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, Muntanier, & 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...
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 interview 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
explored: biographical details as a way of building rapport and contextualising subsequent discussion; understanding of illness and sense of recovery; and consequences of encephalitis on day-to-day living, family relationships and social networks. Our use of interviews gave our research a particular focus. They were of necessity, limited in the extent to which they could reveal the complexity of an individual’s social relationships, being dependent on an individual’s interpretation of his/her experience and reflecting the meaning s/he give to such relationships (see Lee, 2004). It was these perceptions that informed our analysis.

Interviews were audio-recorded and transcribed. Analysis was aided by the use of Atlas.ti (version 5.2) and undertaken by two members of the research team, who engaged in iterative debate when negotiating different analytical themes. We began by identifying themes relevant to an interview. These themes were first interrogated in relation to each individual account, as a means of understanding a particular case. They were then compared across cases by highlighting potential similarities and differences (see Silverman, 2009). Our aim was to move beyond a descriptive account of specific interviews and in keeping with our broad ethnographic approach themes were explicated within existent and emergent theory, suggested by the focus of the paper. When writing up qualitative research, there are no particular rules to suggest how many themes can best represent the diversity of a dataset (Riessman, 2008).

Not all analytical themes are represented here and the dynamics of our sampling frame was used to provide context and diversity rather than specific interrogation. In this paper, our prime interest is in how people made sense of their illness and then how they negotiated this understanding when engaging with others. The insights this generated were explored to give meaning to the more policy focused debates about the meaning of self-management.

Research findings

In bringing together our theoretical interests with our empirical material, we put forward three linking, interpretative themes: the process of diagnosis; reconciling past, present and future; and talking about encephalitis. Each theme reflected the broad study aims and emerged as fundamental when making sense of a person’s illness experience. Through exploring these themes, in the form of a thick description, we connected the social meaning of illness with more explicit policy assumptions implicit in self-management and self-care. Our point is to privilege individual accounts – and their inherent complexity – rather than those presented by policy.

Ascribing meaning and purpose to what has happened to them, as part of maintaining a valued social identity, remained a legitimate exercise for those interviewed. They engaged in various forms of narrative reconstruction, attempting to construct order from the fragmentation of illness. Diagnosis was fundamental in understanding this. Unsurprisingly, encephalitis had little meaning for them when first diagnosed: it was an unknown label. The ‘illness’ emerged through the meanings and interpretations accorded to their experiences by themselves and those with whom they engaged, as they attempted to reconcile past and present, with an imagined future. This embodied the challenge of encephalitis as uncertainties about the consequences of the illness became bound up with an individual’s sense of identity. Individuals, for example, had to constantly juggle what could be attributed to the after-effects of encephalitis with what could be attributed to the consequences of their own ‘personality’. Making sense of this tension created varying expressions of self-doubt as individuals strived to be ‘believed’. Talking about their illness offered a tangible example of how this was negotiated.

Contact with medical practitioners, an instance in which individual experience intimately connected with policy and practice, did not always give the answers people sought. This provided the impetus for this paper. Ed could not reconcile the neurologist’s advice, which ruled out a return to work, with his sense of how he had previously excelled at his job as a social worker. He had been dealing with the after-effects of encephalitis for two years and still hoped for a return to what he regarded as ‘normality’. John, who attributed many of his marital difficulties to his constant headaches, interpreted his consultant’s advice to ‘self-manage’ his pain as questioning the extent to which his symptoms were ‘real’. Similarly, others associated advice about self-management with not being taken seriously. A tendency among health care practitioners to classify the consequences of encephalitis as other disease categories, such as ME or Chronic Fatigue Syndrome, further frustrated those we interviewed. It made little sense to them, as they were dealing with the consequences of encephalitis, not some new entity, defined as separate and distinct by their health care professionals. Interventions informed by these newly imposed disease states, such as CBT, was seen to undermine the legitimacy of their experiences and assumed little credibility. Nor did the individual’s more general suspicion that self-management implied a definition of sickness in which personality or a general inability to cope figured predominately. Struggling with this suspicion alongside the more general need to be believed highlighted an initial tension between how those we interviewed conceptualised their illness and some of the more instrumental meanings implied by self-management. Diagnosis was the starting point in connecting this.

