

MAGAZINE › JUNE 2021 › SOCIOLOGICAL THEORIES

# Contaminating data with theory to reimagine support for 'self-management'

Petra Mäkelä

1st June 2021

Sociological research requires us to scrutinise two practices at once: our own epistemic practice, and the practice that we intend to explore. Using my research on 'self-management' as an example, I propose that each of these practices can be facilitated through an entanglement with theory. A common caveat warns us that "every theory provides both a way of seeing and a way of *not* seeing" (Ray, 1996, p. 674 [<https://pubmed.ncbi.nlm.nih.gov/8942111/>]). By contrast, I argue that the joining of empirical data with theory - the *contamination* of data - can open up multiple ways of seeing that extend beyond our easy and predictable understandings.

'Self-management' by people living with long term conditions forms a core component of contemporary healthcare policy [<https://www.england.nhs.uk/personalisedcare/supported-self-management/>] and has been increasingly emphasised [<https://www.who.int/publications/m/item/support-for-rehabilitation-self-management-after-covid-19-related-illness>] in these times of COVID-19. 'Self-management' typically refers to mitigation of the effects of health conditions, to maintain quality of life. Prevailing understandings privilege the idea of individual rationality, with an implicit assumption is that individuals function as the primary agents in the creation of their own health and wellbeing (Sointu, 2005 [<https://journals.sagepub.com/doi/abs/10.1111/j.1467-954X.2005.00513.x?journalCode=sora>]). The self-management discourse typically focuses on an individual's knowledge, skills and health-related behaviours, with little attention given to the deeply complex and social nature of support for self-managing.

Although it would be impossible to explain all of the factors that might influence success or failure in practices of self-management support, "good patient-professional communication" is typically identified as a key mechanism (Pearce et al., 2015, p. 1 [<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0141803>]). I focus on the clinical interaction as the object of my inquiry, as it

provides the moral environment in which the practice of self-management unfolds and its normative dimensions are sustained. In other words, support for self-management takes place within clinicians' expertise-dominated interactions, where an established order permits certain actions while precluding others. Clinicians' expectations of patients as 'self-managers' may entwine with perceptions of positive moral character, where 'good patients' are motivated to control their health condition but 'bad patients' fail to act according to clinicians' expectations. For example, NHS England proposes that, by using the 'Patient Activation Measure©' [<https://www.insigniahealth.com/products/pam-survey>], the clinician will be able to identify "what would be needed to increase [patients'] levels of knowledge, skills and confidence in order to improve their health and well-being outcomes" (NHS England, 2018, p. 7 [<https://www.england.nhs.uk/wp-content/uploads/2018/04/patient-activation-measure-quick-guide.pdf>]). Such objects maintain clinical authority by deflecting attention to the pathological Other in an interaction that differs, in organised ways, from everyday conversations.

Underlying my interrogation of self-management support is a fundamental social science question that asks how we can understand human agency under conditions of constraint (Hunt and May, 2017 [<https://link.springer.com/article/10.1186/s12913-017-2366-1>]). Individual agency is typically operationalised as decision-making and the feeling of being in control in one's life. However, the varied forms that agency might take, such as negotiation, manipulation, subversion or resistance, raise questions about how far it can be seen as individually - rather than relationally - located. I suggest that theorisations of agency and constraint might open up ways of seeing the clinical interactions underpinning self-management support, while also providing a "bottom-line health dimension to a sociological analysis" (Timmermans and Haas, 2008, p. 665) . [<https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1467-9566.2008.01097.x>]

I explored the potential for thinking about self-management, agency and positions of constraint, during the co-construction of narrative data with people living brain injury, in my doctoral research [[https://westminsterresearch.westminster.ac.uk/download/f1c18ac804afed624984fb6cda7e3aeede1f707cb25957c0bf35a14f6d9575c3/3815978/Final\\_DProf\\_Thesis\\_Petra%20Makela.pdf](https://westminsterresearch.westminster.ac.uk/download/f1c18ac804afed624984fb6cda7e3aeede1f707cb25957c0bf35a14f6d9575c3/3815978/Final_DProf_Thesis_Petra%20Makela.pdf)]. Specifically, I engaged with constructs derived from Judith Butler's theory of performativity [[https://www.amherst.edu/system/files/media/1650/butler\\_performative\\_acts.pdf](https://www.amherst.edu/system/files/media/1650/butler_performative_acts.pdf)]. Butler expanded her seminal work on performative acts and gender constitution [<https://www.jstor.org/stable/3207893?seq=1>] to encompass broader identity categories, Otherness, the nature of being and becoming, and the creation of subjective experiences that deny agency. I drew on Butler's non-dramaturgical understanding of performativity as "a process of iterability, a regularised and constrained pattern of norms...[where] this repetition is not performed by a subject; this repetition is what enables a subject" (Butler, 1993 [<https://www.routledge.com/Bodies-That-Matter-On-the-Discursive-Limits-of-Sex/Butler/p/book/9780415610155>], p. 95) . Performative acts exert power through their iterability and recognition when used consistently, yet their force can be destabilised when a repetition fails to reproduce the established norm, opening up new meanings that can destabilise an identity position.

