Death and rebirth: innovation and diversity

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So farewell, then, Steve Jobs. Can one person change a world? Despite the plethora of earthshaking events, including the ‘Arab Spring’ and other political or ‘regime’ changes in the Maghreb and Mashriq, few things attracted more headlines and media coverage over the past few months than the death of this one man. Clearly, much of the traffic was on channels that he had helped to create and popularise (Twitter and the like), and his impact in that respect has been perhaps unparalleled. But one element of the remembering was of particular poignancy, as the BBC replayed his speech to Stanford University students, in which he stated that his advice to them was to ‘live each day as if it were your last’, and not to be trapped by dogma. Many of us can find resonance in his observation that our life course ‘has been very clear, looking backwards’, and appreciate the ‘lightness of beginning (again)’. This was a man who was famous for never being satisfied, and for being intoxicated by diversity, whether of typefaces or technology.

So we, too, hope that this journal (while not looking for it to come to an end) will never fear engagement with new forms of diversity, and will enjoy and celebrate the ‘lightness of being’ that comes from new ways of looking. That was, from the beginning, the intention we had in starting the journal, providing a home for academically respectable papers tackling unpopular or unexplored areas and issues which were seen as marginal to the concerns of more traditional outlets. In the process, we hoped that cross-fertilisation of ideas and insights might develop, and common themes of structure rather than form might be revealed. It was never our intention to change the world, but we have been heartened to see the growth of other academic serials which offer outlets on topics such as ethnicity and inequalities, or equity in health, and we believe that this does reflect a growing acceptance of the value of academic, scientific enquiry into issues of intersectionality, discrimination and exclusion, and fairness in health and care provision.

Just to nail our colours more firmly to that mast, we shall be refreshing and revising our title from the next issue, to highlight the fact that not only is our concern with diverse world views, but also we believe in equality of treatment and esteem across diverse categories. This journal will therefore be published as *Diversity and Equality in Health and Care*. And, taking another hint from Steve Jobs, we shall also recognise that life is a continual process of learning, and introduce a new continuing professional development element, to assist our readers in learning from our writers and demonstrating this to their appraisers. If any author wishes to submit papers which will be considered for this treatment, we encourage them to look at our new guide for authors, which can be found on the journal website or obtained by emailing us.

Our guest editorial in this issue is by Jane Standing, Chief Executive Officer of Kairos in London, a community development organisation that serves lesbian, gay, bisexual and transgender (LGBT) people in central London. In part this editorial is a response to the paper by Fenge and Hicks (2011) in our last issue, but Jane Standing also illustrates the multiple levels on which exclusion operates, and the complexities inherent in revealing difference. *Coming out*, as we have previously observed, is not a single event, and revealing difference incurs risk because it is the ‘lens through which every other action is noted and judged’ (McGee and Johnson, 2006, p. 157). One of the ensuing consequences is that those who are perceived as different, such as LGBT, black or disabled people, receive poorer quality services or, even worse, ‘special services.’ This reflects the discourse of the dominant majority ‘people’, meaning themselves, who say ‘We do this ... believe that ... It is ‘they’, those who are different, who do not live or think as we do.’ In this context difference is regarded as the defining, most important characteristic. Those perceived as different are gradually ‘othered’, dehumanised and homogenised as, for example, ‘the disabled’, ‘LGBTs’, ‘the Asians’ or ‘the blacks’. A society that is truly committed
to equality focuses on people as persons first and foremost, and seeks to care for all, irrespective of any particular individual characteristics. Jane Standing’s editorial is a reminder that focusing on people first improves the lot of everyone, and then difference ceases to be a big deal.

Since it seems apposite, we shall take the opportunity here to highlight the fact that ‘others’ (on the other side of the Atlantic pond, in the USA), are already acting to improve matters. The Joint Commission is an independent, not-for-profit organisation that accredits and certifies more than 19 000 healthcare organisations and programmes in the USA. Joint Commission accreditation and its certification are recognised nationwide as a symbol of quality that reflects an organisation’s commitment to meeting certain performance standards. The Joint Commission has urged all American hospitals to create a more welcoming, safe and inclusive environment that contributes to improved healthcare quality for LGBT patients and their families. To that end, with the support of the California Endowment, it has published a guide entitled ‘Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community’ (available for download free at www.jointcommission.org/lgbt). The field guide features a compilation of strategies, practice examples, resources and testimonials designed to help hospitals in their efforts to improve communication and provide more patient-centred care for their LGBT patients. Normally, we try to highlight such items in our ‘Knowledgeshare’ section (see below), but the synergy seems to argue for an early reveal here!

