Editorial

Diversity or deviance: the dilemma of difference

Paula McGee PhD RN RNT MA BA Cert Ed
Editor, *Diversity in Health and Care*; Professor of Nursing, Faculty of Health, Birmingham City University, Perry Barr, Birmingham, UK

Mark RD Johnson MA PhD Dip HE (Warwick)
Editor, *Diversity in Health and Care*; Professor of Diversity in Health and Social Care, Mary Seacole Research Centre, De Montfort University, Leicester, UK

Every society establishes norms that define what is expected of members. Certain behaviours are valued and encouraged, while others are prohibited or frowned upon. This issue has been highlighted for the UK during the scenes of mayhem and destruction that took place overnight in most major cities during the early weeks of August, with many commentators speaking of a breakdown of respect for property, law and order, parenting, and social norms. Although there is variation between societies, most seem to expect that adults will adopt particular modes of behaviour and perform specified roles as authority figures, parents, workers and contributors to the society as a whole. Children are expected to learn these norms and roles so that they too may become full members of society when they reach adulthood. Although not all of a society's norms may be to everyone's liking, the benefits of supporting them can far outweigh those of striking out alone. Conformity brings a sense of belonging to a group and access to a wider range of resources, many of them requiring specialist skills, than one person could ever hope to attain. However, this may be subverted when a person seeks instead to gain acceptance by, or belong to, a 'gang' or group that rejects the values of the majority society, or feels excluded by it.

Problems also arise when individuals do not conform to society's expectations and are thus regarded, in sociological terms, as *deviants* in that they are unable or unwilling to fulfil the expectations presented to them (Parsons, 1951). *Deviance* may be regarded as criminal when it is associated with prohibited behaviour, such as violence or theft, but it can also provide a pathway to societal change which, in some cases, leads to a new social order taking over. This has been evident recently in what the UK newspapers have been referring to as the 'Arab Spring.' Substantial numbers of people in different countries have refused to continue to tolerate norms that are used by their governments in oppressive and unjust ways. Some governments may regard such refusals as deviant or even criminal, but the continued strength of the protests and the huge numbers of people participating in them indicate large-scale unrest that presents major challenges to the social contract between the individual and society. The usual methods of social control have been rendered inadequate, and the use of more extreme methods by some governments has attracted worldwide condemnation although little else. People live in the hope that a satisfactory resolution can be achieved, but this is still a long way off. Power is not easily relinquished, and the more power one has the harder it is to yield any of it to anyone else.

There are of course different ways of understanding or expressing the social contract that go beyond the Eurocentric debates originated by the theories of Grotius, Hobbes and Rousseau in the 17th and 18th centuries. Our guest editorial presents at least one of these. Professor Abul Fadl Mohsin Ebrahim, from Durban, who is a new member of our international editorial board, introduces himself and widens our perspective to include the global, from both African and Islamic perspectives. The concept of *Ubuntu* will of course not be unfamiliar to our readers, who may recall its use in the context of anti-HIV/AIDS activity in the Zimbabwean community (Chinouya and O'Keefe, 2006), or by President Clinton shortly thereafter, but in all three contexts it, like the South Asian concept of '*Namaste*', speaks to our essential unity of existence and mutuality. We, as editors, thank our international editorial board for helping us to keep that wider perspective and understand the deeper realities that underlie our shared humanity. Sometimes all that divides us are the terms that we use to describe these common concepts. Other forms of deviance from the social contract are less obvious but equally challenging

(Parsons, 1951). Disease and illness, for example, interfere with individuals' ability to fulfil social norms and adult roles. This lack of ability is tolerated only under strictly controlled conditions. Firstly, the individual must recognise that he or she is ill and seek help from someone appointed by society to determine the nature of the problem and how it should be addressed. Secondly, the individual is expected to comply with this person's recommendations in exchange for being allowed to temporarily lay aside the need to comply with society's expectations. Parsons (1951) referred to this as 'the sick role' which presents 'challenges to membership and normality [of society] which, if not legitimised by a medical label indicating that the person has a right to enter the sick role, may be resented by people who expect the person to play a normal part in social life' (Seale, 2002, p. 26).

The inference here is that illness must be a temporary state. The sick are expected to make an effort to get well, to take up their roles again and to adhere to social norms. The alternative is to die quietly and as quickly as possible. What the sick are not expected to do is to go on being sick. Thus, a long-term or permanent health problem can be seen as a form of deviance, namely lack of compliance with society's expectations. People with asthma, diabetes, epilepsy and other such conditions will be familiar with the sighs of irritation from those around them when they complain of feeling unwell. Comments such as 'you were all right a few minutes ago' or 'Can't you just work it off?' reflect an underlying belief that the individual is really perfectly healthy and just angling for sympathy. Nevertheless, social norms in such circumstances demand that appropriate action be taken because long-term conditions such as asthma, diabetes and epilepsy are legitimated by those appointed by society to decide on matters relating to illness and disease, namely doctors. Therefore, if an individual has an officially sanctioned long-term condition, certain allowances must be made.

Unfortunately, some long-term health problems are not so well defined or so easily accommodated. Elaine Denny and her colleagues highlight the difficulties experienced by those with endometriosis, a painful and disabling condition that affects between 5% and 15% of women. Diagnosis is not straightforward. Women generally can feel uncomfortable about discussing their periods and menstrual problems with other people, especially men. This reticence is compounded by the inconsistent presentation of endometriosis, which means that individual women may report quite different symptoms and experiences. The 'sick role' thus becomes a contested arena in which the women feel ill but encounter disbelief from doctors. Their claims to illness are not legitimated, and instead they are labelled as over-emotional or even mentally ill. Added to this, efforts that have been made to understand how endometriosis affects women's lives have largely been focused on white western populations. We are therefore pleased to present one of the first studies to address this issue by examining the experience of Indian, Pakistani, Greek Cypriot and Chinese women living with this condition.

