

ORIGINAL ARTICLE

Can a disability studies-medical sociology rapprochement help re-value the work disabled people do within their rehabilitation?

Harriet Cooper¹  | Fiona Poland² | Swati Kale² | Tom Shakespeare³

¹Norwich Medical School, University of East Anglia, Norwich, UK

²School of Health Sciences, University of East Anglia, Norwich, UK

³International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, UK

Correspondence

Harriet Cooper, Norwich Medical School, University of East Anglia, NR4 7TJ, Norwich, UK.
Email: h.cooper@uea.ac.uk

Funding information

National Institute for Health and Care Research Applied Research Collaboration East of England at Cambridge and Peterborough NHS Foundation Trust

Abstract

This paper draws attention to the health-related work that disabled people do when engaging with rehabilitation services. Medical sociology has a rich history of looking at the 'illness work' that patients do, while disability studies scholars have explored the cultural value placed upon paid work and the effects on social status of being unable to work. Yet, a longstanding *froideur* between these two disciplines, which have fundamentally opposed ontologies of illness and disability, means that neither discipline has attended closely to the rehabilitation-related work that disabled people do. The concept of 'adjusting' to illness highlights seemingly irreconcilable disciplinary differences. Yet this article argues that the notion of 'adjustment work' can elucidate the socio-political character of the work disabled people do in their rehabilitation, which could create a more substantial and sustainable dialogue on this subject between disability studies and medical sociology. To make this case, we discuss interview data from the *Rights-based Rehabilitation* project, which sought to explore disabled people's lived experiences of rehabilitation.

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KEYWORDS

disability studies, disabled people, medical sociology, patient and public involvement, rehabilitation, value, work

INTRODUCTION

This paper draws attention to the health-related work that disabled people do when engaging with rehabilitation services. Medical sociology has a rich history of looking at the ‘illness work’ that patients do (Corbin & Strauss, 1985), while in disability studies, scholars have explored the cultural value placed upon paid work and the effects on social status of being unable to work (Gleeson, 1999; Taylor, 2004). Yet, due in part to a longstanding tension between these two disciplines stemming from fundamentally opposed ontologies of illness and disability, neither field has attended closely to the rehabilitation-related work that disabled people do. The concept of ‘adjusting’ to illness, in particular, divides opinion and highlights seemingly irreconcilable disciplinary differences (Thomas, 2010). We argue in this article that a notion of ‘adjustment work’ can elucidate the socio-political character of the work disabled people do in their rehabilitation and can create a more substantial and sustainable dialogue between disability studies and medical sociology on this subject. We make this case by discussing interview data from the *Rights-based Rehabilitation* project, which aimed to explore disabled people’s lived experiences of rehabilitation. The project created opportunities for dialogue between the estranged disciplines of disability studies, medical sociology and rehabilitation science.

A starting point for this research was the lack of alignment between the fields of medical sociology, disability studies and rehabilitation science in how they have conceptualised and oriented towards rehabilitation. This non-alignment has created silos between the bodies of research relating to these areas (Cooper, 2021; Shakespeare et al., 2018). Moreover, disabled people’s experiences of rehabilitation are underrepresented across these three fields (Cooper, 2021; Shakespeare et al., 2018), as we explain. The World Health Organization (WHO) defines rehabilitation as a ‘set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments’ (2011, p. 96). While starting with this definition, as we engaged with the cross-disciplinary research literature, it seemed less robust, particularly in terms of how it centred a functional model of disability, which is at odds with the approaches used in disability studies. As our study sought to privilege disabled people’s perspectives, we also came to expand our definition of rehabilitation to include what our participants viewed as rehabilitation.

We therefore begin by reviewing how the concepts of ‘work’ and ‘adjustment’ have been understood within medical sociology and disability studies, exploring the relevance of these terms for studying disabled people’s rehabilitation experience. We then develop this review by briefly explaining how rehabilitation is differently understood across medical sociology, disability studies and rehabilitation science, introducing the *Rights-based Rehabilitation* doctoral study and its rationale. We explain our methodology and then present data from our qualitative interviews which emphasise the hard work that disabled people put into their rehabilitation. This work comprised both the exertion needed to make rehabilitation happen within the context of an overstretched health service and the work of doing rehabilitation, which included adjusting, sometimes abruptly and disruptively, to a new way of life (Bury, 1982; Williams, 1984). In discussing our findings, we firstly centre disability studies scholarship that highlights inequity in how paid

and unpaid work are valued. We argue that this scholarship can enrich discussions of contemporary health discourses of patient responsibility, and of illness work. Secondly, we propose that the concept of 'adjusting' to, or coming to terms with, chronic illness, which is influential within medical sociology but largely met with hostility from disability studies (Thomas, 2010), could itself be 'rehabilitated' for shared use, if disabled people's 'adjustment work' is recognised as work and positioned more fully within its socio-material context. 'Adjustment' can be understood as a site of tension between the two fields, exposing seemingly irreconcilable ontological differences, but therefore offering a potent site to explore a possible rapprochement.

'WORK' AND 'ADJUSTMENT' IN MEDICAL SOCIOLOGY AND DISABILITY STUDIES: CAN THESE TERMS HELP RE-VALUE THE WORK DISABLED PEOPLE DO IN THEIR REHABILITATION?