In our first scientific paper, Rolfe and her co-authors examine the question of what professionals know about an issue of great concern to at least one sector of the minority ethnic community, and ways of overcoming the apparent knowledge gap. Too often, it is the minority groups who are blamed for their own ignorance or lack of proactivity in relation to their health, when in fact the professional ‘experts’ who are supposed to provide care and support for that health may not be as well briefed on issues of ‘minority’ interest as they need to be – unless, of course, these are issues which are prestigious or hold out the promise of a Nobel prize! And, in this context, it is perhaps worth remembering that the polymathic Linus Pauling, perhaps best known now for his advocacy of vitamin C, was one of the very few people ever to have won two Nobel prizes, and that the first of these, for founding the science of molecular genetics, was largely based on his early work examining the haemoglobin molecules of people with sickle-cell disease.

As readers will know, there is a lot more to be learned from the internet than can be found in academic articles and textbooks, although not all of it is of equal quality. Increasingly, however, the use of academic repositories and open-access journals is leading the way in providing more ‘quality-assured’ evidence in the virtual library of the Internet. The authors of this paper show us how they have used sickle-cell disease as a way into this, thus benefiting both higher education and professional development, as well as the population with sickle-cell disease. This paper thus serves a dual role (more diversity!), and may provide a model to ensure further cultural competence learning among the professions. We should note that it also demonstrates how a ‘minority’ interest has major implications for interdisciplinary learning, a third leg of our ‘diversity’ approach, for which we receive rather fewer submissions than we would like. Best of all, this research paper has now led to the creation of an open archive online easy-access resource, ‘SCOOTER’ (www.sicklecellanaemia.org), of great value!

Poureslami and colleagues, seeking to address issues of language, cultural difference, ‘newness’ and health literacy among migrants in Canada, who (as has been found in other settings) are disproportionately likely to suffer from asthma, a respiratory disorder with which they may not have been familiar in their countries of origin, report the findings of a study conducted in the increasingly multicultural city of Vancouver, British Columbia. Researchers (including the editors of this journal) have frequently concluded that in order to be effective, health promotion materials should be co-produced with minority communities to incorporate their values and lifestyles. This team reports the use of a technique that they term community-based participatory research (CBPR) in order to achieve that end. The specific tools (focus groups and the like) are well established, and this general approach, which has been widely used in other areas and conditions, is strongly recommended by the authoritative Agency for Healthcare Research and Quality in the USA (Viswanathan et al, 2004). However, the need for more extensive implementation of the technology remains, and the British Columbian group provides a clear and detailed step-by-step description of their project. A key element of the project was that it was not an exercise in translation and interpretation, but rather it set out to develop new materials to answer questions raised by the communities, using media (‘community video’) that other research has often recommended as more appropriate. Materials were then translated into English for the benefit of younger members of the communities, and perhaps also for professionals, who always like to know what their clients are being told! Readers will also find many detailed insights of interest, such as the observation that Chinese participants did have a spatial (‘Feng Shui’) reading of the video that they were shown, and the finding of variation in different ethnic groups’ attitudes towards smoking and pets. From the perspective of the health promotion practitioner and
researcher, it is also encouraging to record that the team has gone on to conduct studies which will report on clinical and behavioural outcomes. All too often such studies seem to conclude with the description and sometimes process evaluation of the development process. However, knowing that participants ‘liked’ the exercise is not enough. Did it have the effect of changing lives? We are happy to have been able to respond to the pleas by Visvanathan and colleagues for journals to create opportunities to highlight and disseminate CBPR research products, and we hope that healthcare providers and policy makers will indeed be guided by the evidence.

In a paper from the heartland of UK minority ethnic diabetes research, namely the city of Leicester, Patel and her colleagues consider not the more normally described, late-onset type 2 variety of diabetes mellitus (non-insulin-dependent diabetes mellitus or NIDDM), but the likelihood of South Asian people disclosing their insulin-dependent status. In the UK it appears that, perhaps because of increasing ‘integration’, levels of type 1 diabetes among South Asian individuals are rising to the same levels as are found in the autochthonous populations. There is a significant literature on stigma and marriageability issues in the South Asian community, which are often postulated to be a barrier to action with regard to health protection. Here this suggestion is examined directly. If we are to situate health education in a cultural context (as has been suggested in our previous papers), the values and beliefs that underlie ‘courtship’ and marriage must be among the most powerful motivators in a society (among parents at least, if not among young people!). The interesting point about this study is the degree to which the pragmatic decision to reveal status was made, even in the face of strong ‘homeland’ myths or beliefs about its impact on marriage prospects (and these pressures were most certainly present). Such honesty is to be commended.

Moving on to the development of staff to provide care to a diverse community, we are very happy to report on a new message from Galilee, in which Zafrir and Nissim describe a student-led ‘multi-language course’ for nursing students. Language is often the basis for an ‘othering’ process, both as a way of excluding people by reverting to a local dialect, minority or unfamiliar language (‘pas devant les enfants’, as my parents used to remark), and as a way of complaining that the minority migrant (‘they’) will not adapt to ‘our’ ways, and therefore should continue to be excluded. It is indeed alienating, in a real sense, when one cannot understand what is being said about one (and one does suspect, perhaps inaccurately, that one is the butt of such remarks!). The authors report on an experiment in which they encouraged students from a polyglot melting-pot area of Israel to teach each other a few words or phrases in their own languages (Russian, Arabic, Amharic and Yiddish, as well as the state language of Hebrew). The results are extremely encouraging. Barriers were broken down, and most students were amazed how easily they picked up these words and phrases and became more at ease with ‘the others’. An ability to have pride in one’s own culture, along with confidence in that of others, can be an empowering and exhilarating experience. We wish them well as they go out to work with diverse users, greeting them and meeting them in each others’ tongues. What was that about Babel?

