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Being differently the same: The mediation of identity tensions in the sharing of illness experiences

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ABSTRACT

The sharing of experiences between patients has become increasingly privileged as a source of knowledge and support in contemporary healthcare. Despite this, relatively little is known about the processes whereby people's experiences become, or fail to become, valued as sources of health-related knowledge in different contexts. Through a secondary analysis of 87 interviews conducted between 2006 and 2008 in the UK with people affected by motor neurone disease (46 interviews) and Parkinson's disease (41 interviews), we explore the identity work involved in turning other people's experiences into 'experiential knowledge' that can be shared between patients. Of particular interest is how the turning of others' experiences into knowledge is presupposed by negotiating a particular type of identity tension – what, drawing on the work of Paul Ricoeur (2003) on metaphor, we refer to as 'being differently the same'. We examine the way in which people living with motor neurone disease and Parkinson's disease spoke of managing this tension as part of the process of accessing and valuing other patients' experiences, both epistemologically and emotionally. Instead of treating others' experiences as a pre-given source of knowledge, we emphasise how experience comes to be embodied and articulated through different media – bodies, speech, text, and images. Moreover, we suggest that paying closer attention to these media provides opportunities for enhancing our understanding of how people with different chronic and/or terminal illnesses use or do not use different forms of peer support – and in particular online ones – as a source of health-related experiential knowledge. Some of the implications of this are discussed in the specific context of people diagnosed with incurable neurodegenerative conditions characterised by visible physical deterioration and associated emotional distress.

Introduction

The idea that experiential knowledge – defined as 'truth based on personal experience with a phenomenon' (Borkman, 1976, p.445) – can be a valuable resource in healthcare was initially promulgated by the self-help movement during the 1970s. Today, patients' experiences, and the sharing of these experiences, are well recognised as a source of knowledge and support in healthcare decision-making and practice (Abel & Browner, 1998; d'Agincourt-Canning, 2005; Etchegary et al., 2008; France, Wyke, Ziebland, Entwistle, & Hunt, 2011; Lawton, 2003; Locock & Brown, 2010).

Research into the health implications of experiential information-sharing has been carried out from a range of disciplinary perspectives, most notably the medical and nursing sciences, psychology, and sociology. Researchers working within this multidisciplinary space define what counts as a 'patient experience' by drawing on their respective disciplinary repertoires. From a sociological perspective, patient experiences are not treated simply as expressions of internal individual 'truths', even though the experiences in question may indeed be considered 'true' by the person expressing them. Instead, different aspects of the construction(s), dissemination(s) and meaning(s) of patient experiences are explored, such that the socially contingent dimensions of what counts as 'experience' are brought to the fore. This includes, for example, analyses of the role that experience, in the form of narrative storytelling, plays in constructing and re-constructing identities and subjectivities (Bury, 2001; Frank, 1995; Williams, 1984), or explorations of the connections between the construction of patients' experiences and the use of particular media sources and imagery in different contexts (Kitzinger, 2000; Seale, 2003).

One platform for the sharing of experiences that has received particular attention is the internet (Armstrong & Powell, 2009; Bar-Lev, 2008; Coulson, Buchanan, & Aubeeluck, 2007; Drentea &

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Moren-Cross, 2005; Mo & Coulson, 2010; Winefield, 2006). The growing body of work on how people use the internet to share experiences of different health conditions has largely followed two avenues of analysis: the question of how experiences are *(re)presented* online; and the issue of how to measure the various *effects* of the sharing these experiences. In this paper, however, we explore something else – namely, the mechanisms whereby patients turn other patients' experiences into a source of knowledge and support, an issue that is often tacitly implied in the above two dominant analytical perspectives, but rarely explicitly discussed.

Drawing on a secondary analysis of 87 narrative interviews with people living with two neurodegenerative conditions – motor neurone disease (MND) and Parkinson's disease (Parkinson's) – we suggest that in order for *other patients' experiences* to be deemed meaningful, be it psychologically (for example, in terms of emotional support and understanding) or practically (for example, in terms of sharing useful advice), the person receiving the information must identify with the person providing it. In the health context, this sense of identification is typically premised on the existence of a common diagnosis. However, while this identification underpins a great deal of the epistemic and emotional value attributed to other people's experiences, it can, at the same time, be a source of emotional distress, resulting in certain tensions in identity in which people resist cultivating 'disease' identities (Locock & Brown, 2010). Building on this, we explore some aspects of the *identity work* that takes place in order to turn other people's experiences into epistemologically meaningful and emotionally manageable sources of knowledge.

