Forgetting and remembering epilepsy: collective memory and the experience of illness
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Abstract
How do people with epilepsy relate to the long and troubling history of this disease? Drawing on two sets of interviews with people with epilepsy, one cohort from the mid-1970s and one from 2005 to 2006, this article examines how memories of what epilepsy has been shape the individual and collective identities of people living with epilepsy. We find striking similarities in how people in both interview cohorts talk about what epilepsy was in ‘the Dark Ages’, by which they refer to the recent past. Likewise, we find evidence of a collective identity among people with epilepsy. However, memories of epilepsy’s past do not appear to serve as a basis for collective identity. Rather, these recollections are located in narratives of hope, in which people with epilepsy express confidence that the lives and life chances of people with epilepsy have improved – and will continue to improve – over time. Indeed, to the extent that people with epilepsy share a temporal orientation, it is much more to a collective future than to a collective past. Our conclusions, therefore, focus on the ways that the meanings of the past are shaped not only by present events but also by anticipated futures.

Keywords: illness narratives, collective memory, illness identity, epilepsy

Diseases are not stable objects. Rather, they represent multiple, different entities that ‘go under a single name’ across times and places (Mol 2002: 6, Rosenberg 2007). Few diseases demonstrate this variability as vividly as epilepsy. In the many centuries following its description in the Hippocratic corpus in 400 BC (Temkin 1971), epilepsy has been defined as a falling sickness, a supernatural event, a form of spirit possession, an example of moral and physical degeneracy and, more recently, a neurological condition (Dwyer 1992).

Today, scientists, clinicians, people living with epilepsy and advocacy groups, such as the Epilepsy Foundation, understand epilepsy to be one of the most common neurological disorders affecting approximately 3 per cent of individuals at sometime in their lives (Hauser et al. 1991, 1996). However, research has shown that older, stigmatising images of epilepsy, including the representation of seizures as a form of demon possession, persist in the media (Krauss et al. 2000). Further, while there is evidence that individuals’ experiences of stigma have declined since World War II, at least in the UK and the USA, survey research in these countries suggests that pernicious stereotypes remain prevalent (Jacoby 2002, Jacoby et al. 2004). Even in the absence of actual experiences of stigma and discrimination, people with epilepsy describe their fears of experiencing stigma and discrimination (‘felt stigma’) as part of the challenge of living with epilepsy (Scambler 1994).
For over three decades, social scientists have investigated how people with epilepsy experience stigma, and its consequences for their lives and life chances (Gehlert et al. 2000, Jacoby 2002, Jacoby et al. 2004, Morrell 2002, Scambler 1989, 1994, Schneider and Conrad 1983, Whatley et al. 2010). Indeed, epilepsy has served as an empirical basis for the development of the concept of health-related stigma (Scambler 2009). However, research has yet to consider how historical understandings of epilepsy shape the contemporary experience of living with this illness. In this article we ask how epilepsy’s past may enter into the present for people living with epilepsy.

Drawing on two sets of interviews with people with epilepsy, one cohort from the mid-1970s and one from 2005 to 2006, we explore whether and how memories of epilepsy play a role in the individual or collective identities of people with epilepsy. In contrast to the extensive literature that focuses on individual’s experiences of stigma, our analysis examines how epilepsy’s past is recollected in narrative accounts and towards what ends. The unique structure of our data further allows us to examine how these recollections may have changed over time. To our knowledge, this is the first article to explore how processes of collective memory shape the collective identity and illness experience of people living with epilepsy. Our analysis finds that accounts of epilepsy’s past most often serve as a point of contrast or a temporal anchor for narratives that emphasise imagined and hoped-for futures.

Points of departure

Over the past two decades, questions about memory and its relationships to identity have been taken up in studies of social movements and collective action, cultural sociology and historical sociology. In the sociology of health and illness there is a rich literature describing how people who are ill draw upon the past in crafting narratives that help them make sense of their experience of illness. There is also a growing literature on collective identity and collective action among those who are ill. However, the dynamics of memory remain largely unexamined in regard to both individual and collective experiences of health and illness.

Illness, experience and identity

Especially when it is chronic or life threatening, illness has the potential to produce major disruptions in core components of identity, including embodiment, social roles and relationships and expectations regarding life-course trajectories (Becker 1997, Bury 1982, Charmaz 1991, Iphofen 1999). Because dominant biomedical and epidemiological models tend to view the subjects of therapeutic attention through a technoscientific and ahistorical lens (Clarke et al. 2003, Kleinman 1988), it often falls to people who are ill to articulate the causes, experiences and meanings of illness in the context of their particular life stories, embodied experiences, and individual and social identities (Good and Delvecchio-Good 2000, Williams 1984).