Conceptualising 'work' has been a focus in both medical sociology and disability studies. Materialist disability scholars have long highlighted the structuring of 'valued citizenship' around a norm of economic productivity (Abberley, 1993; Barnes, 2012; Fadyl et al., 2020; Gleeson, 1999; Taylor, 2004), with specific effects on how disabled people's (sometimes unpaid) contributions to society are seen. For instance, within university contexts, Oliver (1992) and Zarb (1992) developed the 'emancipatory research paradigm', arguing that unless the social and material relations of research production changed, disabled people would continue to be socially excluded, their priorities would not form the basis of research and their status in society would be unchanged. Such ideas were to become influential, and even institutionalised, within the 1990s policy project of 'consumer involvement' in the UK National Health Service (Beresford & Branfield, 2012). Yet, historically, UK disability studies have been reticent to explore disabled people's experiences of engaging with the health service (Shakespeare, 2014), and indeed their health-related work.

By contrast, within medical sociology, Corbin and Strauss (1985) were formulating *illness experience* as a form of work in the 1980s. They described three main categories of patient work, two seen as the 'basic lines of work to be performed daily, weekly, monthly' (p. 225–6): the first category, 'illness work', includes activities such as managing symptoms and taking medication. The second category, 'everyday life work', relates to interactions with family and health professionals, as well as activities of daily living. These terms help to reframe illness as work and thus valorise the patient's active role in managing it (Grue, 2016). Yet, in practice, these two categories may not be distinct from each other, especially in the case of a disabled person engaged in rehabilitation. Rehabilitation may be expressly focussed on (re)learning activities of daily living, perhaps in helping someone to get to grips with everyday life work. It may also involve administrative work within the rehabilitation process: to include extensive ongoing work to seek referrals, (re) book appointments and liaise with services, additional to expected illness work associated with undergoing treatment. Here we adopt this category of 'administrative work', distinct from those used by Corbin and Strauss, as having particular resonance with our data. It partly aligns with Corbin and Strauss' category of 'articulation work', the planning and coordination work required to enact illness-related work, yet it also denotes some distinctive demands placed on the patient in the late 2010s UK health context. At this time, the government's austerity was making it harder for disabled people to access benefits and support (Duffy, 2013; Spartacus Network, 2015; Tizard Centre, 2020; We are Spartacus, 2013). 'Administrative work', a category narrower than 'everyday life work', captures the additional planning and logistical labour of disabled people in the time of our fieldwork.

'Biography work', Corbin and Strauss' (1985) third category, refers to coming to terms with and narrativising chronic illness and connects closely with the term 'adjustment work' that this article will propose. Biography work can be lengthy; it is 'ongoing' (Corbin & Strauss, 1985, p. 231), contrasting with the day-to-day temporality of the other two types of illness work. Biography work chimes with classic work on chronic illness emerging in 1980s medical sociology, including Bury's (1982) notion of biographical disruption and Williams' (1984) attention to the narrative reconstructive work of patients as they attribute illness to a cause. The small sociology of rehabilitation (e.g. Bourke et al., 2015; Papadimitriou & Stone, 2011; Van de Velde, et al., 2012) has particularly attended to Bury's work on chronic illness as an experience where the 'structures of everyday life are disrupted' (1982, p. 169).

This dominant medical sociology framing includes some notion of adjustment to illness (Thomas, 2010) not translating straightforwardly into the context of disability and rehabilitation. For example, the dominance of the adjustment frame can be argued to direct attention away from the social aspects of disabled people's lives, making a more multi-dimensional approach preferable (Shakespeare & Watson, 2010; see also Thomas, 2010). Yet adjustment itself can be understood as a multi-dimensional, multi-actor practice, comprising, for example, the material work of exploring how one's body fits with a new wheelchair together with the concurrent emotional labour (Winance, 2006). Here we work primarily with the notion of adjustment as a product of narrative work central within 1980s sociological studies of illness experience (Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1985; Williams, 1984), while allowing scope for deploying alternative definitions of adjustment in future work on rehabilitation experience.

Thomas (2010) argues that one key site of contestation between medical sociology and disability studies has been their position on adjusting to impairment, which must be seen within the context of the differing ontologies each field gives to 'impairment' and 'illness'. The emphasis on adjustment in medical sociology must be contextualised within the historical dominance of medico-centrism in this area, which constructs illness as a deviant state (Thomas, 2010; Scambler & Scambler, 2010; see also Parsons, 1951). Earlier disability theorists (Barnes & Oliver, 1993; Oliver, 1993) regarded this social deviance paradigm as reinforcing a widely held view of disability as a personal tragedy to be remedied or mitigated by medicine if possible (Scambler & Scambler, 2010).

