

Tracking Transformations in Health Movement Organisations: Alzheimer's Disease Organisations and their Changing 'Cause Regimes'

Introduction

In this paper we aim to contribute to the elaboration of a framework for the systematic periodisation of health movement organisations, tracking transformations through what have been referred to as phases (Layne, 2006), waves (Crossley, 2005) and generations (Barbot, 2006) in their histories. Although health movements are a key domain of research in social movement studies which has absorbed concepts and perspectives from a number of intellectual sources, Steven Epstein (2008) identifies a gap in research relating to understanding the relationship between the diachronic and synchronic dimensions of patient groups and health movements. Here, we draw on historical and contemporaneous data on two organisations involved in what has been labelled the Alzheimer's movement to extend the conceptual repertoire to understand this relationship. More specifically, where Epstein draws attention to Maren Klawiter's (2004) work tracing phases in health movements' histories related to successive 'disease regimes', we propose to extend this focus to other regimes, and particularly to transformations in health movement organisations' 'cause regimes'. By cause regime we refer to *who* and *what* a health movement organisation is fighting for, as articulated in its public self-identifications. Additionally, it refers to the broader framing of the cause, for example, as a political or charitable one. Lastly, the concept underscores how organisations' public self-identifications of their cause can govern or regulate their operation, including their interactions with and representations of those on whose behalf they advocate. Because movements are continuously 'in process' (Crossley, 2005) cause regimes are always dynamic; nonetheless we argue they can be relatively stabilised, thus making the identification of distinct phases in organisations' cause regimes possible. However, as we will show, the transformation of a health movement organisation's cause regime can give rise to a series of organisational tensions and challenges, including the alignment of the public identification of its cause with the patient identities it promotes, or its day-to-day 'patient identity work'.

We use the phrase 'health movement organisations' while acknowledging the terminological troubles that beset research on this topic. Kyra Landzelius (2006: 530) refers to 'patient organisation movements' and says the term is intended to be provocative, but that it 'clearly calls attention to the figure of the patient, the phenomenon of organisation, and the dynamics of movements'. We deliberately avoided inclusion of the 'patient' in our preferred term for this paper because the specific transformation in cause regime that we consider is directly related to a move over time to include patients in the constituency on whose behalf the health movement organisations in question are fighting. In the past, the

figure of the Alzheimer's disease patient has been beset by cultural representations of alterity and non-personhood. This is because, as Elizabeth Herskovits (1995: 148) suggests, a debased personhood is implicit in the metaphors of Alzheimer's disease as 'the funeral without end' and 'the loss of self'. Noting that even organisations that advocate on behalf of people with dementia conjoin the term Alzheimer's with 'horror' in their efforts to spur potential donors, Janelle Taylor (2010: 38) stresses the very real injury done when care-givers adopt the 'social death' narrative, 'when it leads them to ignore the person with dementia, or to treat him or her in dehumanizing ways'. Initially, the cause around which the first two Alzheimer's disease movement organisations established in Europe that are the focus of our empirical analysis – the Alzheimer's Society (AS) in Britain and the Alzheimer Society of Ireland (ASI) – was to provide support to family carers of people diagnosed with the disease. In this respect, the early European Alzheimer's disease movement resembled the movement in the USA from where it was isomorphically imported in the late 1970s and early 1980s (Fox, 1989). As Renée Beard (2004: 798) puts it, the US Alzheimer's disease movement 'was not initiated by, or originally intended for, people with the condition'. Likewise, the AS and ASI originated as *carers'* organisations. Now, however, both publicly identify as *carers'* and *patients'* organisations, reflecting a process of hybridisation of their cause.

This move to become hybrid patients' and carers' organisations is shown in this paper to be both a consequence of and catalyst for transformations in prevailing collective illness identities of Alzheimer's disease patients, identities that Alzheimer's disease organisations play a crucial role in co-producing. Circulated by Alzheimer's disease organisations, but attributable significantly to the Alzheimer's disease biomedical enterprise's investments in new diagnostic devices and treatments aimed at delaying progression of the disease (Moreira, 2009), recent years have witnessed processes of Alzheimer's disease patient identity expansion and pluralisation. These twin processes and the associated new understandings of what it means to be diagnosed with dementia have been generated largely by the biomedical definition of the stages of the disease. Emerging alongside advanced stage Alzheimer's disease patients, who have been deemed incapable of self-advocacy and self-care, are the recently recognised patients in the early and preclinical stages of the disease who are regarded as capable of being patient activists and of challenging the social disenfranchisement that frequently accompanies a diagnosis of dementia (Beard and Fox, 2008).

The historical research presented here traces the two Alzheimer's disease organisations' trajectories towards an orientation that recognises patients as their primary constituency, alongside of carers, and a hybridising transformation in their cause regimes. Notwithstanding public pronouncements suggesting that the hybridisation of these organisations is complete, we highlight ongoing organisational tensions and the magnitude of the challenges arising from this shift. ~~The concept of 'thirdspace' as used by Alan Beattie (2003) is useful for understanding this shift. It refers to spaces of hybridity, which are~~

~~'neither One nor the Other', but something else besides, where boundaries are remade instead of employing the 'ready-made, the already-named, the pre-set'. Destabilising previous certainties about what it means to be a person with dementia, the transformation of the organisations can be seen to potentially entail a 'journeying into thirdspace' in which, amongst other things, it is recognised that people with dementia 'can speak — can learn to speak, can be encouraged to speak, must be allowed to speak — from positions beyond their conventional (stereotypical) location, beyond their assigned or preconstituted identities' (Beattie, 2003).~~ Furthermore, because our research is based on an analysis of organisations

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that identify as being part of the same global health movement, but which emerged in different national contexts, in addition to tracking change over time we track 'the spatial *diffusion* of the dispositions/schemas generative of the movement' (Crossley, 2005: 22). A broadly simultaneous transformation in the two national organisations' causes can be identified, as can a convergence into a tension between their second phase cause regimes and their patient identity work.