Illness narratives provide an important means of establishing new points of reference between body, self and society and reconstructing a sense of order or continuity from the fragmentation wrought by serious illness (Bury 1982, Kleinman 1988). Illness narratives are temporally contingent, as people reconstruct their pasts in the context of their present condition (Williams 1984), such that people living with illness must be understood as active agents of narrative construction (Bury 2001). At the same time, both experiences and narratives of illness are shaped by broader expectations regarding social identities (Faircloth et al. 2004, Pound et al. 1998, Sanders et al. 2002).
By definition, narratives draw on the past. Indeed, one conventional understanding of narrative defines it as a sequence of non-random past events connected to each other in a way that schematises the meaning for the listener or reader (Smith 2007). Through narratives, individuals select and order events in ways that help them give meaning to the experiences of their lives (Riessman 1993). This narrativising of social life contributes to the development, maintenance and transformation of both individual and social identities (Somers 1992).

Much of the literature on narrative and the experience of illness is based in theories that understand identities as self-concepts internalised by individuals, often in the context of structured role relationships (Owens et al. 2010). However, in recent years there has been a burgeoning of research on health social movements, theorised as a specific form of collective behaviour linked to collective illness identities (Brown et al. 2003, 2004, Epstein 1996). A collective illness identity occurs when ‘individuals, through the illness identity acquired as a result of their illness condition, develop a “cognitive, moral, and emotional connection” with other illness sufferers’ (Brown et al. 2004: 60). As with other forms of collective identity, ‘a sense of we-ness or connection to other members of a group/category’ (Owens et al. 2010: 490) is an essential component of collective illness identities. Health social movements require also the politicisation of the collective illness identity, as when affected individuals articulate a shared social critique centred on the causes of their illness or the availability of treatment (Brown et al. 2004: 60). To date, studies have not systematically examined how collective memories or histories of illness may shape illness identities or health social movement activism.

The sociology of memory
Social theorists have long recognised that past events shape current identities, actions and outcomes (for example, Mead 1929). Through practices of institutionalisation and commemoration, memories of past events become part of the cultural milieu that gives meaning to present events, choices and identities (Cunningham et al. 2010). At the same time, sociological research demonstrates clearly that neither memory nor the meaning of the past is fixed (Griffin 2004, Schudson 1992). Rather, events take their meaning from their position in a series of events (Abbott 2001, Bearman et al. 1999). We propose that there are three aspects of collective memory that might be integrated productively into research on illness experiences and identities.

Firstly, sociologists have explored how communities remember their pasts in ways that create a sense of solidarity or exceptionality within a larger social or political order. Among the questions addressed by this literature are how nations remember specific events and why they are remembered in a particular way, how the memory of groups is conveyed and sustained, and what constitutes the purpose and mechanisms of commemoration (Anderson 1991, Griffin 2004, Olick 2007). This line of research has both been informed by and extended Anderson’s important analysis of how ‘imagined communities’ are created and maintained such that individuals, who might otherwise feel little connection to one another, perceive themselves to be allied with one another in nationalist projects (Anderson 1991). These collective narratives about people, events and action change over time, as they are applied to different purposes, but there are limits to this malleability (Olick and Levy 1997).

A second and related domain of inquiry in the sociology of memory focuses on when, why and how people seek to recover a collective past. Central to this research are questions about how narratives about (recovered) pasts shape social interactions between individuals and groups (Eyerman 2004). Recollected pasts provide people with a basis for socio-biographical memory, which refers to a mechanism by which people feel pride, grief, fear or guilt with
regard to events that happened to a group with which they identify, even if the events happened prior to their joining of the group (Zerubavel 2003).

Thirdly, scholars of memory have posed questions about the relationship between memory and history. Halbwachs distinguished between history as ‘a remembered past to which we no longer have a social relation’ and collective memory as ‘the active past that forms our identities’ (Halbwachs 1992, in Olick and Robbins 1998: 111). Similarly, French historian Pierre Nora contends that the boundary between memory and history is defined by the move from lived experience to practices of preserving and transmitting identities and cultures that might vanish without practices of commemoration (Nora and Kritzman 1996). However, as noted above, present events and interests may reactivate histories that might otherwise have remained static or dead (Bearman et al. 1999). Methodologically, these distinctions suggest the importance of attending to how ‘public narratives’ (Somers 1994) and institutionalised histories enter into processes of collective memory and with what consequences (Cunningham et al. 2010).

**Research questions, data and methods**

Drawing on interviews with people with epilepsy and their immediate family members, we explore the following research questions:

1 What are the forms in/through which people with epilepsy (and their family members) remember what epilepsy was in the past? What kinds of stories do they tell about remembering and/or forgetting epilepsy?
2 Does referring to the history of epilepsy provide people with an imagined community or sense of collective identity?
3 In what ways do individuals’ accounts incorporate public narratives and/or institutionalised histories?