Here, the idea of 'adjustment' came to be seen as aligned with oppressive expectations placed on disabled people to adapt to the social norms of an able-bodied world, exemplified in practices such as expected walking, and associated specifically with rehabilitation (Oliver, 1993). Also focussing on rehabilitation, Abberley (1995) drew on interview data to critically analyse the liberal humanist ideals in the occupational therapy profession and its focus on self-improvement and self-transformation, seeing 'the adjustment of the client's view of reality [...] as part of the therapy task' (1995, p. 227). Emancipation is therefore figured here as resisting an external, professional demand to adjust. As a result, taking an empirical focus on the internal biography work that disabled people do in rehabilitation appears as potentially antagonistic to the early disability studies project. While the newer field of critical disability studies has since taken up and politicised the issue of disabled people's unseen self-normalising work (e.g. Sheppard, 2020), the fear of disabled people's health-related work being framed in normative terms is not baseless. Within recent UK policy, Corbin and Strauss' (1985) scholarship on 'illness work' has been similarly instrumentalised, presented as work that patients with long-term conditions 'should' do, rather than simply as a set of observations about the work they actually 'do' (Bury, 2010). Bury's observation resonates with other scholars' contention that a moral dimension within the new discourses of patient responsibility became dominant in the UK National Health Service in

the 1990s (Armstrong, 2014; Harris et al., 2010). Discourses of the 'involved', 'active' or 'expert' patient can be said to naturalise and conceal health work (Armstrong, 2014; see also Rose, 1999). This has repercussions in terms of constructing patients as deserving or undeserving of care, perhaps in line with government political concerns.

In this section, a tripartite concept of 'illness work' from medical sociology (Corbin & Strauss, 1985) has provided a starting point to consider the kinds of work disabled people do in their rehabilitation. Disabled people's positioning within the world of work has been a key theme within disability scholarship, although health-related work has been under-theorised here. Corbin and Strauss' (1985) term 'biography work', which refers to the sense-making activity associated with coming to terms with illness, also links with a wider medical sociology focus on adjusting to living with chronic illness. The centrality of this trope of 'adjusting' within medical sociology contrasts dramatically with the hostility of early scholars of disability towards an adjustment paradigm: The latter group places the burden of responsibility to 'adjust' upon society, not upon disabled people.

We briefly note here that the early and ultimately flawed insistence of disability studies on an ontological distinction between illness and disability has proven impossible to sustain as disability studies have become more expansive and inclusive. The expansion of disability studies has also generated several competing models and theories of disability (see e.g. Goodley, 2011); the social model has become more nuanced and developed. This newer thinking can even be seen to influence the rehabilitation sciences and professions, with for example, Gibson (2016) arguing for critical dissection of medicine's normalising standards. Yet, a lingering suspicion of 'the medical' within disability studies has continued to limit empirical research on disabled people's views and experiences of rehabilitation (Shakespeare, 2014; WHO, 2011).

DISABLED PEOPLE'S REHABILITATION: HOW IS IT SEEN WITHIN MEDICAL SOCIOLOGY, DISABILITY STUDIES AND REHABILITATION SCIENCE?

Recognising a gulf between disability studies and rehabilitation science on the subject of rehabilitation, our scoping review sought to map key resonances and differences by examining a selected sample of each literature. Medical sociology literature was also consulted for context and comparison.

Across three major rehabilitation science journals, we identified only a small number of studies which explored participants' views of rehabilitation (Cooper, 2021). Experimental studies of interventions dominated in this field, which centred around biomedical or functional models of disability. Relatedly, in 2011, the *World Report on Disability* highlighted the 'absence of engagement with people with disabilities' in the design, delivery and evaluation of rehabilitation services (WHO, 2011, p. 105). Accordingly, our study sought insight into disabled people's views and experiences of rehabilitation, including physiotherapy, occupational therapy, speech and language therapy, psychological therapies, orthotics and prosthetics, sensory rehabilitation, and other services that study participants characterised as 'rehabilitation'.

Within sociology-in-medicine, the relative lack of empirical research on the lived experience of rehabilitation within the field may well mirror the low value given to rehabilitation as a medical specialty (Bury, 1987). Acute, life-threatening conditions have a higher status in medicine than the chronic conditions that are the focus of rehabilitation medicine (Haldar et al., 2016). As we have seen, within disability studies, the suspicion of medicine as a 'normalising' practice

has negatively influenced the extent to which disabled people's experiences of health and health services have been researched. Shakespeare and Watson (2010) argue that the insistence on disability-as-oppression as a starting point for research has occluded alternative perspectives that may exist within the disability community (Watson, 2002) and contend that more empirical research exploring disabled people's experiences is required. They suggest that inflexibly adhering to any given model may hinder research which promotes the human rights of all disabled people and illustrate the advantages of multidimensional approaches such as the WHO's International Classification of Functioning (ICF) (2001). Indeed, the ICF model is productively adopted by qualitative researchers aligned with the rehabilitation sciences (e.g. Mei et al., 2015), yet is not commonly discussed in disability studies or medical sociology. For example, a systematic review aligned with the rehabilitation sciences (Alford et al., 2015) considered the extent to which ICF is used for eliciting personal narratives of chronic conditions. While identifying only a limited number of studies, this review found interest in biopsychosocial and person-centred approaches to be increasingly widespread.

Thus, disability studies have insufficiently emphasised disabled people's own views and experiences of rehabilitation, possibly then limiting the influence of this field on health and social policy (Shakespeare, 2014; Shakespeare & Watson, 2010). Within medical sociology, rehabilitation has remained relatively invisible. Meanwhile, the rehabilitation sciences have tended to operate within biomedical or functional paradigms, rarely drawing on concepts from disability studies and potentially continuing to embed normative understandings of what a body is and what it does (Gibson, 2016; Whalley Hammell, 2004, 2006). Disabled people are infrequently involved in designing rehabilitation research (Shakespeare et al., 2018; WHO, 2011). *Rights-based Rehabilitation* was conceived to promote greater dialogue between these disciplines.