The paper is structured as follows. First we provide a brief introduction to MND and Parkinson's disease. Next we outline the methods we used in some detail. Our findings form the main body of the discussion and are broken into three sections. First, we examine tensions of identity in peer support in general and the sharing of experiences in particular. Second, we develop the concept of 'being differently the same'. Third, we turn our attention specifically to the internet and to broader questions of mediation in the sharing of experience. In conclusion, these three areas of analysis are drawn together and their implications discussed in relation to the concept of metaphor and the role of experiential knowledge in healthcare.

MND and Parkinson's disease

MND and Parkinson's are neurological conditions characterised by the progressive degeneration of nerve cells and unpredictable prognoses (McDermott & Shaw, 2008; Tsouli & Konitsiotis, 2010). Both conditions typically, although by no means invariably, affect people over the age of 40. Parkinson's has an estimated prevalence of about 0.2% (approximately 200 people out of 100,000) in the general population (Clarke, 2007), whereas MND is rarer, with an estimated 7 out of 100,000 people living with the condition in any given year (http://www.mndassociation.org).

While neither condition is curable, the progression of MND is often very rapid and has been described as straddling the terminal and chronic categories (Brown, 2003). In its most prevalent form – amyotrophic lateral sclerosis (ALS) – MND presents in both upper and lower motor neurones. When the onset of the disease is experienced in the form of limb weakness, patients are expected to live between two to five years. When the first symptoms of the disease are experienced in the throat or mouth – bulbar onset – the deterioration is faster and life expectancy may be as short as a few months. The speed of deterioration is very hard to predict and there are two slower progressing variants of MND – primary lateral sclerosis (PLS) and progressive muscular atrophy (PMA). A diagnosis with MND has been described as an 'existential shock' (Brown, 2003), which can result in a process of 'biographical abruption' (Locock, Ziebland, & Dumelow, 2009).

In addition to the psychological distress associated with a diagnosis of MND or Parkinson's, patients have to deal with unpredictable, visibly noticeable and seriously debilitating, symptoms. In the case of MND these include the loss of the ability to walk, talk, eat, drink or breathe (Brown, 2003). The main symptoms of Parkinson's are shaking, stiffness, slowness and difficulty with movement, while later symptoms can include postural instability, dizzy spells and dementia (Clarke, 2007). A range of treatments are available for Parkinson's and in most cases deterioration is slower and less visibly noticeable than in MND. Thus, unlike MND, Parkinson's can more straightforwardly be considered a chronic condition.

Methods

This paper is based on a secondary analysis of pre-existing qualitative interviews carried out with people affected by MND and Parkinson's (Heaton, 2004). All the interviews were collected by the University of Oxford's Health Experiences Research Group. Ethical approval for secondary data sharing and analysis had been received from the Eastern Multi-Centre Research Ethics Committee (ref: 03/05/016). The interviews were collected using maximum variation sampling, with variation across demographic variables and type of experience (Coyne, 1997).

The interviews are in-depth narrative ones, conducted with a view to soliciting experiences of illness across a range of topics. In the first half of the interview participants were invited to tell their story for as long as they wanted with as little interruption as possible. In the second half, a semi-structured interviewing approach was adopted to enquire after topics of interest that had not already been raised and to explore key topics in more depth. The interviews were carried out by three primary researchers: researcher one conducted interviews with people affected by MND; researcher two conducted interviews across the MND and Parkinson's modules; researcher three conducted interviews with people affected by Parkinson's. Since the interviews were collected as part of one programme of work, the same topic guide was used throughout. The majority of the interviews lasted between one and two hours. All interviews were video or audio-recorded and transcribed verbatim. Pseudonyms are used to protect the anonymity of participants.

The work presented here was carried out in order to inform a National Institute for Health Research (NIHR) funded programme of work on the practices and implications of the online sharing of health-related experiences. The overall aim of the secondary analysis was to conduct a 'supra-analysis' on this topic (an analysis in which the data is analysed from a new theoretical perspective (Heaton, 2000)). As one of the authors (LL) carried out roughly half of the interviews with people affected by MND and has published papers based on them (Locock & Brown, 2010; Locock et al., 2009), the present paper can also be considered, in part, a 'personal or inside secondary analysis' (Heaton, 2004, p.12). For a detailed discussion on some of the challenges and opportunities afforded by secondary analysis see Heaton (2004); for an in-depth discussion of the process of carrying out a secondary analysis on some of the same interviews see Locock and Brown (2010).

In the first round of coding all 46 interviews with people affected by MND (35 patients and 11 carers) and 41 interviews with people affected by Parkinson's (37 patients and 4 carers) living in the UK were analysed. Interviewees were primarily white British, but included people of Asian, Pakistani and African descent, as well as two Polish, one French and one Norwegian participant(s). Age at time of interview ranged from twenty-four to eighty-two and