Diagnosis

A third of our interviewees mentioned initial misdiagnosis. Ruth described how prior to diagnosis there were times when she ‘doubted who she was’. It took eighteen months before Judith was diagnosed as having had encephalitis:

And I sort of went on my way feeling, I suppose, relieved that there was something wrong with me...Because I'd got to the point, where nobody believed me.

Table 1

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
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<th>Years since illness</th>
<th>Satisfaction with services</th>
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An initial misdiagnosis of psychiatric illness – a common occurrence in acute neurological conditions – had a particularly profound impact on how individuals saw themselves and how they felt they were seen by family members. Individuals were even less able to understand their experiences. Their ‘diagnostic’ label did not seem in accord with their own feelings about what was wrong. Philip described his four year ‘constant battle’ in escaping from the label of psychiatric illness:

It was all very difficult to accept because it always appeared that somebody's labelled you that you're depressed. They will always look to confirm that, if that makes sense. And that was the major, real fight for me.

For Ruth, it was five months after her illness (and following a self-funded consultation) that a neurologist confirmed she was not suffering from depression but the consequences of encephalitis. A previous contact with a health care professional demonstrated the importance of this to her:

And then she said, ‘you need Citalopram, an anti-depressant. So I said, ‘no, I don't!’ So that really upset me that, because what she'd said, I know it's wrong. Something's not right. But I'm not depressed. And I remember coming home and asking all my friends and family...and I said, ‘please, please will you tell me if I'm depressed! You must tell me because I need to know, because I need to get this sorted!’ And it preyed on my mind a lot.

Tina described how she had lived with ‘psychiatric’ problems for twenty years.

I just thought, 'I can't fight anymore. No one listens to me. Nobody believes me'.

Any retrospective diagnosis meant individuals had to re-evaluate who they were, look back on their previous lives, perhaps reinterpreting specific past events in addition to their own and others' views of them. Finding out that she was living with the after-effects of encephalitis helped Tina make sense of the past, providing clarity to what she had previously regarded as a series of ill-defined problems: ‘I was never seen as a person with a problem, I was always a problem person’. Having thought herself ‘lazy’ or ineffective for not achieving her life goals, she now saw herself as someone who had achieved much in spite of dealing, unknowingly, with the consequences of encephalitis. Heather, who had been living with the after-effects of encephalitis for over twenty years, but who had only received a formal diagnosis seven years ago, described her ‘relief’ at finding out that she had suffered from encephalitis as a teenager and did not have what she described as a ‘flawed personality’:

...and he [a neuropsychologist] started saying to me things like, ‘Do you have problems with time? Do you have problems with organising yourself?’ Things, that no one had ever said to me. And I was going, ‘yes, yes, yes’. And then I just burst into tears, because suddenly everything just fell into place.

A 'correct' clinical diagnosis was especially important to many of those we interviewed, particularly if they felt a previous diagnosis did not capture their experiences, or in some cases threatened the sense of who they were. To this extent, diagnosis could be empowering, providing a degree of certainty and reassurance, or at least a tangible framework in which to make sense of the after-effects of encephalitis. Diagnosis, however, was used as a means to an end, to make sense of their experiences rather than define them. Equally, if a diagnosis was interpreted as inappropriate it could, as we have seen, become oppressive, especially if equated with mental health problems. Without a label they regarded as valid, their experiences made little sense, causing particular difficulties with disentangling those problems that could be attributed to ‘them’ and a more generally inability to cope, or to an organic process, affecting brain function.

Locating the illness within the clinical functioning of the brain was especially important. Those we interviewed not only made the traditional distinction between body and mind when talking about illness, but also mind and brain. To equate ‘brain’ with ‘mind’ and more generally, ‘personality’ would have undermined a person's sense of who he or she were; the condition became them, rather than a separate part of being. Their problems were consequences of ‘an illness’, which affected their brains and not their personalities. Getting others to understand this was frustrating. Albert, who had been living with the after-effects of encephalitis for over 25 years, expressed the concerns of many, worrying that those around him thought his problems were, ‘all in the mind’.

Family members can be especially important allies in gaining legitimacy for the consequences of encephalitis. Many of those we spoke to described supportive and caring relationships. Family members, however, can simultaneously undermine a person's sense of identity, by disbelieving or misinterpreting the consequences of the condition. Tina spoke of her family's guilt when they eventually learned that as a young teenager, she had been affected by encephalitis. She felt that the years of not being believed had damaged her relationship with her family, despite them 'being there' for her. Vicky, whose experience of encephalitis was recent, valued her father's ongoing support but described her shock when she over-heard him say to a hospital consultant: ‘this is not my daughter’:

That was like I'd been kicked in the teeth. I thought ‘great, thanks’. That wasn't really the thing I needed to hear, I needed some positive encouragement.