METHODOLOGY

The data we discuss in this article are drawn from the *Rights-based Rehabilitation* study, which was funded as a doctoral project (2015–2018) at the University of East Anglia by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The project aimed to explore disabled people's views and experiences of rehabilitation services, including their views on how service users could be involved in shaping services. A patient and public involvement (PPI) project advisory group was set up by Harriet Cooper to inform research planning and implementation, its members being disabled people with experience of engaging with a range of rehabilitation services. Harriet Cooper has a lifelong physical impairment, hemiplegia, and has theorised her lived experience of rehabilitation in previous academic-autoethnographic writing (Cooper, 2020). Rehabilitation is a theme that has animated much of co-author and supervisor Tom Shakespeare's recent research output, following his experience of rehabilitation in 2008. Co-author and supervisor Fiona Poland brought expertise on inclusive methodologies and on working with marginalised groups in social research. Co-author and supervisor Swati Kale is a lecturer in physiotherapy with clinical experience, bringing expertise on education and research in the allied health professions.

The project received ethical approval from the Health Research Authority in 2016 and recruited 36 study participants based in the East of England, each living with a long-term physical or sensory impairment and with experience of rehabilitation. Cooper undertook three strands of fieldwork: semi-structured interviews (2017), focus groups (2017) and creative writing fieldwork

workshops (2019). This paper draws on data from only a sub-set of the interviews, selected to illustrate the linked themes of work and adjustment emerging across the data-set. A semi-structured interview method was chosen to enable the researcher to generate context-specific knowledge about the lived experience of rehabilitation (Mason, 2018).

The researcher deployed a pragmatic approach in the study design, centring on abductive critical analysis of the research problem in decision-making about methods (Blaikie, 2007; Creswell & Poth, 2016; Mason, 2018; Morgan, 2014). Given that decisions about study design were being made in continuing consultation with the PPI group, this approach was chosen so as to maximise the accessibility of this planning work for non-academics. Cooper sought to work reflexively with the data, and to explore the interactional specificity of each encounter, yet to engage with the large volume of data collected, a more programmatic thematic approach to analysis was ultimately called for. The researcher analysed each interview individually, making marginal notes on themes and producing mind maps, gradually moving on to build mind maps of the interview dataset as a whole.

Through analysis, Cooper became aware that many participants' narratives identified the time and administrative work they had to dedicate to rehabilitation if they were to gain access to the services they needed, and participants' sense that time was unevenly valued and differentially distributed within their encounters with busy rehabilitation professionals. It is to these issues of 'administrative work' that we turn in the next section; in the subsequent section we consider the work of adjusting to impairment as another category of work.

REHABILITATION AS 'ADMINISTRATIVE WORK'

The theme of rehabilitation as administrative work for the service user was repeatedly seen in the fieldwork. Participant #4 was a young professional living with a life-long physical impairment, who was seeking to continuously engage with rehabilitation activities, such as physiotherapy, to help him maintain his health, fitness and independence over the long term. He recounted to the interviewer a phone conversation with a staff member at a rehabilitation service, who called him on the day of his appointment to postpone it:

And he turned round and went, [*clears throat*] "Well, why can't you just rearrange for tomorrow? We can offer you an appointment for tomorrow. That's what I've been trying to offer you." I said, "I can't do tomorrow." "Why can't you?" And I said, "Not that it's any of your business, but I'm a – I work. I'm not a disabled person in *your* mind, who sits at home counting his tablets and fixing his wheelchair. I actually have a job."

(Participant #4)

[...]

I pay for a PA [personal assistant] to help me and they're all organised and this is what I tried to explain to this guy on the phone. "Why can't you do tomorrow?" "I can't do tomorrow and I can't cancel the PA I've got now. So, I've got to pay for a morning's wage of the PA that if I wasn't going to an [...] appointment I wouldn't have called them in today."

(Participant #4)

In the account he gives here, Participant #4 feels he has to challenge an implicit assumption that his time is disposable and that he is able to change his plans at short notice. In referring to an

imagined individual who ‘sits at home counting his tablets’, Participant #4 invokes a negative trope of the disabled person who is not economically productive, whilst drawing attention to the fact that he himself has a job. This participant refers to waged work here to signify time and social status being valued. When the participant recounts having said, ‘not that it’s any of your business’, this may indicate that he felt that he was being asked to account for his use of his time in a way he experienced as intrusive. In the second excerpt, the participant points out the knock-on effects of this sudden cancellation of an appointment: He has to rearrange his personal assistant (PA) and pay his PA’s wages at a time when he does not otherwise need help. The experience of having his appointment changed thus leads to time-consuming and costly administrative work re-organising his PA’s work pattern.

The administrative work associated with rehabilitation was also given prominence in the narrative of Participant #18, a young professional woman with a relatively rare condition that affected her mobility, diagnosed when she was in her teens. She was well-informed about the biomedical aspects of her condition and had sought to take charge of her rehabilitation. This participant spoke authoritatively about the process of navigating a range of disparate services:

I literally got referred to every department, because the condition doesn’t have clinicians that do everything in one place, it has to be multi-disciplinary. That does, however, mean that it’s a lot of resources that I have to use up [...] it needs to be multi-disciplinary and we just don’t have that in [name of place].