The data for this analysis come from a larger comparative study of people who have epilepsy and their family members. The data are arrayed in two temporal cohorts, with one set of interviews from 1975 to 1978 and another from 2005 to 2006. In both cohorts, data were collected using semi-structured interviews. Each individual interview quoted in the text is identified with a unique name, the age of the speaker and the cohort in which he or she was interviewed. The 1970s interviews are cohort 1 [1], while the 2005 interviews are cohort 2 [2]. All names used are pseudonyms.

In the 1970s, as part of a study of the experience of having epilepsy, sociologists Peter Conrad and Joseph Schneider interviewed 80 people with epilepsy (Schneider and Conrad 1983). The interviewees were initially recruited through contacts with self-help groups, vocational rehabilitation services, classified ads in local and community newspapers and ‘shoppers’ and then through snowball sampling. Theoretical sampling guided the selection of subjects to explore themes emerging in the analysis. Most interviews were conducted in person and audiotaped. Drs Conrad and Schneider generously donated the interview transcripts to this project. They consist of 2000 single-spaced pages of text that we have scanned and digitised. From those interviews, we selected a random sample of 40 interviews for the analysis presented here.2 The age range of the respondents is from 15 to 54 years and there are slightly more women (n = 23) than men (n = 17).

In 2005 to 2006 the first author conducted 40 in depth qualitative interviews with people with epilepsy (n = 22) and their family members (n = 18). The sample for these interviews would be selected to ensure a balance of demographics.
was drawn from a database of families who had previously participated in the Epilepsy Family Study of Columbia University (EFSCU) and who had consented to be re-contacted for research purposes. Due to the requirements of EFSCU, all the people in the database come from families in which two or more individuals have a seizure disorder. Our sampling strategy was purposive, with a deliberate effort made to encompass a wide variation in the number of affected individuals in a family, symptom severity and socio-demographic characteristics that seemed likely to shape the experience of having epilepsy (such as gender, age, educational background and marital status). Despite these efforts, this cohort contains twice as many women (n = 28) than men (n = 12), with ages ranging from 19 to 61 years. Because the respondents lived throughout the USA, most interviews were conducted over the telephone and all were audiotaped. They were transcribed by a professional transcription service. Both sets of interviews were analysed with the use of Atlas.ti, a computer-based analysis package for qualitative data (Muhr 1991).

Many of the questions asked of the participants in the first cohort were replicated in the interviews conducted in 2005 to 2006. Specific topics explored in both sets of interviews include: (i) the interviewees’ experience of learning that they have epilepsy; (ii) how having epilepsy has affected their life; (iii) their beliefs about aetiology and seizure precipitants; (iv) their experiences of stigma and discrimination; (v) their interactions with healthcare providers; (vi) their social networks and practices of disclosure and (vii) their socio-demographic data. Consequently, these two sets of interview data represent a unique opportunity for historical comparison.

In their answers to the interview questions, the respondents spontaneously offered their assessment of the historical meaning of epilepsy and the experiences of people with epilepsy at different moments in time. During the initial coding of the interviews, we noticed the prevalence of comments about epilepsy’s ‘dark past’ in both interview cohorts. Therefore, drawing on the principles of grounded theory (Charmaz 2006), we decided to recode the interviews to specifically examine remembrances and articulations of the past. In addition to the inductive codes developed during the first round of coding (for example, ‘change over time’; ‘changing public views’; ‘shameful past’), we developed a series of codes grounded in the literature described above (for example, ‘positive pasts’; ‘negative pasts’; ‘imagined community’). As we coded, we also developed new inductive codes. For example, early in the recoding process, both authors independently noted the need for a code that would capture a unique aspect of epilepsy; its defining characteristic – seizures – are not remembered and, indeed, may obliterate memories of the hours preceding and following their occurrence. We begin our analysis of remembering epilepsy, therefore, with accounts of forgetting.

Analysis

Forgetting

I never remember any of it. (Kate, 20 [2])

Although epilepsy is broadly defined by recurrent (i.e. more than two) unprovoked seizures (Hauser et al. 1991, 1996), there is tremendous variation in the symptoms, intensity and consequences of seizures. This clinical heterogeneity means that people with epilepsy have a wide variety of experiences of seizures. Nonetheless, a strong theme across both cohorts of interviews examined in this study is the power of epilepsy to interrupt and erase memory.
In both cohorts, the respondents described loss of memory as a central component of having a seizure. Unsurprisingly, this was especially true for people with epilepsy who have full blown tonic-clonic seizures, which involve a loss of consciousness. In their descriptions of their experiences of seizures, many respondents described a set of feelings that preceded loss of consciousness, followed by their experience upon ‘waking up’:

... kind of vertigo and losing consciousness and fighting to maintain your consciousness then finally waking up ... knowing that actually you did have a seizure and just disorientation that you feel and the stiffness of the muscles and the teeth that have chewed gums and that whole smear of things. To me this is an epileptic seizure. (Frank, 38 [1])

Not all people with epilepsy have a series of somatic experiences, or an ‘aura’, preceding their seizures. One respondent described herself as just ‘dropping like a sack of potatoes and having no memory of it’ (Anne, 50 [2]).