How people lived with encephalitis on a day-to-day basis enables us to explore the social expression of these meanings in more detail; although as we shall see, individuals not only struggled to convince others of the consequences of encephalitis but also themselves. Coming to terms with what is or had happened to them had to be reconciled with the more fundamental problem of 'being believed'. Individuals' initial experiences of diagnosis established this tension and it remained an ongoing feature of their illness narratives, as they continually struggled to reconcile adaptation with uncertainty. Reconciling past, present and future as part of day-to-day living was how such uncertainty was embodied and its multi-faceted expression offers further insight as to how self-management might struggle to engage those affected by encephalitis.

Reconciling past, present and future

The present became reconciled with the past, the meaning of which a person could never be quite sure. This is why memory assumed particular importance in individuals' efforts to make sense of who they were and what had happened to them. The uncertainties this created, however, made the straightforward enactment of choice problematic, particularly when considered as part of the broader process of adaptation and self-care. Lack of memory about the onset of encephalitis was common and particularly upsetting. Individuals often had to rely on the narratives of others, such as family members, to help them understand what had happened. This generated a constant struggle and several revisited this stage of the illness, irrespective of how long ago the event occurred, questioning family members in the search for meaning. There were other implications, particularly since the only way some individuals could make sense of important events in their lives, before the illness, was through the memory of others. This caused a sense of dislocation between 'who they were' and 'who they are'. The abrupt nature of the onset of encephalitis further compounded the
Memories represented a core part of who a person was, connecting past and present. Tom, who had gone through extensive rehabilitation, including a referral to a memory clinic, knew he loved his wife and family but sometimes struggled to make sense of these emotions. They seemed located in a past he could no longer quite understand:

It’s just everything that made me who I was and all my feelings [who made me] who I was are not there anymore.

The lack, or more commonly partial lack, of memories from former lives was disconcerting, particularly during the early stages of coming to terms with the consequences of encephalitis. Interviewees could not recall key aspects of their biographies, such as holidays (Philip) or his own wedding day (Oliver). Both reflected that they needed the past to understand who they now were. Oliver explained:

I got married in 2004 but while I was in hospital, I asked [his wife] to marry me. So she then had to explain that we’d done that in 2004…You can see that that’s a pretty major incident in your life not to have a memory of.

Certain aspects of their biography, individuals regarded as important, were now missing. Looking at photographs of past events, which could not be remembered, was especially painful for some, although for others they assumed an important role in what Oliver described as, ‘re-capturing the past’. Whereas aspirations could be re-evaluated, memories could not be so easily replaced. People constantly struggled to reconcile the person they had been with who they were now. Individuals gave priority to this when accommodating the consequences of encephalitis. Establishing their past was, therefore, an important part of adapting to the condition. Any strategies aimed at encouraging them to use their existing or future social resources to enable coping was likely to become entangled in a person’s attempt to engage with their past, adding further complexity to their illness experience. A focus on the future was especially difficult when trying to simultaneously accommodate doubts about who they were/are.

The person they used to be

Those we interviewed often mentioned that they wanted to be the person ‘they used to be’, even if this former self was contingent or imagined, or in some cases constructed from the accounts of others. It enabled individuals to exercise some control over their own and others’ ability to define them. For some, emphasising continuity with a previous self was especially comforting, performing a valuable function in allowing them to make more sense of the present. Consequently, any examples of continuity were highly valued, be they the ability to return to previous employment or to relive key memories and engage in conversation about them. For most, however, some sense of ‘loss’ was evident. Individuals felt that they had become a different and, in some cases, a new person following encephalitis. Elspeth now avoided old work colleagues as she wanted [who made me] who I was are not there anymore.

Perhaps this explains why living in the present assumed particular significance for those we interviewed. Individuals affected by encephalitis had to constantly alter their expectations of themselves. Adjustment (or acceptance) was not viewed as an achievable, finite outcome, but rather as an aspiration, partially realised through daily living. Here was the basis upon which they engaged with the present and why contingency characterised their accounts. For several interviewees time became condensed to the everyday – for example, getting up in the morning, managing a trip to the supermarket or planning and cooking a meal; dealing with the illness focused on living hour to hour or even moment to moment. In the same way, what had happened to them was indistinguishable from what was happening to them.

