



No one listens to me, nobody believes me: Self management and the experience of living with encephalitis[☆]

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ABSTRACT

Over the past twenty years, there has been considerable interest in individuals' experience of chronic illness. In addition to the more established concerns of medical sociology, recent policy reflects an interest in how individuals manage their condition. Using material from qualitative interviews with 23 individuals carried out in the United Kingdom, this paper examines a person's experience following encephalitis, as a way of exploring the potential value of current policy initiatives associated with self-management. Our findings suggest that individuals' illness experiences become embedded in conditional acceptance derived from and sustained through their social relationships. This raises a fundamental policy tension: is the purpose of current self-management strategies to help individuals cope better with illness or with the context in which their illness experience is realised? We conclude that policy needs to question how it 'imagines' long-standing conditions, without recourse to generalised notions of coping and adjustment. This, in turn, means adapting a less instrumental and more contextualised approach to self-management.

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Much has been written about the impact of long-standing illness. Alongside the many productive insights offered by medical sociology, recent policy reflects a concern with self-management and more broadly, self-care (Greenhalgh, 2009). Policy makers find such ideas attractive, associating self-empowerment with better coping and better coping with potential cost savings to health care agencies (Poortinga, 2006). This explains the popularity of self-management in understanding long-term conditions, including those associated with acquired brain injuries, such as encephalitis (NSF, 2005). How such approaches actually accord with the ways in which people make sense of their illness in their day-to-day social relationships emerges as an important research topic.

Recent policy accounts of long-standing chronic conditions can be seen to combine a *post-modern* concern with the reflexive self alongside a more long-standing, instrumental interest in how individuals ascribe meaning and purpose to what they do (Giddens,

1991). Debates on self-management – and an interest in how emotional and social resources enable individuals to counter the more negative effects of long-standing illness in a way that facilitates successful coping – assume significance in relation to this process (Gately, Rogers, & Sanders, 2007). Self-management is said to encourage individuals to actively engage with their illness, using personal and community resources as a means of gaining greater control over what is happening to them, in a way that promotes choice and involves less reliance on health care interventions (Kendall et al., 2007).

Self-management, despite its potential value, is contested and for some politically convenient. Such debates, which equally require conceptual caution, raise several relevant themes. Current policy interest – and its instrumental focus – has been criticised for conceptualising illness in isolation from the broader social, cultural and political context in which self-management occurs (Stephens, 2006). Rather than question how scarce resources, allocated through the operation of the welfare state, support successful adaptation and enhance social opportunities (Lynch, Due, Muntaner, & Smith, 2000), current policy assumptions could be seen to encourage a focus on individuals who potentially find themselves blamed for the situation in which they find themselves, as a consequence of maladaptive behaviour and poor coping skills (Pearce & Davey-Smith, 2003). Social networks are not simply facilitative (Neckerman & Torche, 2007). Hence the need for a more

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critically informed account, highlighting how self-management is realised through individuals legitimating their experience within the context of their social relationships (Edmondson, 2003).

This is where the mainstream interests of medical sociology assume importance (Bury, Newbould, & Taylor, 2005) and despite their potential value, encephalitis has remained peripheral to these debates. Encephalitis is an often life-threatening neurological illness caused by infection, usually viral, affecting the brain. Survivors are left with an acquired brain injury, the degree and severity of which will vary. Prognosis is uncertain and further complicated because the onset of encephalitis occurs as an acute condition, which can be cured through medical intervention. Current medical practice considers the long-term consequences to be distinct from this the acute stage, to the extent that people no longer have encephalitis, but are accommodating its after-effects. This distinction, although helpful in making sense of 'disease', does not necessarily reflect how 'illness' assumes meaning. The emerging conceptual ambiguity is fundamental to how an individual understands encephalitis. Encephalitis is more than simply 'being of' or 'belonging to' a particular diagnostic category. It is an expression of how a person interprets and negotiates their social experience (Kleinman, 1988).

Consequently, individuals might reassess who they are, generating a 'never ending cycle of biographical appraisals' (Williams, 2000: p. 61), involving active formulation and reconstruction as their everyday life becomes reorganised within the context of loss and suffering (Frank, 1995). Autobiographies alter constantly in response to both the consequences and interpretation of illness (Williams, 1984). This process, however, is not simply a reflection of individual agency; beliefs about illness are constructed in relation to broader social, cultural and moral values (Charmaz, 2000). Illness narratives may reflect attempts to construct order and certainty form the fragmentation of illness, acting as a reference point between body, self and society (Williams, 2000). The individual may attempt to assert a valued identity, which has collective meaning, in an attempt to validate and legitimate experience (Hyden, 1997). Meanings, however, are constantly at risk, as individuals strive to explain and gain some control over what has happened to them (Bury, 1991).