Additionally, for some people with epilepsy, seizures are marked by periods of amnesia following their return to consciousness. Upon waking from a seizure, people initially may not know who or where they are:

Usually when I finally come to, I have no memory of anything. It takes a while to figure out my name. It all comes back, but just really slowly. (Christina, 25 [2])

One respondent poignantly described his state upon waking as ‘pretty vulnerable’ (Evan, 47 [2]). This vulnerability can be exacerbated by well-intentioned bystanders who may ‘bombast with questions’ someone who is just coming out of a seizure:

You get very frustrated because you want like hell to answer every question that they can pose to you to show them that you are all right and you want to communicate that everything is great with me and all that and you can’t even say your name. ‘What did you have for dinner?’ I don’t know what dinner is. ‘You remember going to school?’ I don’t know what school is. (Frank, 38 [1])

Moreover, for some people with epilepsy, a seizure will ‘erase’ larger periods of time contiguous with it. As this respondent commented:

Nothing of that day ever comes back. Like I say I had gone to like a movie that day, I don’t remember it ... it’s like that whole day gets erased somehow. (Christina, 25 [2])

Perhaps most dramatically, a woman who had a seizure during the evacuation of New Orleans during Hurricane Katrina in 2005 lost all memory of being evacuated:

[A]nd that was really hard, having to ... wonder why you’re in Dallas and have people tell you, ‘A hurricane wiped out New Orleans. That’s why you’re in Dallas’. (Kate, 20 [2])

The memories of people with epilepsy may also be disrupted by the medications that they take to control seizures. A respondent interviewed in the 1970s commented, ‘I can’t really remember much because my mind was just sort of gone with that medication. I was sort of wasted a year of my life’ (Betty, age unknown [1]). While respondents in the 2005 interview cohort described fewer negative effects of anti-seizure medications, one commented that ‘my
memory was starting to get to the point where I couldn’t function at work … there are some memory impairment problems with Depakote’ (Laura, 39 [1]).

Although forgetting is not itself a collective experience, it has implications for the collective identity of people with epilepsy. Because seizure, the defining symptom of epilepsy, is not subject to memory, the illness experiences of people with epilepsy consist of their experiences preceding and following a seizure, their efforts to avoid seizures (which may include both medications and lifestyle modifications, such as getting enough rest or limiting their consumption of alcohol) and their interactions with significant others (including doctors, parents and romantic partners) about this condition (Schneider and Conrad 1983). As a consequence, the experience of epilepsy has much in common with other chronic episodic illnesses. Indeed, as we describe later in the article, people with epilepsy express a sense of collective identity not only with other people with epilepsy but also with people living with a wide variety of chronic illnesses. However, at the same time, they are well aware of the painful particularities of epilepsy’s past.

Remembering

I’ll be 63 years old in August. So I represent, I guess, a person who experienced epilepsy transition between the Dark Ages and the Enlightenment. (John, 62 [2])

In both interview cohorts, respondents spontaneously offered accounts of epilepsy’s history. On the whole, these narratives emphasise how much worse it was to have epilepsy at a previous historical moment. People in both cohorts used many of the same terms and images to describe progress made the decades just prior to their interviews; the ‘Dark Ages’ may be always just a decade or two in the past.

Respondents in both interview cohorts believe that there was ‘more discriminating years ago … more so than today’ (Caroline, 46 [2]). Respondents interviewed in the 1970s based their assessments either on their own childhood experiences or interactions with people older than themselves who expressed pernicious beliefs about epilepsy, including the notion that epilepsy is a form of possession. As one respondent recalled with heartbreaking directness, ‘They called me “the devil’s child”’ (Jane, 27 [1]). Another respondent reported that when her boyfriend’s father was told that she has epilepsy, ‘he … felt that it was something I was possessed by’. While she rejected this framing of epilepsy, which she describes as a ‘primitive response … a lot of old kind of wives and witches tales related’, she felt ‘blown away’ by it (Hannah, 32 [1]). The respondents also observed that older people maintained a greater social distance from them:

Older people are much more hesitant to get close to you or talk to you … I suppose because when they were growing [up] epilepsy was kind of a dark shadow. (Leah, 28 [1])

People interviewed in the 1970s reported encountering people who believed that they were of ‘lower intelligence’ (Frank, 38 [1]), had ‘lost their ability to learn’ or were ‘out of their minds’ (Norah, 52 [1]) or ‘crazy’ (Eleanor, 20 [1]). However, while these respondents directly experienced stigma in their lifetime, at the time they were interviewed they saw such experiences as part of the past.