Our paper is based on research undertaken as part of a project entitled European Patient Organisations in Knowledge Society (EPOKS) which is investigating patients' organisations' involvement in the production of knowledge across a number of national contexts and condition areas. In the first phase of this project, which began in early 2009, we traced the histories of a number of organisations, including the AS and ASI. Based primarily on documentary-archival analysis, our systematic tracking of the organisations' historical trajectories along a number of dimensions (e.g. cause, constituency and web of relations) was undertaken using sources such as the organisations' websites, annual reports, newsletters, press releases, submissions to government and research reports. The considerable media archives of newspaper articles were a particularly significant source of data on the evolution of the organisations and their discursive trajectories. Ethnographic observations of organisation conferences and seminars were a further source, as were interviews with organisation personnel in the case of AS. The second phase of EPOKS is focused on developing detailed analyses of recent knowledge-related activities of the organisations. Data from both phases of the EPOKS projects are drawn upon in this analysis of the transformation of the two organisations' cause regimes.

Cause Regimes

Following Michel Foucault's identification of the task of the genealogist as the analysis of 'regimes of practices', Maren Klawiter (2004) offers the concept of 'disease regime' as a way of conceptualising the structural shaping of illness experiences. She defines a disease regime as being 'comprised of the institutionalised practices, authoritative discourses, social relations, collective identities, emotional vocabularies, visual images, public policies and regulatory actions through which diseases are socially constituted and experienced' (Klawiter, 2004: 851). In contrast to many Foucauldian analyses of the regimes of practices

of public health and medicine that adopt a totalising view of power, Klawiter illustrates how disease regimes change over time and, in the case of the transformation of the US breast cancer regime between the late 1970s and late 1990s, the significant role played by the breast cancer movement in that process.

As a tool for the historical analysis of health movement organisations, we propose to extend this focus on regimes to cause regimes. By cause regime, we refer to health movement organisations' public enunciations of the missions around which they are mobilized, enunciations that form an important part of organisations' patient identity work and that can regulate their operation. At least three dimensions of a health movement organisations' cause can be identified and highlighted by the questions - for what is the organisation fighting, what kind of fight is this, and on whose behalf is it being fought? Regarding the first of these, adding to his review of typologies of health movements, Epstein (2008) notes that it might be possible to construct a typology based on the diverse goals they pursue, such as

~~*finding (or rejecting) medical cures; improving the quality of life of ill people; cultivating practical advice for the management of illness; raising funds for research; changing scientific and medical practices, priorities, or orientations; rejecting technoscientific approaches; opposing stigmatization and exclusion; and changing more diffuse cultural codes related to the meanings associated with health, the body, and expertise' (Epstein 2008: 513).*~~

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Regarding the second dimension of a health movement organisation's cause, how these goals are framed more broadly can also vary. For example, in Samantha King's (2004) analysis of US breast cancer organisations, she tracks a movement over two decades from breast cancer *politics* to breast cancer *charity* resulting in the disease now being imagined largely as a charitable cause reliant upon consumer-oriented philanthropy. In this framing of the cause, political contention and the 'fight' in which the movement is involved are downplayed and common effort is emphasised. Legislation in different national settings concerning the regulation of charities can be an important contextual consideration in respect of this dimension. So too is the current worldwide dominance of a market-oriented approach to healthcare. Thirdly, causes can vary according to for whom the organisation is fighting. Examples of different identity banners assumed by organisations that point to varying configurations of those on whose behalf they advocate include patients, carers, survivors and consumers. Here, it is important to acknowledge that in some health movement organisations, those who constitute the organisation may differ from those for whom the organisation is mobilized, especially if the latter are deemed to lack the capacity for self-advocacy.

Research focused on social movement 'identity work' is helpful to the elaboration of this third dimension of cause regimes. Coined by David Snow and Doug McAdam (2000), the concept attunes us to the importance of attending to how movement participants contribute to the creation, promotion and maintenance of collective identities, and also to

how these identity processes can be fraught with contradictions. Snow and McAdam identify a number of identity construction processes, including identity amplification, consolidation, expansion and transformation. These involve framing processes whereby 'in the course of identity talk among adherents and activists ...when ...explaining the movement to others ...when preparing press releases and making public pronouncements ... identities are announced or renounced, avowed or disavowed, and embraced or rejected' (Snow and McAdam, 2000: 54). They argue that identity work is likely to vary according to the type of social movement and over the life course of individual movements. Significantly, they emphasise that successful identity work that broadens the base of a movement, referred to as 'domain expansion' (Jenness, 1995), may paradoxically produce dysfunctional movement dynamics such as factional disputes and internal conflict. ~~Informed by this research, we suggest that health movement organisations' public enunciations of who they are fighting for constitute an important form of patient identity work, but so too do their day-to-day activities including their knowledge-related activities. Fusing these ideas with insights from science and technology studies, and particularly about the 'inscription' on technologies of specific visions of the identity of their users (Hardon, 2006), prompts us to consider the interplay between medical and healthcare technologies and health movement organisations' patient identity work.~~

Finally, the concept of a cause regime underscores how organisations' public pronouncements about their cause can have a political dimension, governing or regulating their operation, such as their interactions with those on whose behalf they advocate. Enunciations of an organisation's cause can carry obligations to align that cause with its routine patient identity work. In this understanding, an organisation's cause is viewed as being dynamic, not only in the sense that it can change over time, but also that it is interactional with other aspects of the organisation's work, shaped by and shaping what are deemed appropriate organisational discourses and practices.