All this suggests a degree of fluidity in how people made sense of uncertainty and the ambiguities it created for who they were. Individuals did not always seek to resolve biographical disruptions caused by illness. This was the context in which any sense of choice they thought they might have assumed meaning. Indeed, their engagement with uncertainty made it difficult for them to see their life in terms of choice: their settlement was more the consequence of ongoing negotiation. Uncertainty became incorporated in their sense of who they were, as they negotiated the present, while at the same time reflecting a perceived sense of loss at what they could no longer become. Interviewees’ sense of normality was, therefore, vulnerable. There were times when they were overwhelmed by the consequences of encephalitis. Coping was a variable, exhaustive resource which they did not always have. It could not simply be accessed at will but had to be accommodated into practical expectations about what could be achieved and what could not. Those we interviewed were specifically aware of the contingent foundations of who they were. They were happy to use a reflexive self as a way of maintaining a valued identity, while being equally aware that no outcome was guaranteed. Anna attempted to make sense of this:

I talk a good line but I don’t always do it. You know, as I say, I know the answers but it’s putting them into practice, I still have to…’I’ll get there eventually’. The only advice I can say is try to be as positive, try to get your interests and think outside of it and not dwell on, ‘oh, this happened to me and why?’ and so on and so forth. Consider it as part of the past…just try to get on with life. I wish I could tell myself that. I tell everybody else now, so I’m going to print it up and look in the mirror every morning and tell myself. As I said, I talk a good line, I know I do. I know the answers, I can’t always put them into practice.

Recovery and uncertainty

A person’s sense of recovery became bound up with this contingency. Recovery could never be certain, nor could what a person was recovering from; time did not seem to make a great deal of difference in understanding this. For some, recovery meant getting back to the person they were. This was their future aspiration, expressed in present hopes and part of a person’s dynamic engagement with encephalitis. Many of those interviewed reflected on whether they were ‘recovering’ or had simply adjusted their expectations to give them the impression of recovery. It was why,

Negotiated expectations

This constant reconciliation of the condition, in relation to past, present and future also resonated with how an individual negotiated life goals and expectations. Planning for the future or even the present was difficult and interviewees usually merged the two. The after-effects of encephalitis can be highly unpredictable. Tina, who had 20 years experience of accommodating the consequences of encephalitis, explained:

And I think the erratic-ness of it is very wearing, on the person who has the condition and also everyone else around them. You can never just get up and say, ‘I would like to do this today’. It’s always, ‘what am I able to do today?’

In the early stages of coming to terms with the consequences of encephalitis, explained:

You know, you look and you’re not the same person you were— you never will be that person. I say to people, ‘why that person died four years ago. This is a new person’.

Problem, particularly since it seemed to offer a break between their ‘previous’ and ‘current’ selves.

Interviewees could not recall key aspects of their biographies, such as holidays (Philip) or his own wedding day (Oliver). Both reflected that they needed the past to understand who they now were. Oliver explained:

I got married in 2004 but while I was in hospital, I asked [his wife] to marry me. So she then had to explain that we’d done that in 2004…You can see that that’s a pretty major incident in your life not to have a memory of.

Certain aspects of their biography, individuals regarded as important, were now missing. Looking at photographs of past events, which could not be remembered, was especially painful for some, although for others they assumed an important role in what Oliver described as, ‘re-capturing the past’. Whereas aspirations could be re-evaluated, memories could not be so easily replaced. People constantly struggled to reconcile the person they had been with who they were now. Individuals gave priority to this when accommodating the consequences of encephalitis. Establishing their past was, therefore, an important part of adapting to the condition. Any strategies aimed at encouraging them to use their existing or future social resources to enable coping was likely to become entangled in a person’s attempt to engage with their past, adding further complexity to their illness experience. A focus on the future was especially difficult when trying to simultaneously accommodate doubts about who they were/are.
for some, ‘recovery’ was still ongoing even some years after the illness. Others could not distinguish between recovery and coping. Tom explained:

‘Whether it’s because I’m coping with it better or whether it is getting better is a different perspective on it.’

Uncertainties created by trying to reconcile the extent to which they had recovered and the extent to which they were still recovering were another aspect of people’s perceptions of who they were, adding to the fragility of their settlement and why self-doubt remained such an important part of who they were. The problem of language provides a final example of how this was expressed; further defining the social space in which encephalitis was made sense of, in which both diagnosis and reconciling the consequences of the condition found specific meaning.

