

EDITORIAL

(Dis)abling practices and theories?: exploring chronic illness in disability studies

Introduction

This issue is dedicated to bringing together considerations of chronic illness and disability. In doing so it points to the value of working across what were once pretty strong boundaries between disability studies and other areas of research on health – in particular medical sociology. Changes across both areas open up the opportunity for more productive working relationships and the papers in this volume speak to the benefits of such border crossings.

This editorial aims to pave the way for the articles by engaging with the long running tension between medical sociology and disability studies, in particular the debates about how to explore and understand living with a chronic illness which is disabling. Medical sociology for a long time 'owned' chronic illness, using core sociological concepts such as stigma (Goffman 1963) and biographical disruption (Bury 1982) to explore how illness unsettles people's relationships to their bodies and their social position in society. Disability studies instead looked at impairments, which may be associated with chronic illness, but not necessarily. This separation was also encouraged by disability studies' focus on structure rather than the body and the important argument that an impaired body can also be a well body. The clear separation between both chronic illness and disability and medical sociology and disability studies is now breaking down considerably for a variety of reasons. Medical sociology is more open to disability studies arguments that challenge the boundary between *illness* and its *social effects* by increasingly contesting the neutrality and definition of illness itself. At the same time disability studies, in part due to the influence of critical disability studies and its interest in embodiment and 'non-normative morphology' (Shildrick 2012), is taking an increased interest in the complex dynamics involved in living in a non-normate body. There are now new ideas emerging about chronic illness across medical sociology, critical health studies, feminist work and disability studies. This large body of work reflects a need to rethink our understandings due to (a) important changes in the management of chronic illness due to changes in healthcare organization, and (b) new and expanding diagnostic categories expanding the field of chronic illness made possible by technological developments. Across the current debates shared agendas for those studying chronic illness and disability are emerging, which require a crossing over of medical sociology, disability studies and other critical disciplines. This crossover we would argue offers much to the generation of new understandings of both the politics of living in different kinds of bodies and with different ways of mental functioning, but also how to understand and challenge contemporary medicine and healthcare responses to such bodies and minds.

Shared agendas

People with chronic illnesses are now asked to be expert patients in their treatment, required to take 'control' of their condition, life and behaviour via advocacy of concepts such as health literacy skills and self-management (Phillips et al. 2016; Waverijn et al. 2016). Such moves in treatment management are being critiqued for the governmentality embedded in their requirement that the individual manage their health and illness against established scripts they must follow to be experts (Young 2016). Compliance with self-management is identified across a range of disciplines as a contemporary

form of coercive and oppressive medical practice (Nordberg 2016), which also encourages stigma against those who apparently do not comply (Liu et al. 2016; Mitten et al. 2016; Mussap, Manger, and Gold 2016). Disability studies has a long term interest in how people are coerced into particular medical approaches to understanding their impairments and bodies, the contemporary work on chronic illness medical management can add to that important area of critical scrutiny.

Contemporary expansions of different forms of living and body into new or expanded medical categories is an important area of investigation across work on disability and chronic illness. For example, a central current health policy focus across much of the Global North is obesity, with much of the priority being placed on how it is a result of trends in living (prevalence of high sugar content foods and drinks and lack of exercise) and that what is needed is behaviour change by effected individuals. Instead critical work on disability and chronic illness is repositioning the investigation away from the apparent causes of obesity, towards targeting the discrimination experienced by people judged to be overweight (Farrell et al. 2016) and the social production of the health problem in the first place via the category of obesity and the use of measures such as the Body Mass Index (Mussap, Manger, and Gold 2016).

An interesting area where different agendas can usefully come together is to explore why, even while many people are open to challenge medicine and there are a range of movements and organizations that seek alternative ways to both treat and define illness and disability, medicine

continues to exert great influence on the social meaning of disability in general and the social valuation of various illnesses and impairments in particular. Whereas specific conditions may be socially valued, the overall category and label of disability connotes marginality and stigma. (Grue 2016, abstract)

Patients increasingly engage with online information exchange, creating, in theory, a more empowered and negotiated interaction with healthcare professionals (Suárez Vázquez et al. 2016). Yet there is plenty of evidence that captures how people comply with medical strategies in many areas of chronic illness and disability and how they still desire a medical (rather than social) cure. One way to understand the continued faith in medicine is to recognize how it adapts its practices to reflect broader social changes. So critical scrutiny by 'health consumers' willing to do their own research and develop their own treatment strategies is channelled into the expert patient policy highlighted above. When this occurs the dynamic of empowerment turns into a dynamic of governmentality. What those critically studying both disability and chronic illness can and do share is an awareness of how such co-options occur. What they also advocate is repositioning empowerment away from the individual towards more political engagements with questions of citizenship and collective challenge.