Changes in the cause regimes of two national Alzheimer's disease organisations

We argue that two phases in the history of both the Alzheimer's Society (AS) and the Alzheimer Society of Ireland (ASI) can be identified. During the first phase, their common organisational cause was primarily framed as supporting carers of people diagnosed with dementia. In the second phase, both organisations frame their cause as championing the rights of both people with dementia and their carers. In other words, we observe a hybridising shift in the organisations' cause regimes and a process of domain expansion.

Established in 1979 and 1982 respectively, the AS (initially named the Alzheimer's Disease Society) and ASI were the first two national Alzheimer's disease movement organisations established in Europe. Since then, similar organisations have emerged in many other countries, so much so that the pan-European organisation Alzheimer Europe currently has

member organisations based in 30 countries. Although dissimilar in some respects and embedded in different national contexts, there are many parallels in the histories of the two organisations under analysis.

One common feature of the origin stories of the two organisations is that their founding members were carers of relatives with dementia. Another is that an international orientation characterized both organisations' since their inception, evident in accounts of approaches made by founding members to the then recently established US Alzheimer's Disease Society (Winston, 2008; *The Irish Times*, 1 May 2002). Signalling the formation of what would become an enduring and dense web of relations with Alzheimer's disease movement organisations in other countries, medical professionals and the mass media, (and the consonance of the organisation's orientation with medical orthodoxy) the public launch of the ASI in 1983 took the form of a press conference. The event was addressed by the chairperson of the AS, a high profile neurologist, and an Alzheimer's disease biomedical researcher (Bligh, 2003a). Although the two new organisations' schemas appear to have been shaped by their isomorphic relations with the US organisation, there is however a key difference related to the neoliberal welfare regimes that emerged in Britain and Ireland at that time. Due largely to the outsourcing of public services, the AS and ASI expanded rapidly and became professionalized service provision charities, significantly reliant on State funding. The growing reliance of the AS on government grants is attested by the fact that in 1985 public funds accounted for 85% of the organisation's income (ADS, 1986). By 2009, the AS had an income of £51.7 million, 35% derived from grants and contracts from the State (Alzheimer's Society, 2009: 3). In terms of spending, 74% of its funds were used in care services. In 2007, the ASI had an annual income in excess of €13.6 million, 67% of which came from the State (ASI, 2008). Similar to its British counterpart, 70% of its expenditure was on care services.

The expansion of the two organisations took place in national contexts not only in which the relationship between the State and civil society came to be defined around a 'services paradigm' (Harvey, 2009), but also where a charitable rather than political framing of their cause has been officially encouraged.

~~Commenting on the changes introduced in 2002 to the contracts between the Irish State and civil society organisations, Brian Harvey (2009: 31) has commented that 'Organisations working in diverse areas [...] were told that if they took money from government, which most do, they may not criticise [the government]'. Additionally, in the context of growing competition for voluntary donations and cause~~

affiliation between charities in the 2000s, as registered charities the AS and ASI have operated in contexts in which similar legislation has been introduced aimed at providing a regulatory framework for charitable organisations. According to the UK Charities Act of 2006, a charity is 'an institution which is [...] established for charitable purposes only [and] is for public benefit only' (HMO, 2006). Similarly, the Irish Charities Act 2009 defines a charitable organisation as one that 'promotes a charitable purpose only' and notes that its provisions do not apply to 'a body that promotes a political cause, unless the promotion of

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that cause relates directly to the advancement of the charitable purposes of the body' (Government of Ireland 2009: 8, 10). This official encouragement of a charitable framing of the organisations' causes has been consistent with the non-oppositional framing that has endured since the AS and ASI were first established.

The Alzheimer's Society

The established origin story of the AS tells that 'In March 1979 on hearing a radio broadcast by Professor A N Davison about research into Alzheimer 's Disease Cora Phillips SRN, a former Carer contacted him and in discussion proposed the formation of an Alzheimer's Disease Society' (Winston, 2008). ~~Gordon Wilcock, a doctor, had previously approached Professor Davison with the same idea.~~ With Davidson's support, Phillips wrote to the then recently established Alzheimer's Disease Society in the USA. ~~In parallel, Morella Fisher had written to newspapers telling of her experiences of caring for her husband with dementia, and Phillips wrote to Fisher with the idea.~~ The Society was established with a steering committee composed of carers, doctors and one solicitor.