Although critiqued as empirically awkward, Butler's work on performativity has been joined with empirical contexts that range from care home processes [<https://onlinelibrary.wiley.com/doi/abs/10.1111/jep.12985>] to the lives of donkeys in Botswana [<https://journals.sagepub.com/doi/abs/10.1177/0263775815604922?journalCode=epda>]. I felt inspired by Victor Turner's proposal that theoretical insights can usefully be taken out of context of the theorist's whole system and be applied to scattered data, thereby providing us with "nourishing raisins" in the mass of "inedible dough" of fieldwork (1974, p. 23 [<https://www.cornellpress.cornell.edu/book/9780801491511/dramas-fields-and-metaphors/#bookTabs=1>]). My application of Butler's theoretical constructs (the nourishing raisins) clearly will not be the same as others', when they have entered into such varied assemblages. However, in each case they can act to "counter a certain kind of positivism according to which we might already begin with delimited understandings" (Butler, 2010 [<https://www.tandfonline.com/doi/abs/10.1080/17530350.2010.494117>], p. 147). This became my epistemic intention, when engaging with the question of how practices intending to support self-management support can bolster or constrain agency, and for whom. In this way, my reading of the theory produced a new pathway for thinking, which began with a particular problem in the midst of an inquiry (here, the problem of conceptualising agency under conditions of constraint).

Large amounts of narrative data precluded any attempt to read across my whole dataset using a theoretical application of performativity, and doing so would have risked constraining rather than opening up my ways of thinking with the theory and data. Considering myself to be part of its narrative construction, I became drawn to those parts of research interactions that seemed to contain tension or 'trouble'. These became the points at which I started to engage with theoretical interpretation, as a sensitising lens. I found that the writing tool Scrivener [<https://www.literatureandlatte.com/scrivener/overview>] assisted me during the iterative processes of joining theory with data, by enabling meaning-making connections across times and materials in non-prescriptive ways, instead of forcing the data into predetermined categories of sameness.

I found that, in contrast to the healthcare rhetoric of 'clinician-patient partnerships' [[https://www.bmj.com/content/350/bmj.g7757?ijkey=63a00a32fa108d0e70646d9f1b16d267af6dd768&keytype=tf\\_ipsecsha](https://www.bmj.com/content/350/bmj.g7757?ijkey=63a00a32fa108d0e70646d9f1b16d267af6dd768&keytype=tf_ipsecsha)], asymmetries in forms of valued knowledge and traditional hierarchies were maintained in participants' ways of talking about clinical interactions. Normative expectations invoked performative acquiescence in the face of feelings such as being misunderstood or unheard, as illustrated by Eva who said, "I was seen by a doctor and, er, yeah, he gave me kind of like a test ... And on the basis of what he saw, he thought that, that I didn't need anything [*shrugging*], that I didn't need any other help." Importantly, clinician as well as 'patient' subject positions are enabled but also constrained by repetitions of maintained norms in such interactions, which are very much taken for granted and therefore 'unseen'.

The norms surrounding the role of 'healthcare professional' exert a restrictive force in the clinical interaction and yet appear 'natural'. Role tensions are not widely spoken of among clinicians, though

research into support for self-management alludes to them through discourses such as clinicians “working hard to ... avoid making assumptions about the feelings, needs and preferences of patients.” (Mudge et al., 2015 [<https://bmjopen.bmj.com/content/bmjopen/5/5/e007413.full.pdf>] , p. 8) . Recognising that practices only exist as far as they are enacted and re-enacted, I propose that the “bottom-line” of this sociological analysis is the illumination of unseen norms, and possibilities for their re-imagining when ruptures in practice create space for creativity and change.

If the limits of individual agency, and constraints of subject positions, are not acknowledged in the practice of self-management support, then the intentions of ‘person-centred care [<https://www.health.org.uk/sites/default/files/PersonCentredCareFromIdeasToAction.pdf>] ’ are at stake, through the recreation of the power relations that this practice claims to disrupt. I propose a shift in conceptualisations of agency as individually-located, to instead be understood as a relational co-construction. Conceptualisations of agency through relational processes are not broadly integrated into contemporary practices of Western healthcare (Prainsack, 2018 [<https://journals.sagepub.com/doi/abs/10.1177/0162243917736139>] ) . Inevitably, simply opening up this discursive space through theorisation will do no more than provide “a ticket that allows entry into [a new] theatre...torn up as soon as one crosses the threshold” (Lynch, 1997, p. 18 [<https://books.google.co.uk/books?hl=en&lr=&id=aMu7oldtnSQC&oi=fnd&pg=PP1&dq=Lynch,+M.,+1997.+Scientific+practice+and+ordinary+action:+Ethnomethodology+and+social+studies+of+science.+Cambridge+University+Press&ots=oMUQPhkPVd&sig=TMpwFNmPRpRXNlb7wloXnflPjWQ#v=onepage&q=Lynch%2C%20M.%2C%201997.%20Scientific%20practice%20and%20ordinary%20action%3A%20Ethnomethodology%20and%20social%20studies%20of%20science.%20Cambridge%20University%20Press&f=false>] ) . I suggest that further theoretically-informed inquiry could develop new ways of constituting self-management as an object of inquiry, which might uncover broader contexts that can enable subjects in unanticipated ways. Future inquiry could explore, for example, the transformations which have been unfolding in clinical interactions during the COVID-19 pandemic, potentially disrupting the performative labour of health professionals and of patients.

## About the author

### Petra Mäkelä

Petra Mäkelä is Assistant Professor in the Department of Health Services Research and Policy, London School of Hygiene & Tropical Medicine (LSHTM). She is interested in inquiry that can inform understandings of marginalised people’s needs, and health and social care services’ ways of working with them. In 2019, she completed a professional doctorate on narratives of brain injury and self-management after hospital discharge. Trained in rehabilitation medicine, Petra works voluntarily with a non-governmental organisation providing medical support to people seeking sanctuary in England, alongside her academic work at LSHTM. She tweets @petra\_ob

## Cite this work

Mäkelä, P. (2021, June 1). Contaminating data with theory to reimagine support for 'self-management' [Online]. The Sociological Review Magazine. <https://doi.org/10.51428/tsr.dpbk4673>

## Copyright

© 2021 Petra Mäkelä. This work is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License.

Please consult the Creative Commons guidelines for information on how you may reproduce and reuse the content of this article.