(Participant #18)

Here, the participant’s mention of being referred ‘to every department’ conveys that her rehabilitation is both time-consuming for her and resource-intensive for the NHS. The absence of specialists who ‘do everything in one place’ meant that she did a lot of work relaying information between practitioners, as she later told the interviewer. The treatment she received for one aspect of her condition sometimes had a ‘knock-on effect’ for another aspect of it, and sometimes clinicians ‘didn’t really take [this] into consideration’. These phrases from the transcript highlight the implications of a lack of communication within the multi-disciplinary team: The participant implies that the ‘knock-on effect’ leads to additional illness work for her. The lack of administrative coordination at the level of the service thus leads to demands on her time that are additional to the work of undergoing therapy or following an exercise regimen, which might be expected as part of rehabilitation. Indeed, in Participant #18’s narrative, *she* often appeared as the administrator of her rehabilitation.

Participant #10, a woman in late middle age, had been disabled for several decades and had used many different rehabilitation services over the years, sometimes having to fight to gain access to these. She was living with a condition that was getting worse over time. Her transcript was filled with stories detailing the time taken up both with organising PA support and with getting access to rehabilitation services that would stabilise her condition. She spoke about the interconnections between her social support and health-related support, which could not be disentangled as they were both integral to maintaining her quality of life. She joked rather bitterly about her experience of the administrative work she did to make it all happen:

I can’t retire – I’m very fed up because my husband’s retired and I can’t, I’m still [laughs] going on and on.

(Participant #10)

This joke highlights an important point: Organising rehabilitation is *work* which takes time. For Participant #10, this unrecognised work demands a huge amount of her time and energy, in the

face of shifting goalposts and eligibility criteria. She describes feeling as though she is 'not worth... helping', underscoring her experience of being seen as someone whose social status is low.

Rather than entailing a short, time-bound ('acute') engagement with health services, for many disabled people in this study, including Participant #10, the need for rehabilitation was experienced as sustained. Participants felt that rehabilitation systems were set up to work for people who needed short-term access for an acute issue and did not always accommodate the continuing needs of disabled people. Participant #10 recounted what happened when the NHS tried to withdraw her ongoing physiotherapy:

They said, "oh, we realise that you may have a problem when we discontinue it, but you can refer yourself back to us, [right], um, so you'll have six weeks treatment and then you can refer yourself back," so I said how long would it take to get back on, and it would be another six weeks or something, we worked out the amount of time [...]. I said "look it's easier to keep me on a regular treatment than to, for me to keep referring myself back, because I will do, because I will be so desperate, but each time I will have got worse". And they agreed [...] but that was so traumatic, and during that time I didn't have any physio, so I went downhill again...

(Participant #10)

Here the participant highlights how unhelpful she found this inflexible six-week arrangement, and draws attention to how the rigidity of the bureaucracy, in imposing the six-week wait for a new set of sessions, was itself causing her condition to deteriorate. Implicit in this extract is the participant's administrative work of liaising with the health service and setting up a new referral, which, as we see, she is having to do repeatedly.

REHABILITATION AS 'ADJUSTMENT WORK'

Several participants in this study commented on rehabilitation involving adjustment. Participants undertook 'biography work' as they came to terms with the effects of long-term impairment on their identity and day-to-day routine (Corbin & Strauss, 1985). In this, the study resonates with other qualitative studies in the sociology of rehabilitation (Bourke et al., 2015; Papadimitriou & Stone, 2011) and with influential papers from medical sociology (Bury, 1982; Williams, 1984).

For those with acquired impairments in particular, rehabilitation entailed getting used to a new way of life. This was highlighted when Participant #1 characterised rehabilitation as a 'narrative process', emphasising both the passage of time and the active work individuals did to construct meaning over time. This participant was a man of retirement age, who had lived with a spinal cord injury for several years at the time of the interview. He referred to an experience of psychological therapy coming some years after his inpatient rehabilitation, making clear that he did not think he could have experienced the benefits of it any sooner:

I was pleased I saw a psychologist because I think I was ready then, I was ready for the catharsis and all the talking about what happened to me and all the distress. I was ready to let that go and that must have been the right time – it felt the right time.

(Participant #1)

The repetition of 'ready' three times in this short excerpt, combined with the two references to 'the right time', emphasises this participant's sense of rehabilitation as a process with elements that have to be available within a timeframe that works for the individual. The term 'catharsis'

and the phrase about 'let[ting] that go' depict a therapeutic process that involves a sequence of release, reconciliation and acceptance.

The majority of participants with acquired impairments told the interviewer that they had assumed at the start of the process that they would return to work in a matter of months, but that they had gradually become disillusioned about this. Participant #7 was a middle-aged man who had acquired a brain injury a couple of years prior to the interview and whose identity and sense of meaning was bound up with his work in a blue-collar profession. He spoke frequently about how his life had changed:

Everything is a battle to get up, to get dressed, to play tennis, have a workout, go to [support organisation], to see you, to shave and so here we go again. I'm still adjusting to a life with a brain injury. [...] My quality of life is totally different now, so I'm still adjusting.

