

Editorial

Lest we forget: on not moving on too fast, or too slowly?

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The sonorous lines of the annual November Remembrance Service roll on – ‘They shall not grow old ...’ – but of course, a few of them did, and in the passing of Henry Allingham, Harry Patch and Bill Stone we have lost the last known European survivors of the ‘Great War’, the ‘First World War’ or ‘the war to end all wars.’ The last known German soldier from that era died, untrumpeted, in 2007, and now the story of those days will have to be retold second-hand. However, in their passing, they left us a powerful message. Harry Patch’s funeral in early August 2009 was, by his own insistence, a celebration of reconciliation and not a glorification of war. At his invitation, representatives of the former enemy nation carried his coffin, and the eulogies made much of his belief that negotiation and discussion were better than battle. It is worth noting that those who might be expected to have gloried in the struggle, and those whose names are often linked to vainglorious or nationalist jingoism (such as Kipling, the Indian-born author of ‘Recessional’ and the Remembrance Day rituals), have much to say about the futility of war and empire:

Lo, all our pomp of yesterday
Is one with Nineveh and Tyre!
Judge of the Nations, spare us yet,
Lest we forget – lest we forget!

(Recessional, Kipling, 1897)

Of course, as Harry Patch and his colleagues showed very clearly, they did not see what they had done as being in any way remarkable. Nor did they talk of the glory of war, or accept that the honours that were given them in later life were in any way their due. They accepted them on behalf of those alongside whom they had fought, and who are less remembered. This is not untypical. In an earlier editorial (McGee and Johnson, 2005) we highlighted the role of Rosa Parks, who was similarly modest and self-effacing but not, as her

example showed, unassertive! However, it might be seen as a truism that real heroes, such as Nicholas Winton, the stockbroker and unlikely hero of the Kindertransport (see www.powerofgood.net), do not talk about what they have done or see it as unusual. What is later seen as heroism starts out as doing what needs to be done at the time, what any decent human being would do for another and continues to do, as shown by today’s young people fighting our wars in many parts of the world, or working as volunteers in slums, conflict zones, inner-city schools and the current famines in Sudan and Ethiopia. We need the example of heroes to show us what we can be, not just in war but in our daily lives. Every day in health and social care we are faced with the suffering of others, and this presents us with a choice. We can ignore other people and pursue our own ends. We can just do our jobs, which are often difficult enough, or we can go that bit further and do something that we are not paid to do but which really needs to be done.

For those who may feel that they are already overstretched, or for those who believe that they have no spiritual or faith-based incentive to be altruistic, maybe there is still something else that can be used to explain why it is worth making that extra effort. We cannot live in isolation from others. We depend on them initially for our survival, and later for our emotional and social well-being. Our interactions with and concern for others create meaningful distinctions that both motivate us and provide us with a sense of direction in our daily lives. Without this direction our lives become lonely and meaningless. Thus our true happiness lies in our relationships with others. If we want a *pleasant life* or a *good life* we have to concern ourselves with others (Seligman, 1990; www.authenticchappiness.sas.upenn.edu/seligman.aspx). Moreover, we have to acknowledge that there are points, even in the lives of the most independent individuals, when we need

other people to help us or to care for us because we cannot do this for ourselves. The meaningful distinctions that we have in our lives provide a basis for receiving help and for giving it to others (Benner and Wrubel, 1989). Thus what some might see as altruistic behaviour that is above and beyond the call of duty can also be construed as self-interest, an insurance policy for the future. Heroes go beyond this to achieve a *meaningful life* by making choices and standing up for what they believe to be right and important. Their actions may, by themselves, seem insignificant to these individuals and those around them:

Prophets have honour all over the Earth,
Except in the village where they were born.

(Kipling, 1906)

However, the consequences can be immense, as demonstrated in the current BBC Radio 4 series *The Choice*.

While we are celebrating heroes, let us not forget also to mourn the passing in June 2009 of Cecil Helman, a medical anthropologist, GP and writer who inspired many through his textbooks (notably the many editions of *Culture, Health and Illness* (Helman, 2007)). His approach, which has become known as the *folk model of the consultation*, encouraged patients to give their experience of illness a narrative, as a means of empowerment, and this idea has become commonplace in understanding the dynamics of inequality, too. His books and his example have helped generations of healthcare professionals to see beyond the patient's presentation of symptoms to understand how these relate to their belief system and cultural background, and will go on doing so for years to come.