People interviewed in 2005 similarly asserted that the negative stereotypes of epilepsy are largely the relics of a time gone by. One respondent commented:
I think it's less a shock nowadays as what it once was. You know, years ago people were like... 'Oh, he's possessed!' type thing... and I don't think it's like that now... [not] as bad as it was, anyways. (Mark, 41 [2])

Similarly, a respondent observed, 'It's not like it used to be where they'd shove them off in a closet, you know. People are more open and understanding now than they used to be' (Ruth, 69 [2]). At the same time, as noted by this respondent, these stigmas, stereotypes and the suffering they caused belong to a relatively recent past: 'It used to be a sign that the devil had overtaken your body. And yeah, that was 75 years ago, but that's not that long ago' (Kimberly, 28 [2]).

In contrast to the first-hand experiences recounted by respondents in the 1970s, respondents interviewed in 2005 less often related their own direct experiences of stigma or discrimination and referred, rather, to the experiences of their family members: 'back when my dad’s grandfather had it, it was so shameful that no one really, just a few people knew that he had it' (Kimberly, 28 [2]). Another talked about two great-uncles who she believed had epilepsy; they were perceived as 'a little loony' and:

... weren't really allowed to live in the [house]. These two uncles lived ... out in the barn ... they were really kept away from the family ... it was a big, black secret' (Meghan 57, [2])

Based on such stories, she concluded that epilepsy was then 'a bigger burden', as she noted 'with us it wasn't that way' (Meghan 57, [2]). In part, these familial references are a consequence of the requirements of EFSCU, from which we drew our interview participants; that is, all of the interviewees in the 2005 cohort have at least one family member who has seizures. Nonetheless, it is striking that it is their family members’ experiences, rather than their own, that appear in these accounts.

The secrecy that surrounded epilepsy in the past also was mentioned by respondents in both interview cohorts. Again, respondents’ comments emphasised progress, claiming that whereas in the past epilepsy was 'a forbidden disease' (Michelle, 57 [2]) and ‘wasn’t something that was talked about’ (Kristin, 27 [2]), now ‘we’re more open about such things’ (Amanda, 61 and Jack, 65 [2]). Even in the interviews conducted in the 1970s there is a sense of increasing openness and public awareness of epilepsy. This respondent details changes seen in her lifetime and, as with the respondents quoted above, emphasises that older people have a different ‘dark’ understanding of epilepsy:

I think it’s more in the public eye, I still think there are the ‘dark deep secrets people’ ... especially with older people and I mean like 45 and older. Younger people it doesn’t seem to bother and I think that’s because they’ve grown up with advertisements on TV and a lot more publication about it. (Leah, 28 [1]).

In both interview cohorts, respondents emphasised improvements in both medical options and social support for people with epilepsy. In the 1970s, a respondent stated ‘I am just awfully damn glad I wasn’t born 50 years ago. Then you were just put in the home and they didn’t have the medication’ (William, 25 [1]). In 2005 a respondent commented that the ‘medical understanding’ and ‘support’ that is available now is much greater than what was available to her as a child (Laura, 39 [2]). Her sister concurred, commenting, ‘There’s really no comparison to the kind of resources I have now to what we had growing up’ (Ashley, 40 [2]).
Imagining communities

Anything that I can do to help someone through this mess. (Ruth, 69 [2])

Group identities may derive either from common bonds (relationships between individual members) or common identities (identification directly to the group or category) (Prentice et al. 1994, in Owens et al. 2010). People with epilepsy express both kinds of group identity. For people with epilepsy, a shared disclosure will serve as a bond. However, even people with epilepsy who do not know anyone else with epilepsy articulate a sense of identification with other people with epilepsy. Most often, this sense of collective identity is expressed as an expectation that people with epilepsy will help each other and do what they can to improve the situation of future generations. At the same time, people with epilepsy also express a broader identification with people who are ill, disabled or suffering for other reasons.

Most people with epilepsy do not know other people with epilepsy. The absence of social relationships between people with epilepsy was especially marked in the 1970s, with respondents describing themselves as ‘isolated’ (Alex, 32 [1]) or ‘a loner’ (Anya, 22 [1]). One respondent commented, ‘I thought I was the only one who had it. I didn’t know anybody else who had it, nobody talked about it’ (Leah, 28 [1]). Further, respondents reported that even if they knew of other people with epilepsy, they didn’t feel comfortable talking with them about it:

I know of people but I don’t know other persons with epilepsy. Never talked to anybody else about it. I could have talked to somebody who had it but not about it, ’coz they won’t tell anybody either … it’s this kept secret. (Anya, 22 [1])

Though people with epilepsy interviewed in the 1970s were reluctant to disclose their condition even to other people with epilepsy, when they did disclose, it frequently served as ‘a bond for a friendship’ (Janet, 30 [1]). One respondent described reaching out to the mother of a boy with epilepsy who became friendly after her disclosure (Alicia, 47 [1]). Another respondent commented, ‘having epilepsy makes me closer to anybody who has epilepsy’ (Maria, 23 [1]).