Talking about encephalitis

The lack of linguistic strategies available to a person when describing what was happening to them, further embodied self-doubt. Doubt often missed by conventional approaches, associated with self-management, where diagnoses (and its social description) were assumed to be largely unproblematic. As a consequence of having encephalitis there was, at some point, a shift in recovering from an acute condition (encephalitis) to dealing with a long-standing condition (the consequences or after-effects of an acquired brain injury). There were, however, no neatly defined, socially agreed linguistic terms interviewees could use to capture this experience in a way that made sense to them or enabled them to explain to others. This, if nothing else, might explain the dominant use of what seemed well rehearsed metaphors, often self derived, within interviewees’ accounts. They somehow had to create their own language, which they then had to make accessible to others. This language also helped reinforce people’s ideas that their ‘faulty’ brains were the problem, rather than their personalities.

The extent to which experience is a reflection of language and discourse is perhaps not the point here. Rather it concerns how language struggles to capture the experiences of who these people think they are. Language not only re-creates their illness, which according to medical discourse had been cured. This is also why several were not especially interested in drawing a distinction between the acute stage of encephalitis and its long-term consequences. Professional understandings were challenged, which saw encephalitis as an acute, time-limited event, again raising the potential for disempowerment as notions of disease contradicted individual experiences of illness.

Discussion

Our account explored how people affected by encephalitis made sense of the consequences of an acquired brain injury. We will now use these findings to provide a more critical commentary on current policy ideas about self-management and self-care. In doing so, we suggest sensitivity to illness experience is elementary to the success of any interventions aimed at facilitating successful coping. Our findings specifically highlighted the ways in which people adaptively and strategically configured their lives following illness, as they tried to make sense of what had happened to them. Indeed, the struggle for an ‘appropriate’ diagnosis assumed great importance for some people. More generally, the accounts of those we interviewed offered a reminder of how living with a long-standing condition occurs in a dynamic social space, involving negotiation and engagement.

Encephalitis was especially challenging in this respect. ‘Being believed’, while reconciling past, present and future, emerged as fundamental, although broader expressions of self-doubt complicated the process, suggesting individuals felt they had to convince themselves of the consequences of encephalitis, in addition to those with whom they engaged. This found expression in their ‘never ending cycle of biographical appraisals’. Separating the condition from personality, re-creating a language that gave meaning to their illness, balancing recovery with chronicity and re-negotiating expectations of both themselves and those around them, all reflected aspects of these appraisals, as did the broader negotiation of uncertainty. Our respondents re-oriented their expectations in a way that accepted that there could be no known future, only a desired and conditional one (see also McLaughlin & Goodley, 2008). Those we spoke to were aware of contingent foundations of who they were. The dynamic tensions created by this explained why they were happy to use a reflexive self in maintaining a valued identity, while being equally aware that no outcome was guaranteed.

This is the extent to which maintaining a valued social identity remained a legitimate exercise for our respondents (see also Bury et al., 2005). Interventions informed by self-management could potentially undermine this, particularly if individuals perceived such interventions as implying that their illness were somehow associated with their personality or inability to cope. Admittedly, self-management, as envisaged by current policy, is not without value and the accounts of those we interviewed reflected this. Much illness management took place outside the formal health care system and self-care—in its broadest sense—was an important aspect of the illness experience for most of those we interviewed (see also Gately et al., 2007). Self-management also helped emphasise the active creativity of human interaction, although our account suggested this was also collectively negotiated (see also Beard & Fox, 2008). Those we interviewed could find their sense of who they were confirmed, supported, nurtured, challenged, undermined and questioned through their social relationships (see also Fox, Ward, & O’Rourke, 2005; Pescosolido, 2006). Families could be simultaneously supportive, while casting doubt on a person’s account of who they were. This is the broad context in which a person’s illness assumed social meaning and we suggest that understanding this process might be a more important starting point when trying to make sense of self-management.