There is a need to rethink citizenship and how it relates to chronic illness and disability. For example, much of the current state focus is on citizens who are productive, both as workers and self-managers. This creates a problem for those who fall within the categories of disability and/or chronic illness, it is their (apparent) inability to match such social norms that legitimates the removal of rights (for example to welfare, income, access to cultural and recreational activities) and the assumption that they are 'non-citizens' – a burden on everyone else. Critical work on disability and chronic illness is exploring alternative accounts of who can be a citizen and what it involves so that broader constituencies of people can be included, whether able or unable to work, think and act like other people, or feel a sense of well-being. We are seeing such advocacy in areas such as neurodiversity and Mad Studies (McWade, Milton, and Beresford 2015). These activities are producing counter-hegemonic politics, where health activists and health social movements challenge and transform medical treatment, promote public health policies, and extend civil rights for people with illness and disability (Burchardt 2016; Kumbier and Starkey 2016; Zoller 2016).

The shared agendas highlighted here are generating overlapping research in a number of areas. In what follows we want to highlight some of the research now taking place that deliberately crosses the boundaries of chronic illness and disability and what that productive crossing of boundaries is generating. The three chosen areas reflect also the focus of the papers in this issue.

(Dis)location/locatedness of chronic illness and research on chronic illness

Researchers within geography of disability are exploring the location of disability, whether this be global questions of systemic inequality and environmental destruction, or micro studies of the complexity of social space (Freund 2001; Gleeson 1999; Kitchin 1998). Similarly, illness, and perhaps particularly chronic illness, can be analysed in terms of its (dis)locations/locatedness. Locatedness is on the research agenda both as a material dis-location from society and also a metaphorical capturing of how people with chronic illness, particularly those with mental illness, are placed outside the category of legitimate social beings:

imprisoned, first within their minds, and secondly by the state ... Consequently, they become socially unworthy – the socially dead. The seriously mentally ill experience both spatial and moral dislocation. They are cast out as flawed consumers and failed workers, and more importantly, due to the stigmatization of mental illness, they are disavowed of their humanity, rendering them socially dead. (Rothe 2016, abstract)

Locatedness is also a dynamic present in the research process. Research is an interactional dynamic that can locate the participant, particularly when considered vulnerable or less able than the researcher, as less powerful. When this occurs the dis-location experienced by the participant in social life is replicated in the research context. Across contemporary work on chronic illness and disability is research that not only critiques how dis-location occurs in society, but also in the research space. As part of this agenda Tangvald-Pedersen & Bongaardt in this issue ask:

Can we create a research process that allows for dialogue between an academic and a user participant researcher that leads to growth of insight rather than to controversy; a research process that has rigour as well as relevance, ideological flexibility as well as conceptual coherence?

Their answer is 'Our experience is that the answer is a definite "Yes!"'. Therefore, it is important when working with people whose life is shaped by chronic illness and/or disability to develop the practical techniques and research values and relationships that can turn dis-location into recognition and belonging. This needs to occur in both in the intimacy of the research interaction and in the broader social world that research then seeks to make a contribution to.

(Dis)abling institutions and policy production of illness

A diagnosis of chronic illness or disability triggers an entanglement with a range of policy and institutional actors offering both support and ways of understanding the person's body or mind that can further (dis)able them. The significance of policy processes and institutional structures for shaping the lives of those with categories of chronic illness and disability is one of the major contributions research in these fields is producing. There is a continued need to engage with how policies can be part of what locates people with disabilities or those living with chronic illness as problematic or in need of fixing. Policies can also contribute to the conditionality placed on those with chronic illness or disability. By this researchers mean the way people can be required to show how much they are trying to get better or more adapted in order to be seen as legitimate social actors. Central is experiences of disablism, discrimination and exclusion and how such experiences affect people with chronic illness or disability in important realms of life (Hughes, Corcoran, and Slee 2016). This work is not about rejecting that people do need support and an institutional response, instead it is about understanding how care and support can occur without the person being treated an object of intervention. For example how support can move away from being guided by protocols unable to both engage with the individual and the social barriers and inequalities experienced by that individual (Bê 2016; Gomes et al. 2016; McKernan, Nash, and Carr 2016). Mach and Paylor, in their paper in this issue, examine how problematic policy interactions occur in the area of Hepatitis C when assessing welfare and evaluating employability. In the era of welfare austerity scrutiny of fitness to work is one of the key shared experiences of people who are within the categories of chronic illness and disability, it is therefore of crucial importance that this shared

agenda continues. It speaks to the contemporary exclusions occurring over who is and is not the deserving welfare recipient – a key theme addressed by Mach and Paylor.