In contrast to the respondents in the 1970s, the people with epilepsy who we interviewed in 2005 have family members with epilepsy, to whom they turn for support:

No, but it’s a lot easier when you have another family member to share it with. Better than being all alone. (Rebecca, 36 [2])

Only a few respondents in this cohort reported involvement in support groups for people with epilepsy. However, many respondents in the 2005 cohort told us that they didn’t know anyone who had epilepsy beyond their family.

In these interviews the strongest expression of a collective identity among people with epilepsy is found in their expectations that people with epilepsy should help each other. This serves as a motivation to engage in collective and individual action. For example, respondents in both interview cohorts describe becoming involved with the Epilepsy Foundation as a means of fighting against stigma and discrimination on behalf of all people with epilepsy: ‘I feel it’s my duty to be an advocate for epilepsy’ (Maria, 23 [1]). A respondent in the 2005 interview cohort described helping others with epilepsy as a way of finding meaning in her personal suffering:
And as my time has gone on and as I’ve been able to help other people, I don’t look up at the sky anymore and go, ‘Why did you do this to me?’ because I realise that if I hadn’t had the experiences that I have, I would not have been able to help other people with their experiences and that’s really important. (Susan, 35 [2])

In addition to involvement with the Epilepsy Foundation, people interviewed in 2005 spoke of their participation in research as an expression of their commitment to helping others living with epilepsy.

Unique to the 2005 interviews was a series of questions about respondents’ motivations for participating in research and what interest they had, if any, in obtaining genetic information about epilepsy (such as undergoing genetic testing, if it was made available to them). Here, people with epilepsy and their family members repeatedly expressed their desire to help ‘anybody who is in that situation’ (Denise, 48 [2]) or the ‘pool of people that have epilepsy’ (Evan, 47 [2]). Respondents stated clearly that they did not expect personal benefit from participating in research:3

It’s not about me. It’s not about whether they can help me. It’s about whether they can help any other child that has to grow up with epilepsy or anybody. Period. (Zack, 33 [2])

Some respondents commented that they hoped that their participating in research would help their younger family members, ‘so that my nieces and nephews don’t have to go through this’ (Anne, 50 [2]). However, others emphasised that their intentions were not limited to their family members: ‘even if it don’t help my family, but it [could] help others’ (Josh, 55 [2]). Some respondents were focused broadly on being of service to future generations (David, 46 [2]): ‘Maybe it will help somebody else … somebody else in the future. Some little kid in the future or something’ (Michelle, 57 [2]).

There’s no time like the future

You have to be hopeful. (Meghan, 57 [2])

Indeed, in so far as people with epilepsy share a collective orientation to time, it is the future, rather than the past, that appears to be significant. As dark as the past may be, the future is hopeful. However, the social institutions expected to be the mechanisms of progress have shifted over time. In the interviews conducted in the 1970s the respondents expressed the hope that changes in the law and public policy would improve the condition of people living with epilepsy. Indeed, the respondents noted that even recent changes in the law ‘especially just since I have had it [epilepsy]’ had improved their situation (William, 25 [1]). In the 2005 interview cohort, respondents are focused firmly on biomedicine as a means of improving the lives and life chances of people with epilepsy. The respondents envision a future in which the ‘progress of medical science’ results in new medications (John, 62 [2]), gene therapies (Kimberly, 28 [2]), or environmental interventions (Josh, 55 [2]) that lessen the burden of epilepsy so that ‘future generations won’t have to worry about it’ (Stacey, 56 [2]).

In addition to tangible advances in biomedicine, people with epilepsy and their family members who were interviewed in 2005 expressed a belief that with scientific research and the media attention generated by major biomedical advances will come greater understanding and public acceptance of epilepsy. Some respondents suggested that genetics research, in particular, might offer a powerful means of increasing public understanding of epilepsy and dispelling fear about seizures (cf. Phelan 2005):
Because then … you take away an element of fear from it. It’s not such an unknown. It’s not such a scary thing. It’s genetic. There’s an answer to it … and so if you have this huge press release of genetic testing in relation to epilepsy all of this and people are talking about epilepsy and just that conversation can just having in the mainstream media is going to be so helpful alleviating people’s fear and unknown. (Kimberly, 28 [2])

Respondents contend broadly that research helps to cultivate awareness, comparing the public attention paid to epilepsy with that attracted by other diseases:

You know, cancer is terrifically [visible] – we have walks and Relay for Life … all of things that we do to raise money. We pray for people when they have cancer and they’re diagnosed and we pray for them during their treatment and all of these things because it’s much more of a known factor. So I think that [research] might influence public perception. (Susan, 35 [2])

Another respondent asserted that because diabetes and heart problems are ‘more commonly known and understood’ people ‘don’t mind talking’ about them (Christina, 25 [2]). It is quite striking here that people with epilepsy see biomedical research and treatment not only as a means of ameliorating the physical symptoms of the condition but also as redefining its social meaning.