(Participant #7)

Here Participant #7 twice explicitly refers to adjusting over time. The qualifier 'still' in both occurrences of the term highlights how much time this process is taking him. He refers to a range of activities that are now a 'battle', suggesting both that these were straightforward for him before he acquired this impairment and that they now require huge amounts of energy. The participant gives narrative significance to this series of routine activities by listing them in full, inviting the reader to recognise the way in which 'everyday life work' has effectively become 'illness work' in the context of cognitive impairment. As we see, adjusting to the new difficulty associated with such tasks also involves 'biography work'.

Some participants had been supported through their transition by occupational therapists, who were helping them to identify alternative vocational pathways or goals for the future. Yet, even if this was helpful, sometimes the sense of loss associated with adjustment was hard to contain, as Participant #7 revealed:

Because it's only up to me to adjust [to] it and all these health professionals who are absolutely fantastic and mean well, they don't really grasp the fact that because they are all working people, they get up and go to work, da, da, da, - fine.

(Participant #7)

Here he speaks of the difference between being a healthcare professional and *knowing about* how to treat his impairment and actually *living with it day-to-day*. This comparison highlights his own sense of being isolated with the burden of having to do the work of adjusting, even if the health professionals 'mean well'. The tone of his 'fine' at the end of the excerpt is quite sharp, in the sense of, 'it's fine for them'. Here, he contrasts the relentless quality of undergoing the continuing *lived time of adjustment* with the finite *lived time of doing one's job* and going home afterwards. In this example, adjustment takes work, and yet it is not explicitly conceptualised as work: Instead, work is associated with the busy lives of the health professionals. The sharp expression of routine work as 'fine' and the reference to 'working people' as a group to which this man no longer feels he belongs suggests that something is not at all fine for him in having to live with the differing social status given to the work of adjustment, compared with the work of delivering healthcare. Making this contrast draws attention to adjustment work as a practice of comparing; Participant #7 continually compared past with present and his own life with that of others he perceived as different.

Rehabilitation may involve work to adjust to a different identity, body, lifestyle or routine; it may entail work to organise and administer rehabilitation as well as work to maintain one's health. Yet, within participants' narratives, their rehabilitation activities did not have the cultural status of work. In the next section, we consider scholarship within disability studies and medical sociology that may help to re-situate the data within the frame of 'work'.

DISCUSSION: FRAMEWORKS WITHIN MEDICAL SOCIOLOGY AND DISABILITY STUDIES FOR REVALUING DISABLED PEOPLE'S WORK WITHIN THEIR REHABILITATION

Rehabilitation is under-explored in both disability studies and medical sociology, yet the data collected through this study reveal that it may be a facet of disabled people's lives, a facet in which they invest time, energy and expectation. A common theme among participants was the hard work they had to do to make rehabilitation happen and thereby maintain their quality of life (administrative work), as well as the work they did to come to terms with impairment (adjustment work). In the first part of our discussion, we identify what may be at stake in attempts to re-frame rehabilitation as socially valuable work, which connects our data with the thinking discussed earlier in the article.

The inequitable valuing of different types of work: Thinking with disability studies and contemporary discourses of patient responsibility

Participants in this study placed emphasis on their current or past status as employed or economically active, sometimes signalling the social value of the paid work of healthcare professionals to contrast with their own sense of being undervalued. The tethering of social status to certain forms of work, highlighted by disability theorists (e.g. Gleeson, 1999; Taylor, 2004), can illuminate study participants' attribution of value to themselves. It arises, for example, in Participant #4's insistence on belonging to the valued group (paid workers), which further devalues his (already low status) health-related work of organising PA support. It is also seen in Participant #7's separation of himself from the 'working people' who treat him, but who do not experience what he goes through and from whom he therefore feels alienated.

Thus, the emphasis in disability studies scholarship on the material basis of social status (Fadyl et al., 2020; Gleeson, 1999; Oliver, 1992; Taylor, 2004; Zarb, 1992) can be applied within *Rights-based Rehabilitation* to underscore participants' sense of the relationship between their social status as *disabled people* and the (in)visibility of their unpaid administrative work within rehabilitation. This relationship was very apparent in participants' narratives of being seen (or coming to see themselves) as unproductive, marginalised or worthless following the onset of conditions that altered their ability to participate in the labour market, paradoxically, even as they found themselves burdened with socially invisible rehabilitation-related 'work'. This contradiction is critiqued via Participant #10's 'joke' about being unable to retire: the joke achieves its effect by highlighting that the work of organising rehabilitation and care is unending, yet it is excluded from a usual socially agreed notion of work. One reason for using the term 'administrative work' in this study, rather than the related 'everyday life work' term foregrounded by Corbin and Strauss (1985), is that 'administrative work' connotes the kinds of activity undertaken in offices and more accurately characterises the burden of organisational labour falling on

the shoulders of the disabled people in our study in 2017, during the UK government's austerity programme. The inequity of Participant #10's social arrangement underscores the important role that a disability studies perspective can play within the health research field. The socio-political character of disabled people's work within their rehabilitation risks remaining implicit in studies aligned with medical sociology (Scambler, 2009). Therefore, by engaging with disabled people's experiences of using health services, disability studies can constructively influence the cultural framing of health-related work and its inequitable consequences.