Staying away from the European melting pot for a little longer, we travel down under to Australia to examine the application of the principles advocated in our papers and editorials to fall-prevention strategies. It is known that as people get older, they are more likely to trip or fall, and that this can lead to other problems and an early death. Prevention is known to be helped by taking part in exercise activities, and by home-based risk assessments, all of which are less accessible to (or less accessed by) people of migrant and minority ethnic origin, or, in the Australian language, ‘CALD’ (culturally and linguistically diverse) people. Some of this failure to engage arises from a lack of awareness of the risks, over-confidence in one’s own abilities, or maybe even a fear of the risks of exercise. And it appears that this is another sector where CALD or black and minority ethnic (BME) people have historically been excluded or omitted from research and indeed from service development. This will become increasingly unforgivable and indeed risky as such groups of migrant origin grow older and form a larger proportion of the so-called ‘elder population.’ Indeed, by 2006 it was already estimated that one in five older people in Australia were migrants from countries of non-English-speaking background (NESB, another acronymic label!). The results of this service development project were promising, but await the longer-term outcomes, for which we (and the Cambodian, Croatian, Turkish and Arabic speakers of Melbourne) earnestly hope that the improved monitoring also advocated in these pages will be in place.

And finally, we are delighted to highlight and salute a paper in the open-access journal ‘Public Library of Science’ (Ostlin et al. 2011), laying out an international consensus on Priorities for Research on Equity and Health. This is based on an extensive review of global evidence, and presents the recommendations of the WHO Commission on Social Determinants of Health. The authors call for a ‘paradigm shift’ away from the traditional disease-based models to one that explicitly addresses social, political and economic processes. They believe that this shift is already under way, and that it will provide a valuable and necessary complement to existing research in medicine, the life sciences and public health. Although there has been a move in that direction, not least because of the publicity given
to the work of such luminaries as Michael Marmot, there is still room for improvement, especially in considering issues beyond the socio-economic and questions of poverty, such as the question of why some groups are more affected by those structures than others, including migrant and minority ethnic groups, people with disabilities, and people whose sexual orientation is not seen as fitting some ‘orthodox’ view of heterosexuality, which is where we started this issue!

At the back of the journal, but perhaps the first place to which some readers will turn, are our three regular feature items. These offer practitioners and those who have not previously written for an academic journal an opportunity to get on the ladder of publishing, or to critique research, policy and practice from a grounded perspective, by challenging a research or policy paper (Did You See?), reflecting on an incident in the everyday workplace (the Practitioner’s Blog), or writing a short description of some innovation or attempt to develop services (KnowledgeShare). Maybe new entrants to the field could regard this as part of their continuing professional development, an area where we feel that the journal in its new guise will be expanding its impact.

In this issue, our KnowledgeShare content covers many of this journal’s familiar themes of mental health, diabetes, and culturally competent nursing. The book review assesses one of the few evaluative descriptions arising from the Developing Race Equality (DRE) initiative, a highly resourced activity on which many expectations were placed and which closed earlier this year with little fanfare. Cathie Lloyd reports on a further development in her diabetes workshop series, Irena Papadopoulos reflects on the growing strength of the European Transcultural Nursing Association (ETNA), and we present a few more resources you might not have seen. In the Practitioner’s Blog, our guest author talks about an almost invisible, socially excluded or marginalised minority which, as our guest author talks about an almost invisible, socially excluded or marginalised minority which, as we feel that the journal in its new guise will be expanding its impact.

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ACKNOWLEDGEMENTS

We extend our thanks to the enormous number of people who help to make this journal what it is, not least of whom are the often unsung heroes of the peer-review process, who read the papers we send them before they are accepted for publication. They help us to see what is good, what is unoriginal, and what needs to be worked on further. Most of our authors have cause to be grateful for the care that these people from around the globe devote to reading and improving their work, even when the initial response is ’reject’!

Very seldom is that all that is said, and usually a detailed critique is provided that often assists the authors to resubmit a much improved product for the edification of us all, and the enhancement of the evidence and knowledge-bases for practice. Many thanks to you all.

Finally, we wish to add a small acknowledgement of support to the paper published in our previous issue by Denny et al (2011), which was accidentally omitted from that article. The authors gratefully acknowledge funding of the Endocul Project by a grant from the National Institute for Health Research, Research for Patient Benefit Programme.

REFERENCES


Fenge LA and Hicks C (2011) Hidden lives: the importance of recognising the needs and experiences of older lesbians and gay men within healthcare practice. Diversity in Health and Care 8(3):147–54.