In making comparisons with other diseases, people with epilepsy also gestured towards the power of effective biomedical interventions as a means of lessening the physical and social burden of illness. For example, a respondent noted, ‘It used to be like that with diabetes [difficult to talk about], but then in 1926 they came out with the insulin shot’ (Nora, 52 [1]). Another respondent categorised epilepsy with other previously debilitating conditions that no longer pose barriers to participating in society (Frank, 28 [1]). Put differently, people with epilepsy recognise that the social significance of biological differences can change over time and they find hope in such possibilities. Making comparisons with other medical conditions provides models or tropes through which people with epilepsy imagine a hopeful future.

Compassion, comparison, community

I … make myself available for those who struggle. (Laura, 39 [1])

Further, by making comparisons with other diseases, people with epilepsy define and identify with a community that includes but extends beyond people with epilepsy. Indeed, while people with epilepsy express a commitment to helping others living with seizures, they also state that the experience of having epilepsy makes them more compassionate and leads them to identify with people with other diseases, disabilities, or kinds of suffering.

In both interview cohorts, respondents reported that epilepsy ‘makes you a more understanding person’ (Rachael, 18 [1]). Frequently, people with epilepsy commented that they have more compassion for people living with challenging life circumstances:

[Epilepsy] made me more empathetic to other people with other diseases. (William, 25 [1])

I just think I may be more aware of other people’s disabilities. I think I have more compassion … towards different peoples … for different things that they go through. (Caroline, 46 [2])
Respondents in the 1970s described this greater compassion as extending not only to individuals with illness, but to strangers in need of money (William, 25 [1]). Likewise, respondents in 2005 described themselves as ‘more compassionate to other people in general’ (Susan, 35 [2]), in part because ‘there’s something wrong with everybody, [you] just don’t always know it’ (Michelle, 57 [2]). Women with children commented that it made them ‘more sensitive towards my kids’ (Hannah, 32 [1]) and better mothers (Anya, 22 [1]). In the 2005 interview cohort, family members of people with epilepsy also commented that by virtue of having illness in their family they felt different growing up and, as a consequence, ‘I’m sure I have more compassion on special people than someone who’s never had a brother or a sibling with any illness’ (Denise, 48 [2]).

Especially in the 2005 interviews, people with epilepsy and their family members frequently made reference to a number of other chronic conditions. Most often, mentioning other illnesses served as a means of contextualizing some aspect of the experience of living with epilepsy, such as resisting stigma (Sarah, 27 [2]) or the dynamics of disclosing their illness to others (Eric, 40 [1]). Repeatedly, the claim was that having epilepsy is ‘not as devastating’ as another condition (Evan, 47 [2]) or, similarly, that while having a child with epilepsy can be challenging, ‘it could be worse’ if she had another condition (Amanda, 61 [2]). Respondents in the 2005 interview cohort told us that while epilepsy is stigmatised, other diseases, such as AIDS, bear an even heavier burden of stigma (Kimberly, 28 [2]). As mentioned above, references to other diseases, especially diabetes, also appeared in narratives about how biomedical interventions are improving the lives and life chances of people who are ill.

While we clearly see elements of a collective identity among people with epilepsy, their sense of their group appears to extend beyond people living with seizure disorders. People with epilepsy identify more broadly with the chronically ill. Especially because seizures themselves are not available to memory, many of the central aspects of living with epilepsy, such as taking medication, interacting with healthcare providers, strategising to avoid the emergence or exacerbation of symptoms and negotiating the social meanings of the condition – are shared with others living with chronic illness. Moreover, identifying more broadly with people who are ill offers people with epilepsy a means of mitigating some of the burden of epilepsy’s history and focusing, rather, on a hopeful future.

**Anticipating the future, giving meaning to the past**

One might hypothesise that the relative absence of close social ties among people with epilepsy would serve as an impetus for individuals to turn towards a shared past as a means of constructing an imagined community. As described above, we do find remarkable similarities in how people in both interview cohorts talk about epilepsy’s dark past (see also Reis 2010). However, we find little evidence that such memories serve as a basis for collective identity among people with epilepsy. How do we account for a past that is frequently and commonly recollected but does not serve as a basis for a collective identity?

To begin with, this analysis demonstrates that there is a sense of a group or collective identity among people with epilepsy; the illness serves as a bond. Although many people with epilepsy do not know others living with this condition, they express a sense that people with epilepsy should help each other. Further, in the 2005 interviews, respondents expressed a commitment to helping others with the disease, now and in the future.

Respondents in both cohorts of interviews also express a more general sense of identification with people living with a wide variety of chronic illnesses and life challenges. We contend that this broader identification serves two main purposes. Firstly, it provides a
mechanism for contesting the singularity of epilepsy, grouping it rather with a wide array of chronic, episodic and life changing conditions experienced by many individuals. By drawing comparisons to both more and less stigmatised conditions, people with epilepsy seek to improve public understanding of epilepsy and undermine hurtful stereotypes and stigma. Thus, this article demonstrates that processes of recollection and collective identity formation shape how people with epilepsy understand and represent what it means to live with this condition.