The rise of discourses of patient responsibility may have further contributed to the concealment of the 'work' status of rehabilitation-related work (Armstrong, 2014; Rose, 1999); this may also affect the status of *adjustment work*, which we discuss further in the next section. Participant #7 takes ownership of adjustment as 'up to [him]', but does not explicitly place this activity in the category of work; in fact, it is contrasted with the activity of 'working people'. The concept of 'adjustment', described earlier as a site of antagonism between the two fields of disability studies and medical sociology, is often transposed directly into studies in the sociology of rehabilitation. Can the disability studies scholarship on how work is inequitably structured help us to 'rehabilitate' the concept of adjustment? And can the burgeoning sociology of health-related work, a subdiscipline of medical sociology, potentially create a bridge between the two fields to frame a discussion of disabled people's 'adjustment work'?

Does scholarship from both fields open up a way to 'rehabilitate' the maligned medical sociology concept of 'adjustment'?

As our review of the literature demonstrated, the focus on *adjustment* within medical sociology has been seen by certain disability studies scholars as an artefact of the dominance of a paradigm that positions illness as social deviance (Barnes & Oliver, 1993). An apparent consequence of this is the under-theorisation of the social aspects of adjusting to life with an acquired long-term impairment from a disability studies perspective (Thomas, 2010). Yet, as Bezmez (2016) shows, engaging with the fine-grained detail of disabled people's rehabilitation narratives does not mean disengaging from a contextual or politicised analysis; instead, it leads Bezmez to understand how disabling cultural narratives about re-learning to walk can shape how patients in Turkish rehabilitation hospitals imagine and measure their trajectory through rehabilitation. Similarly, in *Rights-based Rehabilitation*, it appeared that a core aspect of the work of rehabilitation involved articulating a changed, or changing, relationship with the world and exploring how to re-locate oneself as an actor in the social world (see also Bourke et al., 2015). As Participant #1 said, rehabilitation was a 'narrative process'. Drawing on resources from both medical sociology and disability studies, participants' narrative reconstruction work can be said to involve *making sense of impairment within a disabling sociocultural context* (Thomas, 2010; Williams, 1984). Becoming disabled was associated not just with a loss of self (Charmaz, 1983) but with a loss of the social status, as in Participant #7's sense of being an outsider to the world of work inhabited by the rehabilitation professionals he encountered.

Adjusting to life with an impairment was a demanding project that Participant #7 experienced as 'up to [him]', which he contrasted with the valued activities of 'working people'. Here a personal narrative emerged that positions the disabled person as simultaneously responsible for self-transformation yet socially devalued, as in Abberley's (1995) findings. Since Abberley's study, the UK National Health Service has adopted a language of patient expertise and practices of patient-centredness, and there have been policy changes promoting disabled people's

inclusion in UK society. Yet the structural relationship between social status and activities recognised as 'economically productive' remains largely unchanged (see Fadyl et al., 2020), with disabled people's unpaid work on their rehabilitation seen here to be given a lower status than the paid employment of the clinician. Moreover, as a notion of patient responsibility becomes embedded in the health service via the discourse of the 'involved' patient, the 'work' status of what the patient does may be further obscured. The 'emancipating' energy that Oliver (1992) and Zarb (1992) originally directed as an outward-facing demand upon institutions is, via a discourse of patient responsibility, slowly subsumed into an internalised demand upon (in this case) disabled people to attend to their health-related adjustment work.

Adjusting to life with an acquired impairment may be hard work, but in the clinic it is not valued in the same way as the expert clinician's work. What is at stake in recognising adjustment as a form of *work* that is differentially and unequally distributed? Can we 'rehabilitate' Bury's concept of biographical disruption for a disability studies audience, to recognise experiences in which the 'structures of everyday life [*work*] are disrupted' (1982, p. 169)? As we have seen, the onset of impairment can turn everyday life activities, such as shaving or getting dressed, into work, yet as Participant #7 suggested, these experiences could neither be presented in narratives as socially valuable work, nor could the practice of presenting such narratives be seen as work. As Fadyl et al. (2020) have shown, rehabilitation services may unwittingly prioritise a return to 'productive citizenship' for disabled people, reinforcing less inclusive cultural norms that valorise paid employment and bodily autonomy. Drawing on such thinking, and that of Armstrong (2014) and Harris et al. (2010), we argue that the narrative reconstructive work disabled people do to make sense of biographical disruption takes place in a cultural context which conceals its status as work. Discourses of patient responsibility that downplay the status of this work risk re-embedding an individualised narrative of disability-as-disruptive-tragedy within rehabilitation services. This narrative presents disability as a state that must be overcome (Clare, 2015), in order to return to productivity and belonging. If, however, disabled people's narrative reconstructive work could be valued as work, just as the rehabilitation professional's clinical 'sense-making' work is, this could change the social status of impairment-as-devalued-tragedy and allow for greater value to be given to a wider range of narratives of living with long-term impairment. Such a shift could in turn help naturalise models of service use in rehabilitation that are long-term, flexible and more suited to the disabled people involved in *Rights-based Rehabilitation*.