We saw above that self-management is a central thematic of contemporary treatment of a wide range of chronic illness, including those relating to mental health. Here recovery is framed as something the ‘patient’ can take control of – if they work towards being better (Gambino, Pavlo, and Ross 2016; Singh et al. 2016; Thomas and Rickwood 2016). These recovery techniques do not deny that individuals, particularly in contexts of stigmatized ways of being such as mental distress, face social challenges and barriers. However, they also propose that such challenges can become an ‘excuse’ and what is needed is to build the resilience of the individual and their ability to manage both their own health and their responses to social problems such as poverty and discrimination. Critical work in areas such as Mad Studies and critical health studies is examining why current policy in this area is so much focused on getting the individual to adapt to the social problems they face and whether this is a fair and just response. One area of the debate is to trace the influence of neo-liberalism, both through the focus on enabling the person to once again be self-reliant and also in the role of non-governmental agencies in the provision of this type of care via contractual relationships that are based on performance targets. These debates are picked up in the paper of Timander and colleagues, here they highlight how oppression and discrimination affect how people are able to engage with recovery processes, but that the recovery process itself is unwilling to engage with those contexts for the people they treat. It powerfully exposes the systemic and symbolic violence that lie at the core of the psychiatric system and the oppression by wider society. The paper by Olin also explores the institutional logics that shape the perceptions and ideologies embedded in treatment, support and control, and thus the identity of mental health service users. The paradoxical role that the service providers play both as a provider of crucial support and a source of stigmatization is once again highlighted in the form of entitlement to services. Olin concludes that power and normality are at the core of othering mental health service users.

Alongside recovery approaches, rehabilitation techniques are also under scrutiny across disability and chronic illness. This scrutiny, as in the areas above, looks at how norms of what a good rehabilitation and a good approach to achieving that rehabilitation looks like influence priorities of treatment and judgements made about ‘patients’. The key (problematic) medical sociology concept biographical disruption remains a central feature of rehabilitation in its belief that its aim and a good outcome is to get the person back to their previous life and capacities (or as close as possible). The symbolic feature of leaving the wheelchair behind and walking ‘normally’ again remains a powerful value of rehabilitation and of wider cultural narratives around injury and illness. However, this prioritization is increasingly challenged, including within rehabilitation itself, with the recent emergence of ‘critical rehabilitation studies’ leading to important debates about what its values and priorities are (Gibson, Carnevale, and King 2012). This is producing new ideas about how to help people to adapt their lives to living with impairment or illness, to see a life that involves assistive technologies such as a wheelchair or a walking stick as not less of a life (Li et al. 2016; Nierenberg et al. 2016) rather than some abstract measure of a normal life. In the paper here by Røberg and colleagues, rehabilitation is presented as a contested field where debates about its purpose and priorities are being played out between different scientific, activist, and political perspectives. The authors argue that formal practice in Norway still privileges aiming for as much improvement of individual function as possible, rather than living with limitation well in a way that remains problematic.

Intersections with other social categories

The third and final area of overlap between research on chronic illness and that on disability is how neither exist in isolation from other factors that influence people’s lives. The contemporary focus on the intersectionality of social categories draws questions of gender, ethnicity/race, class, age and sexuality into understanding how the key dynamics we are exploring here of vulnerability, difference, discrimination occur in the context of chronic illness and disability. As a side point we think it is worth pointing

out that there is a greater willingness in work on disability and chronic illness to engage with the significance of other social categories than exists in the willingness of research of other social categories to draw disability and illness into their accounts. If we look at gender briefly we can point to research looking at areas such as (a) the gendering of chronic illness via how women are diagnosed and treated (e.g. Church 2016; Langer 2016; Neitzke 2016); (b) the long term repositioning of women's reproductive capacities into illness (Shor and Moreh-Kremer 2016); (c) the way societal norms regarding masculinity can form a barrier to treatment (Heckert 2016) as well as many others. In the paper here looking at bleeding disorders by Diesen & Grut, intersections of impairment and gender is examined to produce an argument that a particular illness may not become similarly disabling for men and for women due to a variety of gendered factors. This paper also draws in disability studies perspectives by examining the varied social consequences of the material limitations that emerge from unresponsive environments.

Concluding reflections

Connecting the papers in the first issue 2017 of *SJDR* is chronic illness, or a critical repositioning of how we engage with chronic illness, institutional responses (particularly recovery and rehabilitation) and the languages available to understand them. This repositioning is enabled by drawing upon contemporary ways social research on chronic illness engages with notions of self-management, expressions of governmentality and discrimination, and the continuing influence of medicine (including increasingly the neurosciences) in social meanings of both disability and chronic illness. Collectively the papers within the issue reflect the possible reframings that can emerge via productive border crossings between disability studies and social research on chronic illness. We have chosen to engage with three fruitful cross roads; the (dis)locatedness or the spatiality of both chronic illness and disability; how both chronic illness and disability is being produced through (dis)abling institutions and policies and in the intersections with other social categories. All include critically looking at how both chronic illness and disability are produced in relation to ability and wellness through a diverse range of spatial, institutional and intersectional practices. Through thinking about meanings of language, the body, normality and institutional power joint testimony becomes possible of dynamics of stigma, discrimination and marginalization, alongside alternative imaginaries.

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