

Dementia: Human Rights and UK Black, Asian and Minority Ethnic Communities

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There is an increasing international interest in the achievement of a rights based approach to dementia care, with the current Scottish Dementia Policy seen as a flagship example of this approach to dementia policy. The inclusion of people living with dementia as self-advocates in decision-making in all aspects of care and policy making for dementia is overdue, as is their inclusion on an equitable basis in all aspects of education, employment and social life.

Since the implementation of the Human Rights Act in the UK in 2000 concerns have been raised about the lack of impact this has had on healthcare provision. In 2003 the Audit Commission reviewed staff training on human rights across the public sector and found that only 50% of health organisations had training in place and unlike other public bodies had shown no improvements from their previous level of training in 2002. This provided impetus for the implementation of a programme of work on a more rights based approach in health. In due course the Department of Health for England and Wales in conjunction with the British Institute of Human Rights produced a policy framework in 2007 setting out in detail the context for a human rights based approach for health care linked to international policy commitments and the legal duties of public bodies reflected in European Human and UK Human rights legislation. This policy framework also included examples of good practice arising out of the Department's Human Rights in Health Programme that began in 2005.

However, Dyer in reviewing the impact of the Human Rights in Healthcare Programme in 2015 found its impact in practice has been limited. Most notably system wide failures in a large scale as identified at the Mid Staffordshire NHS Foundation Trust in the 2013 Frances Report demonstrate how lack of recognition given to human rights in healthcare can have a pernicious and wide ranging impact at an institutionalised level [1-3].

The dramatic institutional human rights failure of Mid Staffordshire illustrated how the institutional practices across an NHS organisation can be conducted in isolation from central policy developments such as the Human Rights in Healthcare Programme. But such dramatic organisational failures are not the only evidence of limited impact of the programme. Some of the detailed commissioning guidance emerging over that same period seems to also have been developed in isolation from these higher level policy commitments on human rights. For example the 2011 Guidance for commissioners of dementia services by Joint Commissioning Panel for Mental Health, a significant document providing guidance on the commissioning of dementia services, makes no reference to the human rights obligations of dementia services in defining service standards and outcomes.

McGettrick and Williamson's outlined a dementia and human rights approach in their 2015 briefing paper for the Mental Health Foundation and set out an important challenge for the predominately medically oriented approach to move to a broader social model of disability in developing dementia care provision. Moving to a wider understanding of dementia incorporating a proactive approach to

enabling the human rights of those living with dementia also presents a challenge to how one understands evidence of quality in setting standards of care and evaluating outcomes. Unnithan discusses what form this understanding might take when evaluating the impact of human rights interventions in healthcare. It is worth bearing in mind that "Standards and methods of measuring compliance which did not focus on the effect of a service on patients" (p4) were identified as one of the key causes of institutional failure in the Frances report [4-6].

Invariably when the experience of dementia is solely considered within the paradigm of the medical model evaluation of services is primarily through quantitative methods and measures. Within this paradigm qualitative evidence, if considered at all, is usually regarded as secondary and as less substantive than quantitative evidence. The limitations of this approach are evident as the Frances Report shows in an institution where experiential accounts were routinely disregarded. Unnithan's argument is that critical evidence of the health impact of human rights based intervention is to be found in the narratives of the experience of patients and clinicians. These narrative accounts are as important for understanding service quality as quantitative measures.

Using the examples of WHO maternal and reproductive health programmes in support of her argument, Unnithan observes that narratives about rights coalesce around the people within the programmes who already enjoy significant social privilege rather than disseminate into the wider total population covered by the programme, for example to poor people from rural areas for the maternal and reproductive programmes she examined. Unnithan's account also explores the tension between kinship traditions and obligations and the concept of individual rights, where the obligations of kinship may directly conflict with claiming of individual rights and where claiming individual rights risks expulsion from the family and community.

The complexity of the subjective narrative account of the experience of illness and healthcare is as rich a source of information on the impact of healthcare interventions as quantitative measures. These narratives cover areas of the practical everyday management of illness that are often not covered by quantitative measures. In the context of complex illnesses such as the dementias, a sophisticated understanding of the impact of programme level changes in care practice on individuals based must be based on a balanced combination of quantitative and qualitative evaluation. For the World Health Organisation the right to health "require governments and public authorities to put in place

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policies and action plans which will lead to available and accessible health care for all in the shortest possible time” (p: 11) This right to health is closely linked to securing a range of other rights. Providing a right to health and rights based health service cannot merely be evaluated from quantitative medical data but must always be validated by the testimony of lived experience [7-9].

Securing a right to health and the full range of legal rights that are a consequence of international human rights legislation is further complicated for migrants, who routinely face overt and covert discrimination in host communities in the exercise of any or all of the whole range of their human rights.

If people from UK Black and minority ethnic communities as members of migrant communities are to secure their human rights within the evolving context of moving towards a rights based approach to dementia service provision in the UK it must be recognised that assumptions about the ability of the populations living with dementia to equally participate in both self-advocacy and in securing benefit from the advocacy of a rights based approach will need to be challenged.

Although any developing gains in achieving an improved human rights perspective in dementia provision are important, some partial achievement of progress that serves only a limited demographic of the population living with dementia has to be viewed with caution. In the broader context of international human rights conventions, embedded within these conventions is the obligation to support groups with particular vulnerabilities. Migrant populations living with dementia are enormously disadvantaged often with longstanding histories of multiple discrimination.