Secondly, such comparisons provide people with epilepsy with a means of articulating the possibilities of a hopeful future. That is, by referring to diseases that have become less burdensome as a consequence of biomedical progress, people with epilepsy express their conviction that the experience of living with epilepsy is improving – and will continue to improve – over time. Indeed, we find that the collective identity of people with epilepsy orients not towards the past, but rather to the future.

In their stories of progress, people with epilepsy draw on powerful public narratives (Somers 1994), not about epilepsy per se, but about the possibilities and mechanisms of social change that will improve the lives of people with epilepsy. The mechanisms highlighted in these narratives have changed over time. In the 1970s people with epilepsy pointed to the role of law and public policy and the rights of people living with illness: medical progress was mentioned but played a less prominent role. In 2005 their accounts focus rather on the promise of biomedical research and its potential not only to generate a variety of new treatments but also to shape the public’s understanding of epilepsy. These narratives locate epilepsy’s past in a particular series of events that moves, in the words of one respondent, ‘from the Dark Ages to the Enlightenment’ (John, 62 [2]). In this framing, participating in biomedical research appears as a form of collective action among people with epilepsy; it is a mechanism through which they act to bring a desired future into being, not just for themselves but for others (Novas 2007). In this way, anticipated futures simultaneously shape a range of possible actions in the present and give meaning to the past (Adams et al. 2009).

This article has several important limitations. Firstly, the 2005 interviews were conducted with people who previously had participated in scientific research on epilepsy. As such, they clearly do not represent the total population of people with epilepsy, especially in regard to appraisals of science, medicine, their promise and possible contributions. Secondly, while respondents in both interview cohorts varied in their symptom severity (and both cohorts included people whose seizures are not completely controlled by medication), we anticipate that people actively struggling with severe uncontrolled seizures would be less likely to participate in interviews and that their perspectives, which may be more critical of biomedicine, are likely to be underrepresented in this study. Thirdly, we are aware that the tendency of respondents in these interviews to locate stigma in the past – if only in the recent past – runs counter to research that finds that felt stigma remains a concern for many people with epilepsy, as well as a major advocacy focus for many nationally based epilepsy associations (Reis 2010). We tend to believe that these themes in our interviews represent not only the remarkable successes of anti-stigma advocacy on the part of the Epilepsy Foundation (among others), but also the efforts of our respondents to narrate the past, present and future of epilepsy in ways which further mitigate possible stigma. That said, there can be no question that future research based on a broader sample of people with epilepsy is needed in order to delineate a more complete spectrum of orientations to the past and the future, to science and medicine and to felt stigma. Given the international scope of biomedical research on epilepsy (for example, International League against Epilepsy n.d.) it is especially important that research investigates how narratives of the future shape the way
in which individuals with epilepsy and the advocacy groups that represent them engage with science and medicine.

Despite these limitations and the exploratory nature of our research, this article demonstrates the analytical leverage gained by considering illness experience through the lens of collective memory and identity. This novel combination of foci allows us to demonstrate that recollections of epilepsy’s dark past provide people living with illness with a means of developing a collective identity that emphasises progress and hope. In the case of epilepsy, anticipated futures – in which legal and biomedical advances greatly improve the lives and life chances of people with epilepsy – are recasting the horrors of the past.6

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Notes

1 These critiques often emerge from individuals’ common experiences in government, medical and scientific institutions, pertaining to (i) access to or provision of healthcare services (health access movements); (ii) health inequality and inequity based on race, ethnicity, gender, class and/or sexuality (constituency-based movements) or (iii) disease, illness experience, disability and contested illness (embodied health movements) (Brown et al. 2004: 52–53).

2 This sampling was undertaken to ensure equal representation of the perspectives and experiences of respondents in each cohort.

3 This understanding is likely to be shaped by the informed consent process for EFSCU, in which participants are informed that this research study cannot provide any meaningful information about individual participants.

4 These included asthma, diabetes, cancer, cystic fibrosis, heart disease, HIV/AIDS, cancer, lupus, mental illness and migraines.

5 As Reis (2010) notes, such strategies of normalisation may have unintended consequences.

6 As noted by Bearman et al. (1999), the contingent and conditional nature of the past – and the recognition that later events can reactivate occurrences whose meanings were thought to be fixed – poses the methodological challenge of ‘casing’, that is, determining the start and end points of event sequences. There is no question that the end point to this sequence is as yet unknown; while available medications do control seizures for most people with epilepsy, we cannot speak meaningfully of disease prevention or cure. Conversely, the re-emergence of severe stigma or discrimination against people with epilepsy could give new salience to interpretations of its past.

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