This can be a complex process for those affected by encephalitis. The consequences of the condition seem to strike at the essence of 'who a person is'. Memory problems are common, resulting in a lack of continuity and order in one's life, posing fundamental questions about who one was, who one is and who one is to become. This requires a narrative reconstruction, evoking ongoing adaptation (MacKian, 2000): a situation compounded because, unlike other conditions which affect memory such as dementia or stroke, encephalitis has little collective meaning with which a person can engage (see MacRae, 2008).

The research process

Our findings are taken from a mixed-methods study, which aimed to provide individuals' perspectives on living with the consequences of encephalitis by exploring how they made sense of their condition within the context of broader family and social relationships. The study took place between February 2006 and ended April 2009 and ethical approval was obtained from the University of York, Research Governance and Ethics Committee as well as the Scientific Panel and Management Committee of the Encephalitis Society. The material generated in answering this broad research question was used to explicitly question the extent to which debates about *illness experience* can be reconciled with discussions about *self-management* and more generally, *coping*. Being able to discuss the ways in which a person accommodates

and ascribes meaning to their illness in their day-to-day lives can provide for a subtle and nuanced account in which to understand any specific health care intervention. In exploring this we present qualitative material drawn from in-depth interviews. A qualitative methodology is particularly effective in exploring complex, sensitive and potentially contested themes, while in-depth interviews enable us to understand how people interpret what is happening to them (Denzin & Lincoln, 1998).

No representative sampling frames exist for those with encephalitis and, more importantly, the lack of sound epidemiological data means we have little idea of what a representative sample would look like. Consequently, certain compromises in sampling had to be made. A postal survey conducted as part of the study and conveniently sampled using the membership records of a national voluntary organisation ($n = 1281$) provided the basis for our qualitative sample. (We report elsewhere on the survey's findings, which examine the range and frequency of the reported after-effects of encephalitis in a UK population. A full copy of this report is available from <http://www.encephalitis.info/Info/Research/Studies/SocietyCompleted.aspx>) Fifty individuals, who completed a questionnaire, indicated they would be happy to be interviewed and we aimed to recruit 25 of them, as we felt this was a manageable size for a qualitative piece of research. These potential interviewees were then reviewed against a purposive sampling frame, suggested by our initial literature review and supported by our analysis of the postal survey. Our initial literature review, for example, suggested gender and age at which encephalitis was first diagnosed mediated how people made sense of their illness. Satisfaction with service provision emerged from the survey as being especially important in understanding people's perceptions of how well they were accommodating the consequences of their condition. We wanted a purposive sample to ensure our research reflected a diverse range of experiences. This was given priority over using the key variables as a way of explaining individual experience, although where relevant our analysis reflects this.

Twenty-three people agreed to be interviewed and we struggled to meet our sampling targets. There were pragmatic reasons for this. Some people could not be contacted or no longer wished to be interviewed. We also struggled to find sufficient people to interview, in accordance with our intended sampling frame. More women than men, for example, agreed to take part. Our eventual sample, although broadly purposive, reflected these difficulties. Consequently, 14 of our sample were women and nine were men; five had encephalitis as a child, seven in early adulthood and 11 in late adulthood; and seven were satisfied with service contact, three were unsure and 13 were dissatisfied. There was a lack of ethnic diversity among people willing to be interviewed and those in the sample regarded themselves as 'white' British. This reflects a potential bias in our original sampling frame, but one unfortunately common in the UK. Ethnic minorities are less likely to be members of large national voluntary organisations. There might also be a social class bias, with anecdotal evidence suggesting those from middle class backgrounds are more likely to join such organisations. Equally, and especially important in the context of this paper, those joining such organisations might be assumed to have a strong identification with the condition.

Interviews took place at locations across the United Kingdom, in the respondents' own homes and lasted between one and two hours. All names appearing hereafter are fictional (Table 1).

We used a guide, informed by specific topics, to facilitate 'guided conversations' (Fielding, 1993: p. 144). We wanted to cover similar ground with our interviewees, to ensure we could compare responses, while at the same time creating an environment enabling them to reflect on their specific experiences. Interviews

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