On becoming a charity, the Alzheimer's Disease Society established its main aims as providing carer mutual support and providing information on the illness, gathered and credentialised by dementia specialists, to members and the public. In its organisation and objectives, as well as its isomorphic relation with the US organisation, the origins of the AS can be closely related to the processes underpinning the emergence of Alzheimer's disease in the 1970s. This resulted from the alignment of a new understanding of the illness that differentiated it from normal ageing, increasing clinical interest and the organisation of groups of concerned carers (Moreira, 2009)

Growth of the organisation in the first five years was reliant on government grants, which put it under public scrutiny. A 1987 report from an audit to the Department of Health and Social Security found the organisation's accounts not to be within the 'standards of accountancy' in a manner that put public funds at risk. The internal response to this challenge was to attempt a strategy of crisis management of reconstruction under the leadership of Nori Graham, a psychogeriatrician. This 'major re-organisation' (ADS 1988: 5) entailed three changes: firstly, a centralisation of management, with the transference of powers from the steering committee to the chairperson and directors; secondly, to imprint on the organisation a business-like approach; lastly, and relying on the two previous ones, a focus on the provision of care services. This established the identity of the organisation for the years to come.

The profile and capacity of the organisation grew exponentially as result of these strategies and the functions of the AS became increasingly interlinked. The focus on caring services saw the organisation fill a niche in service provision, supported by volunteers aided by the information and advice provided by the AS. The expansion of the branch structure of the organisation was linked to its growing 'awareness raising' activities, which saw the disease

become recognised in the public sphere and, in turn, fed into the growth of membership and branch formation. This included the creation of an 'Alzheimer's awareness week', with targeted media interventions and advertising and the involvement of the organisation in commenting on research and therapeutic news in the field of dementia that were emerging in the later part of the 1980s. During the 1990s the organisational blueprint established during the crisis was further developed in a way that can be best described as a rooting and branching strategy. The organisation's role in care provision was deepened, with an increased reliance on professionals and standards, as 'new legislation mean[t] that all branches require professional advice and support more than ever' (AS [Annual Report](#), 1991: 13). Such a strategy of professionalization of care (Bond, 1992) reinforced the individualisation of illness and of illness related behaviours and caused tensions between the 'grass-roots' and 'the centre' within the organisation, tension which would remain in the AS for the next decade.

In 1999-2000, the AS produced a series of policies and campaigns that articulate a shift in the cause regime towards recognition that people with dementia 'can speak' and their integration in the governance of the organisation and its dementia services and research. In 2000, Peter Ashby, a person diagnosed with dementia, was nominated for the AS' Council. In parallel, the CEO of the AS urged the National Institute of Clinical Excellence (NICE) to include the views of people with dementia in their assessment of dementia drugs which had just been commissioned. The newly formed Quality Research in Dementia programme, that replaced the previous fellowship scheme in existence since 1989, included a component of consumer review and evaluation of projects that ultimately aimed to integrate people with dementia as consumers (AS, Annual Report 2000). This represented a challenge to the organisational blueprint that had been established at the end of the 1980s and to its identity as a 'carer's organisation'.

Further centralization of management and discussion on how to ensure quality of service across branches was interpreted by some sectors within the AS as a challenge to the role of the volunteer (usually ex-carers) and to their experiential knowledge base. The realisation that the 'goodness of someone's heart is not enough'¹ re-enforced tensions on who was deemed to represent the needs of people with dementia and better implement the policies of evidence-based, patient-centred care within the AS. The response of the organisation was to conceive of their cause as an hybrid one.

The hybridity of cause within the AS is reflected in the dual function of care delivery and standard-setting and the search for a cure, on the one hand, and on the other, an increasing emphasis on people with dementia as the centre of the organisation's activities with carers taking a secondary role. The first aspect of this is organized temporally in its affiliation seeking and fundraising: 'Alzheimer's Society needs to raise money to care for people today and to find a cure for tomorrow' (AS Annual report, 2003) This differentiates between the

¹ Interview with Eileen Winston, London, 11 October 2009.

two types of knowledge that the AS sees itself as fostering: one the one hand, an aggregation and evaluation of heterogeneous 'evidence' that will inform standard setting in care, and on the other, a shaping of the research agenda in Alzheimer's underpinned by a therapeutic expectation (Moreira, 2009).

The main difficulty of this strategy comes from the second aspect of the hybridity of cause within the AS. As people with dementia become more prominent as the AS' main constituency, so does their role as organisation members. If before carers' experiential knowledge has been the main resource the AS drew on in campaigning and need identification, the recognition of people with dementia as full members of the organisation implies that such status should also be made available to them. This strategy has been implemented through the Living with Dementia programme through which 'people with dementia have been sharing their experiences and knowledge, and raising awareness of dementia at local and national levels' (AS, 2003).

But tensions arising from this bifurcation of the organisation's constituency and '~~journeying into thirds~~space' are fully recognised:

I recognise that tension and I think we have that quite a lot, particularly our heritage, [...] and I think when we last did the strategic review [...] we said very strongly that we wanted to develop our work with the people with dementia. And I think we are still struggling to make that a reality. [C]arers have specific set of needs [...] and their contribution is important but what we mustn't confuse it and I think we should have a discrete service offers if you like for people with dementia²

This differentiation of institutional spaces within the organisation appears as the only solution to the predicament. Speaking with a director of the AS about forums of discussion within the AS, such institutional divisions were strikingly articulated:

[Discussions go on] in things like our 'Talking Point'[on-line forum, which] is very clearly targeted for carers and we have had instance where people with dementia have gone on and been quite horrified at what they see and quite upset.³