Just as this issue of *Diversity in Health and Care* was about to be finalised, the *Guardian* carried an obituary of Kate Jagoe-Davies (*Guardian*, 25 September 2009, p. 28). Kate, spurred on by a personal accident that left her paralysed from the shoulders down, fought and won for acceptance of her ability to train as a teacher in South Africa. Along the way, she also became an activist and champion of the rights of women's and gay liberation, as well as an activist in the Black Consciousness Movement. All of this reminds us that diversity is not a disconnected struggle but a unified one. An injury to one on the basis of one strand is an injury to all and a setback for the cause of equality across ethnicity, faith, language, disability, gender or sexual orientation, and indeed age.

During August, while this editorial was taking shape, a new controversy flared up. In response to President Obama's efforts to improve medical care in the USA for the uninsured and those with long-term conditions, a British Tory MEP with no responsibility for health services, Daniel Hannan, received wide coverage for his remarks criticising the NHS. For

once there was a united response, from across Britain and many Americans living in the UK, one of whom said that 'the most important fact is that no one I know here is afraid to be sick.' There are 46 million people in the USA who are not covered by medical insurance, Medicaid, Medicare or the Veterans Administration schemes, and who therefore cannot afford to seek healthcare. Other facts that have been brandished included the life expectancy of people in the UK (78 years, compared with 77 years in the USA), the under-5 mortality rate (6%, rather than 9%), and the number of acute beds per 1000 people (3.6 in UK, but only 2.8 in the USA), for a cost of 8.3% of the British GDP, as compared with 16% of the US GDP (Sparrow and Campbell, 2009). Interestingly, Ruth Thorlby of The King's Fund, the respected UK health charity, comments in her blog that one reason why it was so easy to criticise the NHS is that we on this side of the Atlantic do at least publish monitoring data, whereas private firms and commercial interests do not (www.kingsfund.org.uk/discuss/the_kings_fund_blog/a_healthy_debate.html).

The cause of this sudden rush of solidarity is perhaps best understood in cultural terms. British culture, particularly English culture, appears to thrive on criticism and apparent negativity. Moaning is one of the rituals of Englishness and serves many different functions that help to bind social groups together, providing 'an opportunity to establish and reinforce common values by sharing a few gripes and groans about mutual annoyances and irritations ... there is a tacit understanding that nothing can or will be done ... we just want to enjoy moaning' (Fox, 2004, p. 199). To try to proffer solutions or stop a mutually enjoyable moan is not acceptable. Moaning is about reinforcing belonging, a factor that outsiders cannot understand. Let us take the weather as an example. It is universally accepted that the weather in England is awful. The most sensible advice that can be offered to the traveller to Britain is to take warm clothing, waterproofs and sensible shoes. No conversation among the English is complete without a good moan about the weather. However, this is an activity in which foreigners are not allowed to participate, because the English treat 'the English weather like a member of our family: one can complain about the behaviour of one's children or parents, but any hint of censure from an outsider is unacceptable and very bad manners' (Fox, 2004, p. 33). And so it is with the NHS. The health service is very much a part of the English family. Others criticise it at their peril, and successive generations of politicians know that although the service is expensive to provide, any attempt to dismantle it would be political suicide and a cause for revolution.

At this point it is worth reminding ourselves why such a service was thought to be necessary in the first place, and why, in a country that had been bankrupted

by six years of intense warfare, one of the first major developments was healthcare for all. Quite simply it was an attempt to treat everyone equitably. Everyone had played their part in fighting against a foe that was subsequently revealed to be far worse than anyone could have imagined. People were at rock bottom, and many were homeless and had few possessions. Let us also remember that in those days doctors had to be paid in advance. People feared illness because they could not afford treatment. They suffered with what we might nowadays regard as minor, easily treatable ailments (e.g. fistulae after childbirth, hernias, chest infections, boils) because they could not afford to see a doctor. Every year thousands of people died unnecessarily, even given the relatively primitive antibiotics that were available at that time. Now we, the descendants of those who started their families under the protective umbrella of the 'nanny state', can look back with gratitude, even if at the same time we are hoping and seeking to improve it. Yes, the notion and design adopted by that post-war government, which saw a real chance to make a difference and took it, were impossibly idealistic, but those ideals remain:

- that it meet the needs of everyone
- that it be free at the point of delivery
- that it be based on clinical need, not ability to pay.