What Rights and Whose Rights are They Anyway?

A number recent authors who themselves are living with dementia have eloquently and forcefully outlined the argument that the development of appropriate support for people living with dementia is a human rights challenge, not simply confined to the delivery of health and social care services.

However from talking to those working with people from Black, Asian and minority ethnic communities living with dementia it is evident that the ability to exercise self-advocacy in claiming rights and through this achieve access not only to health and care benefits and but also to the wider range of rights allowing choice in living can be difficult as result of both cultural beliefs and the experience of discrimination.

Cultural stigma and cultural norms of personal resilience and reliance on family support characterise the response to dementia for a number of Black, Asian and minority ethnic communities in the UK and there is increasing awareness amongst health professionals that people from these communities are unlikely to come to the attention of diagnostic service until their illness is relatively advanced. Raising awareness about dementia in these communities has to be combined with an encouragement of both those living with dementia to exercise their right to healthcare and also the right of their carers to healthcare.

People who migrate to the developed world from developing nations may have no basis from their own experience for assuming they have a right to health. In the contemporary social and politic milieu of the UK, they will find the mainstream media often contesting the right to the free NHS health care for UK residents for new migrants. Asserting an entitlement to health care rights in relation to a health condition (such as dementia) that is stigmatised within one’s own community is a not a task for the faint-hearted. Support has to be in

place for people living with dementia from Black, Asian and minority ethnic communities and their carers to assert their rights to healthcare as a necessary preliminary to asserting the full range of their universal human rights. This is not currently the case [10,11].

The risk is that the general advocacy of increasing rights for those living with dementia may not be mindful of the specific issue of healthcare rights as a priority issue for migrant communities living with dementia dementia linked with their specific vulnerabilities as a population. The risk is that in the euphoria of identified progress with the human rights agenda the lack of advancement of securing healthcare rights for migrants with dementia is regarded as an issue at the margin of the agenda.

This would simply replicate other well-known forms of institutionalised marginalization of access to health for migrants. It is insufficient to suggest that in this arena of historic institutionalised marginalisation that the migrant community must simply ‘be more assertive’ and advocate for itself within the arena of securing greater respect for human rights for people living with dementia.

A more fundamental levelling of the playing field in recognising the need for a human rights approach in dementia would be the prioritization of securing healthcare rights for people living with dementia and their carers from BME communities as a precondition for their developing access to the wider range of human rights. In the context of projections that the greatest extent of the rise in dementia over the next XX years will be in the developing world the prioritising of securing healthcare rights for those living with dementia as a global issue is a sobering but urgent challenge.

Important as the articulate self-advocate is as the vanguard for promoting and advancing the agenda for a rights based approach in dementia, the full scope of the achievement of a human rights approach in dementia must include the rights of the inarticulate, incapacitated and profoundly afraid, which would include many of those from Black, Asian and minority ethnic communities who are living with dementia. These may be populations for whom self-advocacy is too daunting contemplate, yet whom by the very nature of their multiple vulnerabilities to discrimination might be an appropriate focus for particular attention for support with achieving health rights and the wider range of human rights. The human rights agenda in in dementia must ensure that its gains are not the restricted preserve of a selective sector of the population living with dementia. Those in need of recognition and support with their rights may be those least able to put up a fight for them for themselves.

Dementia is a stigmatized and often misunderstood disease within Black, Asian and minority communities and those in these communities living with dementia and their careers may well be isolated from wider community support and understanding within their community. Contrary to UK mainstream media and political stereotyping, the elderly first generation migrant will often have spent most of her/his life making sure they are not ‘a burden on the state’, and see personal psychological and physical resilience and self-reliance as an important feature of his/her identity. The symptoms of Alzheimer’s disease or vascular dementia provide a devastating challenge to this sense of self [12,13].

A human rights approach in dementia must proactively include enabling representatives from migrant and minority communities to become self –advocates for their healthcare rights. This is approach is more challenging than a simple appeal for more people to ‘speak out’ and presents a practical challenge to the pragmatics of organising focus

groups, consultations and coproduction workshops, which is often the approach used by mainstream commissioners and providers of services.

Expecting community representatives to ‘come forward’ has little constructive value in this context. It requires some flexible thinking, for example, about the role of carers in enabling the voice of those they are supporting [14].

One hurdle to overcome is enabling people living in those Black, Asian and minority ethnic communities where dementia is highly stigmatised to speak out for themselves, risking as they do further isolation and loss of support within their own community for airing ‘dirty laundry’ outside the community. There needs to be some reaching in to educate communities to change attitudes within those communities. Also, working to secure an individually based right that is differentiated from and oppositional to obligations of kinship or other culturally normative obligations may well be impossible for some people.

A person in a developing country seeking services within the resource poor health service in their own country has to battle with the lack of resources across the whole spectrum of the social infrastructure in securing both their health rights and their wider universal rights. The migrant in a developed country may face battling for access not only to a healthcare resource that may be more developed than they could have hoped for in their country of origin but which they may feel (or be told) as a migrant they do not deserve. They may be engaging in this battle at the most vulnerable point in their lives after a lifetime of experience of discrimination in employment, education and access to health care.

There is a case therefore for insisting that in addressing the issue of human rights in dementia care a more careful attention is placed on supporting an approach that is more mindful and active in including a broad and diverse representation.

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