People with dementia are thus deemed to need their own space of interaction within the organisation, however, constructing this other space is not straightforward. The main challenge appears to be the construction of implements that enable people with dementia to speak meaningfully in a variety of situations and arenas: in care, at home and in civic life. These include a variety of techniques, from the use of visual maps in everyday communication to the setting of dementia forums where people with dementia can participate with assistance from professionals and carers. But making these 'voicing' implements work is a challenging task. An illustration of this is the *My Name is not Dementia* initiative. ~~To understand this, some background is necessary. Between 2005 and 2007, the~~

² Interview with Ruth Sunderland, London, 20 April 2010

³ Idem, note 2

~~AS was involved in a major public controversy over access to dementia drugs. The controversy was sparked when NICE suggested in 2005 that dementia drugs might be taken off NHS prescription packages on the basis of a cost effectiveness evaluation of those therapies. From the start, the AS attacked NICE's focus on changes in cognitive scores as outcome measures in the assessment of dementia drugs and suggested that NICE had failed to model the benefits of these drugs on carers' well being, which in turn benefited patient's quality of life. Their appeals were rejected and in 2006 dementia drugs became only available for patients with moderate dementia.~~

As a National Dementia Strategy was being discussed in 2007-08 within British policy circles, the AS commissioned a piece of research that focused on the experiences of diagnosis and management of dementia. This research was commissioned to the Mental Health Foundation (MHF), a charity concerned with researching and disseminating information about the prevention and management of mental illness across the life course.⁴ The MHF is recognised by policy makers for its ability to use qualitative research techniques to gather and summarise the views and experiences of services users, including people with dementia. Asking the MHF to perform such research marked a shift in the AS' approach to the public representation of 'experience'. Whereas previously the AS would have conducted its own 'in house', informal gathering of members' experiences to articulate demands with public bodies such as NICE⁵, the negotiations around the National Dementia Strategy and the threats to public credibility that accrued from the AS' involvement with the private corporation Esai in the judicial review of NICE decision [on dementia drugs](#) in 2007 ([Moreira, 2010](#)) worked together to produce such an alliance. In 2008, the AS and the MHF published the *Dementia Out of the Shadows* report.

Drawing on focus groups of people with dementia and carers, the research suggested that a) diagnosis processes were key in people's experience of dementia, b) coping strategies were fundamental for preservation of the self and, c) the experience of stigma was still pervasive. The report advised that awareness should be raised in the general public and service providers, and that people with dementia should be involved in shaping the services they use. The awareness and involvement agendas became well represented in the National Dementia Strategy, partly because they were shared already between government and dementia charities.⁶ However, how to articulate this agenda with evidence-based practice principles in health and social care is a significant challenge. Indeed the coordination of evidence and experience appears to be a recurrent problem in contemporary health care (May et al, 2006). In dementia, this problem is compounded by the fact that assessments of effects of interventions and services are either clinically based or drawn from measurements of quality of life that use proxy-respondents (carers). The problem became

⁴ <http://www.mentalhealth.org.uk/about-us/>

⁵ E.g. 'Alzheimer's Society submission to NICE's TA19', London, Alzheimer's Society, 2001

⁶ Transforming the quality of dementia care: Consultation on a National Dementia Strategy Department of Health 2008 http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_085570

apparent quickly in discussion about the principles that should underpin commissioning decisions in local health care authorities attempting to implement the National Dementia Strategy, as commissioners were confronted with the uncertainty of quality of life measurements in dementia that had been the focus of the controversy on access to dementia drugs just few years before.

The obduracy of this technical problem constituted a politico-epistemic opportunity for the AS to change the expert tools that support the regulation and implementation of health technologies and services. In 2009, as the implementation mechanisms for the National Dementia Strategy were being discussed, the AS commissioned two pieces of research about the issue of measurement of quality of life in dementia: a literature review conducted by academic researchers and, again, a mixed-method qualitative research project focusing on the views of people with dementia conducted by the MHF in association with the AS. We will focus on the latter.

My Name is not Dementia used a mixture of interviews, questionnaires and focus group techniques to gather the views of 'seldom heard groups' in quality of life in dementia research: people with moderate-severe dementia, people with learning disabilities and dementia, ethnic groups and lesbian, gay, bisexual or transgender people. The project was encumbered by recruitment problems and methodological challenges. First, researchers were confronted with the difficulty to identify participants on the basis of their 'sociological' characteristics. Secondly, ethical requirements for research made it impossible 'to involve anyone who lacked the mental capacity to give their consent to participate' (Williamson, 2010). Thirdly, specific techniques had to be deployed to gather the views of participants: picture cards representing domains of life, which participants displayed in boards by order of importance, and a communication package Talking Mats, geared towards the elicitation of preferences within a predefined set of options. The research suggested that for people interviewed 'quality of life is possible following a diagnosis of dementia'. However, the recognised weaknesses of the research presented in the *My Name is not Dementia* report made it difficult to translate it into a public message and pointing to the need to develop quality of life indicators that include the views of people living dementia was all it could do.⁷ In this regard, it reinforced the need to involve people living with dementia in implementing the National Dementia Strategy but could not present a clear, achievable solution to how this should be done. Despite its dissemination within ageing and dementia websites and blogs, *My Name is not Dementia* is not considered an achievement within the AS.