However, we have to acknowledge that these ideals need to be reinterpreted for our modern society. Change is essential in any system if stagnation is to be avoided, but change is difficult to cope with. Change incites defensiveness, especially when it is poorly executed, but it is worthwhile for professionals to remember that others can feel defensive, too. Migrants and members of minorities can feel just as overwhelmed and resistant to change if their cherished practices and ways of life are blamed for their ill health or poor prospects.

In this issue, our first guest editorial again presents us with a fresh view. Ruth DeSouza and Donna Cormack take a challenging stance in which they question the processes of 'Othering', especially where there are more than two 'teams' or players involved. Colonisation did not end with political independence when the colonisers went home. It continued in the minds and hearts of many of those who were most anxious to see them leave, and in the social institutions and systems that they left behind. Thus the education, legal, health and political systems continue to reflect vestiges of the colonisers' values and attitudes. Looking at things from a different perspective, which is after all what diversity is all about, as Ruth DeSouza and Donna Cormack suggest, can create a social space that is indeed better for all of us. If we can do this in more than one dimension at a time, so much the better.

Our second guest editorial, by Raj Bhopal and Aziz Sheikh, comes from Scotland, a land which gave many

names to places in New Zealand (as DeSouza, Cormack and the Maori would no doubt correctly observe, 'new', Pākehā or Anglo-Celtic ones). Bhopal and Sheikh reinforce the argument put forward by Iqbal and her colleagues in a research paper that appears later in this issue, and draw upon a powerful epidemiology to insist that the exclusion of migrant and minority others from research is neither ethical, scientifically sound nor safe. Nor can there be any justification for using that artificial lack of evidence as a reason for failing to act on the inequalities in health that are so often demonstrated.

We begin our research papers with what is, for this journal, a novel dimension of diversity. Ruth Parkinson's paper on nurses' attitudes addresses what for most of us is a new area of identity and disadvantage, namely homelessness. There is, to be sure, a literature on the needs, numbers and attitudes of homeless people dating back to Dickens and Seebohm Rowntree, much of it deeply disturbing, but we seldom hear about the attitudes of professionals towards those who lack the most basic necessities. Homelessness means not only lack of a permanent roof over one's head, but also lack of access to much of what is taken for granted in a developed society (bank account, healthcare, education, facilities for personal hygiene and cooking, somewhere to sleep and shelter from the elements). It is very easy for professionals to overlook the enormity of what is lost when someone is without a home, and to look down on those who are struggling to survive. Hamilton's systematic review highlights some important messages that we have encountered in other contexts, reinforcing our belief that inequalities are indivisible and that processes of 'Othering' are key. Negative attitudes among service providers act as barriers to needy users accessing services. Professional standards, and cultures, need to reflect on and react to this, and to recognise that these unprofessional views should be extirpated.

The next research paper focuses on another fairly new aspect of diversity, namely disfigurement. Those who are visibly different experience prejudice and discrimination, but they are starting to stand up for themselves, engaging in actions that require great courage in order to challenge seemingly accepted views. The recent case of Riam Dean is a case in point. This young woman challenged the attitudes of managers in a branch of an up-market high-street fashion store, who had transferred her from the shop floor to the stockroom because she had a prosthetic arm and so did not fit the image they wanted to present to customers. Ms Dean won her case, which was one small victory for all those who have to cope with such treatment every day, and in this context she is a modern heroine (BBC News, 24 June 2009; <http://news.bbc.co.uk/1/hi/england/london/8116231.stm>). In the research presented in this issue, a group of new professionals challenged

themselves to look beyond the world of those who live with what the majority call 'disfigurement', and to examine how this is viewed within the minority cultures of Britain's south Asian communities. Their findings show many perceptions, values and stereotypes that are evident in other cultures, but also some culturally specific factors, such as the belief that, in a religious setting, all are equal in the sight of (which-ever) God. It is hoped that the insights gained will inform the remainder of the working lives of those who took part in this project.