We continue our focus on deviance and illness with our second paper, by Aimee Afable-Munsuz and colleagues. This addresses health beliefs about colorectal cancer among Filipino women living in California. For Parson's idea of the sick role (Parson, 1951) to work there has to be some convergence in belief between the person who is ill and the doctor. Where there is wide disparity in belief about the nature and causation of illness there is less likelihood of a successful outcome. Treatment and care have to be meaningful, at some level, in order to be effective (Leininger and McFarland, 2002). Colorectal cancer 'is the third most common cancer in men (663 000 cases, 10.0% of the total) and the second in women (571 000 cases, 9.4% of the total) worldwide', and approximately 60% of cases occur in developed countries (http://globocan.iarc.fr/factsheets/cancers/colorectal.asp). Western health services emphasise the importance of screening in order to reduce mortality. Early diagnosis also results in less costly interventions and better quality of life for many individuals. However, as this paper shows, if people cannot see the point of screening, do not believe that there is a need for it, or do not believe that colorectal cancer could affect them, they will not put themselves forward for this procedure. It is easy, in these circumstances, for professionals to feel irritated by this lack of response to their good intentions. As this paper also shows, the slide from there into stereotypical beliefs does not take account of, or engage with, the complex socio-cultural contexts in which people live. As our readers will be aware, this is a common refrain in our pages.

We move on from here to another equally contentious aspect of deviance, namely sexuality. We have noted elsewhere that humans are extraordinarily preoccupied with sex; who should put what into where is an endless source of debate at the centre of which is the male–female dyad as the archetypal expression of what sex should be all about (McGee and Johnson, 2006). In many societies this is the only form of sex that is considered to be legitimate, a view that is bolstered by the majority of religions. Other forms of sexual expression are outlawed, and in some societies are considered to be a capital offence (BBC News 2010; http://news.bbc.co.uk/1/hi/8693560.stm). Despite these strictures, there are many people (no one knows how many) who find it impossible to conform to their society's emphasis on male–female sexuality. This is not a lifestyle choice. Some people are born with differences in their chromosomes or physical or other attributes that cause ambiguities in determining their

gender and sexuality. Others have less obvious differences but find that their sexual preferences and expressions are same-sex oriented. Thus, it would seem that there are multiple forms of sexuality and sexual expression, of which that which takes place between males and females is just one. Recent reports suggest that multiple forms of sexuality are not confined to humans. Similar behaviour has been observed among some other mammals and birds.

The issue here is that society's negative and punitive responses to those whom it regards as socially deviant cause those on the receiving end to hide their sexuality and sexual preferences. Thus, no one knows how many people are lesbian, gay, bisexual, transgender, intersex or asexual (LGBTIA). Even more importantly, no one knows very much about health and illness among members of these groups. For example, is being LGBTIA linked with an increased or decreased incidence of any particular conditions, such as cancer or cardiovascular disease? Do LGBTIA people show differences in patterns of ageing and lifespan? Again no one knows the answers to these questions. In societies in which LGBTIA sexual expressions are outlawed no one is likely to show much interest, and life for most members of these groups can be, to use Hobbes' phrase of 1651, nasty, brutish and short. However, in societies that have begun to bring about change on this issue, where LGBTIA people are gaining the same civil rights as everyone else, there is a growing understanding that sexuality is far more complex than it was believed to be in the past. Legislating for equality is not enough. Social processes and institutions also have to adapt, and social norms have to expand. Leaving aside sexual expression for a moment, let us look at one small example from another part of daily life, namely filling out a form. Whatever the form is for, whether it is for applying for a job, opening a bank account or admission to hospital, the respondent will probably be asked whether they are male or female. This question may seem straightforward enough, but it immediately excludes those who are intersex, transgender or undergoing gender reassignment. Daily life is filled with examples of this kind, and our third paper in this issue illustrates the matter further. Lee-Ann Fenge and Christina Hicks report on the challenges faced by older lesbians and gay men in accessing health and care services that are still designed for people in male–female couples. Moreover, these older lesbians and gay men will have lived through a period in which they had few civil rights and, if they live in countries such as the UK, a time of transition. For them, coming out is likely to be associated with the legacy of oppression and the continued fear about how people will react. We are pleased to present this paper and hope that it will encourage service providers to critically review their practices and procedures.

Undertaking such a task requires people to step outside their usual sphere to try to gain an understanding of what it is like to live outside society's norms. Our final papers in this issue represent two attempts to do this. First, in an unusual study, Sarah Salway and her colleagues report on an attempt to enhance rigour in the presentation of research on ethnicity and health through the guidance provided for authors by professional journals. Secondly, Margret Lepp and her colleagues present their second paper on the Jordanian–Swedish exchange programme for nurse academics (see also Määttä and Lepp, 2010). This last paper illustrates the need for careful planning to enable individuals to learn from the experience of being an outsider. Without such planning they will simply feel cast adrift and unable to function.

Finally, we commend to our readers our usual features, Did You See?, the Practitioner's Blog and Knowledgeshare, all of which provide further food for thought and access to resources that may help in personal, professional and practice development. We would especially, perhaps, urge our readers to consider the dilemma posed by the Practitioner's Blog, in which the 'norm' of speaking a common language is challenged, as is the accepted best practice of using an interpreter in such circumstances! One thing stands out, namely that all absolute rules are misleading. We would welcome contributions on this or any other topic deriving from practice, for inclusion in this feature, as well as your submissions for reviews of items that others may have missed, and resources that deserve a wider audience.

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