The Alzheimer Society of Ireland

In one recounting of the ASI's origin story, a founding member notes that what the organisation was fighting for initially was the provision of 'information, understanding and

⁷ Interview with Toby Williamson, 21 January 2011.

solidarity to those caring for a loved one with Alzheimer's disease' (ASI, 2008). She recalled that 'Feelings of isolation and abandonment were common in '82 for families unable to access even the most basic information about Alzheimer's disease and how to provide family care'. In 1983 it was reported that the ASI was established to 'help the stricken relatives of those afflicted by this chronic ailment' (*The Irish Times*, 18 May 1983). Likewise, a public notice of the 1986 AGM noted that 'The society's main aim is to provide support to the families of those who suffer from Alzheimer's Disease' (*The Irish Times*, 5 February 1986). In these early enunciations of the ASI's cause, the figure of the patient was largely invisibilised and their family members were framed as the primary sufferers of the disease. Improving the quality of life of carers and cultivating mutual support between them were the initial goals around which the organisation was established.

Similar to Alzheimer's disease movement organisations in the USA, the ASI's identity work during this phase reflected an engagement in the 'health politics of anguish' (Fox, 1989). Designations such as 'a fate worse than death' and references to the 'horrors' of the disease which could 'tragically destroy' featured prominently in the framing discourses of ASI spokespeople (*The Irish Times*, 20 March 1989). As late as 2003, in the foreword to a book of poetry, the royalties of which were donated to the ASI, an ASI founding member drew on a discourse of personhood that emphasised the centrality of memory:

The key to defining who we are, and establishing our personal identity and sense of worth, is memory; without memory we are non-persons living in a strange, barren, limbo land...sense of self is eroded. (Bligh, 2003a)

A feature of this construction of the collective identity of Alzheimer's disease patients as non-persons was the associated idea that those diagnosed with the disease were incapable of self-advocacy. This rejection of the meaningfulness of the voice of people with dementia was articulated expressly by a former ASI president in 1994. In response to a call for people on whose behalf charitable organisations advocate to be included in organisational decision-making processes, he argued that 'My society, being unable to involve any of the 25,000 victims of Alzheimer's disease, is organised and managed mainly by their carers, past or present' (*The Irish Times*, 1 April 1994).

By the late 1990s, however, the beginnings of a shift in the ASI's organisational habits of thought and talk in respect of the identity of people with dementia can be discerned, together with an associated shift in the framing of its cause. As noted above, shifts in the Alzheimer's disease biomedical research enterprise, particularly the development of techniques for early diagnosis and drug therapies, have been identified as crucial precursors to Alzheimer's disease movement organisations' reconfiguration of Alzheimer's disease patienthood and discomfort with organisational habits of paternalism (Beard 2004; Moreira 2007). In an address to an international conference in 1998 entitled *Alzheimer's Disease In Europe*, a consultant psychiatrist with a long-standing involvement in the ASI's Medical Committee argued Alzheimer's disease is not a 'death sentence' and stated 'There are

treatments; there are things we can do' (*The Irish Times*, 10 March 1998). Destabilising previous certainties, the patient identity 'inscribed' on these treatments differed significantly from the identity of one who had experienced a social death. Further evidence of the move towards a hybrid space and recognition of the meaningfulness of the speech of people with dementia, in 2003, the ASI CEO announced that alongside the carers support groups that the organisation had run since it was first established, it was 'working towards setting up the first support group for sufferers themselves' with a view to giving 'patients in the early stages of dementia an opportunity to speak about their issues and get support with their diagnosis in peer groups led by a trained facilitator' (*The Irish Times*, 14 April 2003). In other words, the sharing of experiential knowledge that had been promoted by the organisation since its outset would no longer be confined to carers, but would now be extended to patients too. Subsequently, in 2005, the ASI established social clubs with the aim of providing 'an informal, flexible and fun opportunity' for those with dementia and their carers or family members to meet together in a supported environment (ASI, 2010a). The following year the organisation established a Dementia Rights Advocacy Service, the slogan of which is 'making your voice heard'. A disease awareness campaign run by the ASI in association with Pfizer Healthcare Ireland in 2006 with the slogan *Keep You Being You* is a further example of the ASI's second phase identity work; through this campaign it promoted a collective identity of early stage Alzheimer's patients as technologically empowered consumers (by early diagnosis and medical intervention) and capable of informed decision-making and self-care.

By 2007, public pronouncements about the cause of the ASI point to an indisputable move to the foreground of people with dementia; by then the ASI publicly identified itself as 'the leading national voluntary organisation responding to the needs of people with dementia and their carers' (*The Irish Times*, 9 February 2007). Disavowing the organisation's previous framing of the identity of the Alzheimer's disease patient, the speech of the person diagnosed with the disease was announced as being meaningful. This is evident in an advertisement that asserted 'We in the Alzheimer Society of Ireland believe that every person with dementia has a right to be heard, a right to lead as normal a life as possible, and a right to be supported in doing that' (*The Irish Times*, 9 February 2007). The ASI now declares that its mission is to 'to advocate the rights and meet the needs of people with dementia and those who care for them'⁸. Additionally, reflecting a synthesis of 'war on disease' and identity politics, the vision around which the organisation is now mobilised is to 'promote a world free of Alzheimer's disease / dementia and ensure that those with the condition and their carers occupy their rightful place in society, are respected and understood and have fulfilling lives.'