Continuing with South Asian communities, Keval's paper addresses a common concern, about living with non-insulin-dependent diabetes, in a somewhat neglected subgroup of the larger South Asian population, namely the Hindu Gujarati speaking group. In so doing, it draws attention to the need for micro-differentiation of the key facets of identity which inform our coping strategies for health. Living with a disease or condition is not necessarily a passive activity, any more than cultures are themselves fixed. Heroes can emerge here, too, within condition-specific communities.

Without either champions or evidence, change is unlikely to occur, and even heroes need some ammunition or weapons with which to fight. However, there are still gaping holes in the evidence base of the NHS and other care services and professions. In particular, the great and until recently unspoken feared killer disease, cancer, was believed to have little relevance to most black and minority ethnic communities. Iqbal and her colleagues set out to examine and to challenge the apparent lack of statistics and research in the field of cancer, in relation to the experiences and needs of people of minority ethnic origin. Shockingly, they found that many, indeed perhaps most, trials of new treatments were not tested on members of such minorities, for what seem to be spurious reasons. Researchers had developed a fatal stereotype, namely that 'these people' (never 'we') preferred not to be invited to take part in such studies, or would refuse to take part. The team examined the field with a comprehensive systematic review, which again we are glad to present in its entirety for our readers' reference. They conclude that there is an urgent need to encourage the collection of data by ethnicity, and to use it to improve service planning. Happily, coinciding with the publication of this paper, we can report that the first national set of data drawn from the cancer registries and linked to data with an 'ethnic group' classification (Cancer Research UK and the National Cancer Intelligence Network, 2009), albeit flawed, has been published by the National Cancer Intelligence Network (NCIN) on behalf of the National Cancer Equality Initiative (NCEI) in the UK, supported by the National Cancer Action Team. Alongside this a new 'Principles' document has been produced for service planners and commissioners, which was launched at

the start of October 2009, based on a review of current 'best practice' (National Cancer Equality Initiative, 2009), as highlighted by Paula Lloyd, Associate Director of the National Cancer Action Team, in an 'Evidence Update' for the NHS Evidence ethnicity and health specialist collection (www.library.nhs.uk/ethnicity), October 2009.

No service, however good the quality of its knowledge, data and research, can function without its staff. Migrant workers have formed a key part of the NHS in the UK since its inception in 1948. What happens to them there, and how this affects services, is a story that is less often told. Raghuram and colleagues show, through a detailed oral history, how occupational clustering affects not only unskilled but also highly skilled workers. This can of course be a means of creating and thriving in an ecological niche, but it is also a disadvantage. Moving into elderly care was, for many, a form of resistance strategy to the discrimination that they experienced elsewhere, but it also made the field less popular in general, to the disadvantage of an ageing population. This paper presents some aspects of their experiences through the medium of methodology, which is not often used in health and social care research. Oral history provides a powerful medium for recording accounts and enabling voices to be heard.

Finally, in this issue, we present another sideways look in the 'Did You See?' series, where Zarina Anwar challenges the new 'outcome measure' of patient satisfaction, drawing our attention to a study from the USA which demonstrates that this concept is not uniform across groups. There is, as ever, a selection of good things and useful tools for practice in the Knowledgeshare section. Somewhat to the embarrassment of two members of the editorial team, there is also a very positive review of a book in which both were involved, although it is nice when one gets confirmation that one is doing something right. This, looking back to the opening section of the editorial, perhaps means that encouragement of champions and heroes should not wait until they are history, but is an essential part of the process of achieving change. So if you know of 'good practice', let us know, and also please tell those who are involved, so that they gain strength from your support. And, as ever, we invite our readers to share their contributions or to join us in debate. Details of the journal's submission criteria are given on the website (www.radcliffe-oxford.com/journals/J26_Diversity_in_Health_and_Care/M10_Contributing.htm). These criteria have recently been updated, to reflect the strictures of the Committee on Publishing Ethics (COPE) and the International Committee of Medical Journal Editors (ICMJE), and to keep abreast of changing good practice (as well as some changes in our own contact details). Please check the new guidelines before you send papers to us.

Finally, we give notice that we shall shortly be issuing not only a call for papers for the next volume, but also an invitation to apply to join the Editorial Board of the journal. We wish to maintain a balance between academic, user and practitioner perspectives, and to ensure that expertise from all the fields of diversity that we try to address is represented, including ethnicity, faith, gender, orientation and disability, as well as across the professions that are involved in health and care. If you are interested, please let us know by sending a CV to the editors using the normal routes for authors.

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