, approaches, negotiations and parameters can emerge in similar or unit-specific ways. Thus, rehabilitation's relationship with normality is complicated and deserves multifaceted lenses.

Limited but valuable empirical work comment on some of these points. McPherson *et al.* (2004) and Bright *et al*. (2020) draw attention to the multitude ways in which outpatients hope to recover following a lifechanging condition. Similarly, Wiles *et al*. (2008) and Ostler *et al*. (2014) demonstrate that patients can accomodate contradicting ideas about recovery. There is also few studies highlighting the importance of time in inpatient rehabilitation. Van de Velde *et al.* (2016) emphasise patients' shifting prioties during neurological rehabilitation and Papadimitriou and Stone (2011) discuss human temporality in inpatient rehabilitation. This work is important but rare, with its potential contribution to rehabilitation theory remaining largely unexplored.

Liminality These findings compel us to rethink the concept of liminality in relation to inpatient rehabilitation. The transitory character of rehabilitation has been discussed by several scholars (Devlieger *et al.* 2007, Arntzen *et al.* 2015), and some have referred also to the concept of liminality (e.g. Hammell, 2006). The acquisition of impairment often comes with a "biographical disruption" (Bury 1982) and involves a transition to a new, often socially more devalued, bodily state. This is where rehabilitation occurs, referring to the liminal phase, between the separation phase, when impairment is acquired and the individual is cut off from her former social status and everyday life, and the reintegration phase, when the patient is

discharged and expected to make the transition to a new bodily state and social status- (Hammell 2006: 112-116). Yet research has often focused on the second part of this liminal state, the time of discharge (e.g. Wiles *et al.* 2004, Cott *et al.* 2007). It demonstrated that rehabilitation may serve to delay the "re-orientation of the sense of self in relation to the changed body and life circumstances" (Arntzen *et al.* 2015: 312), that if the rehabilitation process is not able to prepare the individual for a new life, the liminal phase can continue long into the years after discharge.

Our study calls attention to the impact of the pre-inpatient rehabilitation phase (acute care) on rehabilitation. Few studies hint at this impact. Wiles *et al*. (2002) mention that expectations of recovery "may be encouraged by health professionals in acute settings" (841). Hitzig *et al*.'s (2020) recent discussion of the role of rehabilitation consultants in acute care on rehabilitation is exceptional. Our findings suggest that the pre-rehabilitation phase's impact on inpatient rehabilitation deserves more in-depth scrutiny. Although the two units have their differences in how this impact manifests itself- e.g. in neurological services this impact diminishes over time-, both units call for attention to the acute care phase.

Depersonalisation The discussion on the challenges regarding the reproduction of the everyday life in neurological services refines rehabilitation theory further. Inpatient rehabilitation is situated in the context of UK's statutory health service system. It functions within a bureaucratic structure that assumes its constituents will cooperate. Yet, this assumption contradicts some of the key tenets of rehabilitation. The goal of disability-related inpatient rehabilitation is not to cure, but to facilitate the transition to a new life. The time spent in inpatient care is often longer than in other treatments (Bezmez *et al.* 2019). The requirements of the context, in which this transition can be facilitated (e.g. the need to reproduce everday life whilst still inside the hospital) contradict with the conventional requirements of a bureaucratic health care structure. Disability-related inpatient rehabilitation makes this contradiction particularly apparent. Few

empirical work pointed at this, again with limited connections to theory. For instance, Cott *et al*. (2007) argue that rehabilitation services for stroke patients pay little attention to "a return to meaningful activities and roles" as defined by patients (1566) and suggest that this is related to rehabilitation's being based on an acute care model rather than a chronic disease management model.

Theoretically, Twigg's work (1997, 1999) on the spatial ordering of care at home, especially her reference to "depersonalisation" (1999: 387) can help us understand this aspect better. Twigg (1999) explains depersonalisation in reference to Goffman's (1961) account of the Total Institution as: "…to lose your name, your history, your identity; it is to be literally and metaphorically stripped, made subject to anonymous and collective regimes" (387). "Depersonalisation" can happen because institutions deprive patients of their familiar everyday life routines and environments. Her examples of institutional settings include residential homes (386), day centres (395), and hospital wards (1997: 228). This analysis is useful, because it contributes to a theoretical understanding of late-phase neurological rehabilitation, where hospital risk averse culture undermined families' efforts to reproduce familiar everyday life routines inside the hospital. Yet inpatient rehabilitation is not just another example like residential homes, hospital wards and day centres. It is neither community nor acute care; it provides long-term care, often associated with community care, in a hospital, often associated with acute care. Thus the clash between the requirements of both environments when they overlap in a single setting makes the adverse effects of depersonalisation especially apparent, which is worthy of theoretical exploration.

Conclusion

This paper aimed to contribute to rehabilitation theory. Combining empirical data with theory-building, it utilised data on family role in inpatient rehabilitation, to understand the general functioning of rehabilitation as an institution. Data were collected in the amputee and

neurological services of a UK hospital and analysed in light of the key actors, their negotiations, the parameters shaping them and this analysis' contribution to rehabilitation theory, which appeared in three themes: normality, liminality, and depersonalisation. At a lower scale of analysis, this study also demonstrated the similar and unit-specific ways in which these three themes become visible.

Sociological interest into disability-related inpatient rehabilitation can contribute to a multitude of scholarly writing. It fills in a gap in disability studies through an in-depth analysis of empirical data from the field capturing the lived experience of rehabilitation. It fills in a gap in rehabilitation sciences by introducing a critical yet nuanced discussion of how rehabilitation operates. Such sociological interest contributes also to the sociology of health and illness due to its potential to combine an analysis of bodily difference, within a context that integrates aspects of longterm and acute care simultaneously. As such, it presents a fruitful ground for theoretical exploration of the overlaps between sociology of the body and sociologies of medical and social care.

The study has several limitations: First, the theoretical conclusions of this study are not generalisable. To produce sounder conclusions, further research is needed in diverse health cultures and impairment groups. For instance, it would be interesting to focus on health settings with lower levels of regulation seeing how this structure potentially impacts degrees of (de)personalisation. Similarly, research in settings with diverse cultural understandings of bodily difference and an analysis of their impact on actors' negotiations can contribute to the question of theoretical generalisability. Further research that compares rehabilitation to process in other health care settings would also contribute to the production of sounder theoretical conclusions. For instance are there other settings-e.g. hospitals focusing on mental health- that combine acute care bureaucracy with the institutionalising aspects of long-term care? If yes, what can this comparison tell us about the specificities of rehabilitation? Second, the challenge

regarding interviews with patients with neurological impairments limited the prospects for patients' voices in that unit to be heard. Further research should improve interview process, perhaps in collaboration with speech therapists. This paper is a modest attempt to consider rehabilitation theory and to point at the myriad research gaps waiting to be filled in.

These theoretical considerations and empirical evidence discussed here also have policy relevance. The experience of rehabilitation might be improved by pointing at the concrete actors, discourses, practices, relationships and factors that shape the process. How, by whom, to what degree, why exactly is rehabilitation reproducing existing social biases? Which aspect of the whole institution needs to be improved as a priority? Which aspect needs to be conserved? Such questions might be answered through in-depth field analysis in combination with theoretical considerations. Changes to professional training and rehabilitation management might follow.

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