Disabled people's adjustment work in rehabilitation should also be seen as a practice patients may have to enact so as to differentiate themselves as 'deserving' of healthcare. The study data displays effects of patient responsibility discourses in action: some participants sought to distance themselves from negative stereotypes of disabled people as economically inactive. This research took place as the UK government's austerity programme implemented cuts to the social security budgets on which many disabled people rely (Duffy, 2013; Spartacus Network, 2015; We are Spartacus, 2013). Furthermore, at this time, dominant media discourses were demonising disabled people as 'scroungers' (Crow, 2014; Strathclyde Centre for Disability Research and Glasgow Media Group, 2011). Such contextual factors may have heightened research participants' sense of needing to prove themselves as 'good' patients who are 'deserving' of resources. Narrative work can thus take on a moral dimension in addressing people's perceived need to 'rehabilitate' their image at a time of scarce resources and hostile cultural representations of disabled people. Dividing service users into 'good' ('deserving') and 'bad' ('undeserving') patients could serve to naturalise adjustment work as an inevitable consequence of having a chronic condition, rather than, for example, highlighting this work as an additional burden for disabled people, adversely affecting how much spare time they have. This analysis builds on Bury's (2010) observations

about ways in which the established concept of illness work (Corbin & Strauss, 1985) had, in the 21st century, taken on a normative character in health policy on patient 'self-management'.

In making the case for 'adjustment work', we have linked concepts from disability studies and medical sociology to argue that the sense-making work disabled people do within their rehabilitation reveals how (disabling) identities can be produced and internalised in healthcare encounters. Adjusting to living with impairment is not *inevitably* a disabling process, nor one that inducts people into a narrative of disability as a personal tragedy, nor one that 'normalises'. But within a disabling socio-material climate, it may take on such a character. By recognising and attending to disabled people's adjustment work, we can better understand how we might then dismantle disabling encounters and interactions within healthcare in general and rehabilitation in particular.

CONCLUSION

While rehabilitation has not previously been explicitly framed or valued as 'work', medical sociology has a rich history of looking at the 'illness work' of patients (Corbin & Strauss, 1985). In contrast, in disability studies, materialist approaches show how certain sorts of work accrue cultural value and status, while work which cannot be framed as economically productive is sidelined (Gleeson, 1999; Oliver, 1992; Taylor, 2004; Zarb, 1992). We have therefore argued, drawing on both literatures and on the study dataset, that re-conceptualising disabled people's rehabilitation activity as a form of work can create a more sustainable dialogue between disability studies and medical sociology on the subject of rehabilitation. We conclude by summarising the two main intersections discussed in this article and the role of *Rights-based Rehabilitation* in illustrating their relevance to policy and practice.

Our discussion has drawn attention to under-appreciated disability movement scholarship which underscored the material basis of inequitable social relations while interrogating connections between paid work and social status. This highlighted a culture in which health work, especially the health work of disabled people, is not made visible as work. Within this framework, study participants' allusions to losing their vocational identity and their sense of malaise about activity being unvalued can be seen as mutually reinforcing. We have argued that the wealth of disability studies scholarship on disabled people's undervalued work places this work more fully within the socio-political sphere and enriches the medical sociological concept of 'illness work'.

We developed our case for revaluing the concept of 'work' in rehabilitation using the notion, so far theorised only by medical sociology, of 'adjusting' to chronic illness or impairment. Re-framing 'adjustment' as a form of narrative *work* makes it possible to politicise the time that disabled people put into their rehabilitation. In this study, participants foregrounded their concerns about how different actors' work was unevenly valued within the rehabilitation process; such experiences had contributed to participants' disabling internal narratives about whose work matters. The socio-material context of narrative reconstructive work therefore makes a difference to how impairment can be processed and to how adjustment activity can or should be valued. We have argued that more dialogue between the disciplinary perspectives of disability studies and medical sociology could help recognise and revalue adjustment within the work that disabled people do within their rehabilitation, which may in turn sensitise future policy and practice development to this important aspect of disabled people's lives.

AUTHOR CONTRIBUTIONS

Harriet Cooper: Conceptualisation (lead); Data curation (lead); Formal analysis (lead); Investigation (lead); Methodology (lead); Project administration (equal); Resources (equal); Writing

– original draft (lead); Writing – review & editing (equal). **Fiona Poland:** Conceptualisation (supporting); Formal analysis (supporting); Funding acquisition (lead); Investigation (supporting); Methodology (supporting); Project administration (equal); Resources (lead); Supervision (lead); Writing – original draft (supporting); Writing – review & editing (equal). **Swati Kale:** Conceptualisation (supporting); Investigation (supporting); Methodology (supporting); Supervision (supporting); Writing – review & editing (equal). **Tom Shakespeare:** Conceptualisation (supporting); Data curation (supporting); Formal analysis (supporting); Funding acquisition (lead); Investigation (supporting); Methodology (supporting); Project administration (equal); Resources (lead); Supervision (lead); Writing – original draft (supporting); Writing – review & editing (equal).

ACKNOWLEDGEMENTS

We are grateful to the PPI advisory group members who helped us design this project and to the study participants for sharing their stories with us. We also thank the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust for funding the PhD studentship which enabled this research.

This study was funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions.

ORCID

Harriet Cooper  <https://orcid.org/0000-0002-0510-2669>

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How to cite this article: Cooper, H., Poland, F., Kale, S., & Shakespeare, T. (2023). Can a disability studies-medical sociology rapprochement help re-value the work disabled people do within their rehabilitation? *Sociology of Health & Illness*, 1–17. <https://doi.org/10.1111/1467-9566.13627>