In some ways our findings are not surprising. They support the idea of agency as conceived by Pierre Bourdieu. He was concerned that an individual is simultaneously defined and realised through the processes of social negotiation and the specific context of power relationships. Identities become legitimated through this process as outcomes are not guaranteed but subject to ongoing negotiation. Strategy and struggle creates potential for relationships to be challenged and altered (Bourdieu, 1990). An individual, as part of active agency, is able to use norms, attitudes and beliefs to define who they are. This, however, raises the possibility that more structural aspects associated with these norms and values, can also impose themselves. Self-actualisation involves collectivity and individuality. We live ordered lives; not everything is possible (Jenkins, 2004). Such tensions remained at the heart of interviewees’ narratives. Encephalitis did have consequences for individuals’ lives, but at the same time these consequences had sufficient fluidity to ensure the experience of illness was not predefined.

To work successfully, we would suggest self-management strategies need to engage more with the contingency of individual experience, particularly since the priorities of the individual might not be the same as those assumed by policy. Our respondents’
accounts provided many examples of this as individuals’ interpretation of their illness became embedded in a conditional acceptance derived from and sustained by their perceptions of the social relationships surrounding them. Self-management assumed meaning within the context of this negotiation. Questioning how this context defines a person’s experience is as important as understanding how it can support successful coping and enhance social opportunities.

This is why the instrumental and reified nature projected onto ‘self-management’ by current policy did not always find meaning among those we interviewed. To some extent, policy notions rely on what Frank (1995) would describe as either a restitution narrative and the hope of ‘things getting better’ or ‘quest narrative’, in which illness is used to generate ‘self-awareness’. These narratives, however, were never quite fully realised in our interviewees’ understanding of encephalitis. Rather there was an underlying and ongoing threat of a chaos narrative because of the struggle for validation; a reflection of fragility, vulnerability and self-doubt (see also Nochi, 2000). Encephalitis is a ‘disease’ which causes conceptual ambiguity; an ‘illness’, in which a person can never quite be sure of who they are; and a ‘sickness’ in which the consequences of encephalitis can become associated with an individual failing. This process also explains how positive coping can be a celebration of active agency, while also evoking negative moral judgement when people do not cope (see Mol, 2008).

Such complexities begin to explain some of the emerging difficulties associated with self-management, especially where greater confidence in developing self-care is not always realised by individuals (Wilson, 2008). Some question whether existing outcome measures, used to gauge the success of self-management, capture the everyday experience of those with long-standing conditions (Rodgers et al., 2008). There is even doubt that such initiatives reduce use of formal health care (Gately et al., 2007). Our account would support this scepticism. Critical engagement with how policy defines and ‘imagines’ long-standing illness, without recourse to generalised and poorly contextualised notions of coping, would seem a more helpful starting point. As long ago as 1991, Bury reminded us of the specific value of distinguishing between coping, strategy and style. Individuals actively engage and adapt to illness as way of maintaining self-worth, but given the diverse contexts in which they have to do this, a range of coping styles (where their illness is presented and its symbolic meaning negotiated) and coping strategies (where they attempt to mobilise resources, to maximise favourable outcomes) emerge. This involves choice and constraint, which in turn become mediated by age, gender, ethnicity and socio-economic position (see Atkin, 2009). Unfortunately, our study’s focus made it difficult for us further exploration, although the patterning of social disadvantage is likely to be an important variable, mediating the meaning accorded to formally sanctioned self-management strategies.

To conclude, the experience of encephalitis is more than simply belonging to a defined diagnostic category. It is an expression of a person’s negotiation of the social meaning of his/her illness. This is not to deny the potential value of ideas such as self-management, particularly in relation to self-efficacy (Sanders, Rogers, Gately, & Kennedy, 2008). Nevertheless, these might not have the same meaning for everyone, particularly since interventions embody a fundamental ambiguity: is their purpose to help individuals cope better with their illness or with the context in which their experiences of illness are realised? Legitimacy is ongoing; a settlement is never quite reached. Successful coping is not only realised by a reflexive self, able to use self awareness and proactive engagement, but also by an individual’s struggle to engage with the social meaning of his/her condition. This is why we argue against generic approaches to self-management and for a more pluralistic response which involves being aware of how people adapt to their illness. Some of the policy literature has begun to take note of this; emphasising both the importance of understanding multi-psychosocial responses with more social contexts of health and the broader discontinuity between policy and individual account, which also reminds us of the political nature of such interventions (Bury et al., 2005). In addition to reflexive patients, we need reflexive practitioners, able to apply critical insight in responding to an individual’s circumstances. This includes understanding how coping is socially negotiated, defined by the social space in which it takes place, while adapting a less instrumental and more contextualised and nuanced approach to self-actualisation.

References
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