The ASI's current epistemic work includes participation in an advisory group overseeing the compilation of a research review aimed at providing 'the evidence base for government

⁸ For the ASI's current mission statement see <http://www.alzheimer.ie/eng/About-us/Mission-Statement>

policy development' in respect of a National Dementia Strategy, commitment to which was announced by the Irish government in 2010 (Cahill, 2011). Indeed, lobbying for and producing and compiling research evidence in support of such national strategies have been common actions of increasingly 'Europeanized' (della Porta and Caiani, 2009) national level Alzheimer's disease organisations throughout the European Union. In February 2007, the ASI launched a *Dementia Manifesto* that called for such a national strategy. Presented as the cornerstone of the organisation's political lobbying for greater public expenditure on dementia care, the *Manifesto* serves as an example of the organisation's mobilisation of recombinant evidence in its efforts to influence public policy. Noting the combination of different types of knowledge underpinning its claims, it notes that 'The process of gathering the information was grassroots-led and was supported by well developed and evidence-based economic and social policy positions' (ASI, 2007: 5). The *Manifesto* is presented as having been informed by a synthesis of experience and evidence, experience reconstructed as knowledge produced at a National Consumer Summit on Dementia, surveys of the organisation's 'stakeholders', and expert evidence commissioned from an academic health economist. The ASI can thus be seen to assert that its claims-making is evidence-based, but it is the recombinant nature of the evidence that it produces and circulates that makes it distinctive. Its knowledge is positioned as being doubly authoritative and legitimate because it is at once scientific and democratic. However, the ASI's epistemic work has been confronted by significant challenges. As will be illustrated below with reference to the ASI's involvement in two telecare pilot projects, the organisation can be seen to grapple with aligning its epistemic work with its patient identity work, and with its more recent cause regime.

Demonstrating the organisation's commitment to telecare prior to the two pilot projects, a 2007 commercial publication on telecare includes a foreword by the ASI CEO in which he stated

Persons living with dementia have a right to make choices around how they live with their disability. Improvements in community care supports and advances in technology are bringing new options to people wishing to remain at home. Telecare, when used appropriately and in a person-centred way, can offer another piece of the care jigsaw. Used as part of a holistic plan of care, telecare can be both an unobtrusive solution towards living as normal a life as possible for the person with dementia and a reassurance for the carer. (Emergency Response, 2007: 2)

Here, consistent with the ASI's hybridised cause regime, telecare was constructed as being mutually beneficial to people diagnosed with dementia and their carers. Furthermore, reflecting a departure from previous organisational identity work, people with dementia were configured as consumers capable of making informed choices about new technologically generated options and of living 'normal' lives.

Prior to the ASI's completion of its interim evaluation of its initial telecare project, its commercial partner in the project circulated the claim that 'The Alzheimer Society of

Ireland's pioneering new project enables people with dementia to remain independent for longer, receiving the care and support they need in their own homes through the use of assistive technology' (Emergency Response, 2007: 9). However, this was at odds with the evidence produced by the ASI's evaluative research which noted that the majority of carers reported no change in the independence of people with dementia since the introduction of the pilot telecare service (ASI, 2010b). Discordant knowledge was produced by the research about the effect of telecare on the independence of people with dementia and the tendency for these people to resist the technology. Ironically, one reason cited by ASI staff for this resistance was that 'they feel that it reduces their independence' (ASI, 2010b: 18). Underscoring how the organisation's recent identification of its constituency as a dual one has created a new regime of obligations, a researcher on the project reported that the evaluation 'highlighted the thorny issue of who benefits from a specific intervention, and how we should negotiate between the respective needs and rights of people with dementia, and those of informal carers' (Delaney, 2010).

Notwithstanding ASI commitments in recent years to recognising the meaningfulness of the speech of people with dementia (O'Shea 2007: 3), they were excluded from direct participation in the initial telecare evaluative research. The research process framed carers rather than people with dementia as the users of the telecare technologies and as the key actors whose perspectives and experiences the research sought to ascertain. The social disenfranchisement of people with dementia through their exclusion from direct participation in the initial pilot project was compounded by constructions of their resistance of telecare as, in some instances, a consequence of their failure to come to terms with their diagnosis. Furthermore, in most cases, people with dementia were excluded from the decision-making process about participation in the pilot project and whether or not to install the telecare devices (ASI, 2010b: 28). As is evident from the interim evaluation report, this identity work that emphasised incompetence in respect of choice and consent was not confined to those in the late stages of the disease:

While introducing telecare to a person who has early stage dementia may appear to make sense, in their [ASI staff] experience it was difficult to achieve as often clients who are in the early stage of dementia may not have been told that they have dementia, or, if they have been told are not in a position to accept assistance (including telecare) because they feel that it reduces their independence to do so. (ASI, 2010b: 15)

The discordant findings of the initial telecare project which were at odds with the ASI's commitment to the technology as a 'solution for independent living' were explained by the researcher in a way that questioned the validity of some of the knowledge produced by the research. Disqualifying carers as interlocutors of patients' experiential knowledge, in a presentation about the research she addressed the 'mystery' of carers' inability to identify benefits of telecare for the person with dementia, noting

In the literature on quality of life it is shown that carers tend to underestimate the quality of life of the people they care for. So is this an expression of that trend? That's what we are going to have to find out. (Delaney, 2010)

She explained that a second and more recent ASI telecare initiative, the Irish strand of the EU-funded project, INDEPENDENT: ICT Enabled Service Integration for Independent Living, aims to further explore the benefits of telecare by including people with dementia as research participants. Reflecting the now hegemonic understanding of the disease as a progressive staged condition that produces categories of patients corresponding to these stages, she said:

We will be doing a detailed assessment of the quality of life with people with dementia. Hopefully, we'll be working with them directly to understand their view of ...what is important in quality of life for them and how telecare might impact that. Now obviously we can do that with people with mild to moderate dementia. We have to work really carefully with people who are further on in the disease to see what is the best way of communicating with them to get this information. (Delaney, 2010)

Albeit impelled by the discordant knowledge produced by the initial telecare project more than tensions with its avowal of a new identity for people with dementia, a key difference in the styles of doing research between the two ASI telecare initiatives is this shift in research practice, and identity work, towards (at least, an intention of) including people with dementia, in all three stages of the disease, as research participants and collecting and formalising their experiential knowledge. Similar to the AS' *My Name is Not Dementia* project, this second initiative is addressing the epistemic challenges of developing voicing and translation implements that enable people with dementia to communicate the impact of telecare services on their quality of life. This challenge is constructed as requiring skills in what we might call 'experiential literacy' to enable the accurate interpretation and reporting of the experiential knowledge of people whose cognitive and communicative capacities have been compromised by dementia. In sum, reconstructing the personal experiences of people with dementia into experiential knowledge that can be shared with other patients' and used as a resource by the hybrid patients' and carers' organisation continues to be a significant challenge.

Conclusion

Based on an analysis of the origin stories and other historical and contemporary data on the first two national Alzheimer's disease movement organisations established in Europe, we have offered the concept of a 'cause regime' as an addition to the conceptual repertoire for the systematic analysis of health movement organisations' transformations over time. The specific transformation that we track using this notion relates to the broadly simultaneous hybridisation of the Irish and British Alzheimer's disease organisations from originally being carers' organisations to their current public self-identifications as patients' and carers'

organisations. Closely linked with changes in the Alzheimer's disease biomedical enterprise, this transformation is shown both to have been impelled by and to be impelling an altered form of organisational patient identity work, one that disavows past framings of the identity of people with dementia as nonpersons and embraces a new identity that emphasises their humanity and capacity to be full and active members in the governance of the organisations. Let us now return to the questions noted earlier that call attention to the three dimensions of health movement organisations' causes: for what are the organisations fighting, what kind of fight is this, and on whose behalf is it being fought? Reflecting greater biomedical optimism internationally about the disease than was evident in the early years of the two organisations, the AS and ASI are now fighting for a cure for dementia, high standards of care, and social recognition and respect for people with dementia and their carers. In the context of both organisations' heavy reliance on State funding and donations from the public, their causes continue to be framed as charitable ones. Finally, the organisations are now fighting for two constituencies, people with dementia and carers, where the former is an expanded and internally differentiated category of actors all of whose 'voices' are deemed to be meaningful. The broadly similar service provision orientations and causes of the two organisations have also been shown to be consonant with biomedical, consumerist and neoliberal welfare state orthodoxies, a consonance that helps explain their emergence as amongst the biggest patients' organisations in their respective countries.

However, the broadly similar transformation of the two organisations' cause regimes is also shown to have produced new organisational tensions and challenges of considerable magnitude. These are apparent in the AS' and ASI's current grapplings to align their new cause regimes with their epistemic work so that the latter fully integrates people with dementia as knowing actors with valuable experiential knowledge. As seen in respect of the AS, one response has been to attempt to construct differentiated institutional spaces for carers and people with dementia within the recently hybridised space of the organisation. This is also evident in the ASI's endeavours to create support groups for people with dementia modelled on the carer support groups that have been in place since the organisation was first established. However, this strategy has proven to be less than straightforward. In initiatives such as the AS' *My Name is not Dementia* and the more recent of the ASI's telecare initiatives, INDEPENDENT, reconstructing the personal experiences of people with dementia into experiential knowledge, especially of those in the late stages of the disease, is deemed to require communication and translation devices. While recognising that protagonists can speak and moving beyond the certainties of the previous patient / carer dualism to elaborate new grounds of difference are crucial to the organisations' new cause regimes, considerable distance remains in the 'journey to the thirdspace' where 'the negotiation of incommensurable differences creates a tension peculiar to borderline existences' (Bhabha cited in Beattie, 2003). While both organisations recognise the need for

such communicative devices, especially in respect of assessments of the quality of life of people with dementia, the search for them is ongoing.

In addition to tracking moves over time in the two Alzheimer's disease organisations, we have also tracked moves over space illustrating the diffusion of similar organisational sensibilities in the two national contexts. The parallels in the histories of the AS and ASI may also be related to their geographical proximity and the historical colonial links between the two countries in which they are located. What remains to be done is to identify the specific contextual factors in Britain and Ireland that help explain the specificities of the two organisations' endeavours to combine a commitment to meeting the needs of people with dementia and their carers. We have focused on the similarities between the historical trajectories of the two organisations, but the causes and consequences of differences between them also warrant investigation. Differences in the regime component of their cause regimes may, for example, help explain why the AS has moved to include people with dementia in its formal decision making structures in a way that the ASI has not. Given the proliferation of Alzheimer's disease organisations throughout Europe and beyond, understanding their contextual embeddedness is all the more important. Furthermore, these differences are an important to understanding the challenges facing the increasingly vociferous European and international coalitions of Alzheimer's disease organisations that aim to represent not only patients and carers, but a growing number of national level organisations with diverse orientations.

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