Questions we should ask about research into community nursing practice: a multi-ethnic perspective: Response to the paper presented by Jean McIntosh

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As our communities become more and more diverse, those undertaking research into community nursing practice have a responsibility to incorporate a multi-ethnic perspective into their studies. Primary Care NHS Trusts are increasingly powerful institutions in respect to addressing the needs of minority ethnic groups. As with other public bodies, they need to demonstrate that they are promoting race equality in order to comply with the Race Relations (Amendment) Act 2000. Research into the experiences of families affected by sickle cell disorders and thalassaemia are employed to illustrate nursing accountability for the quality of patient and client care.

Key words: community nursing; ethnic minorities, thalassaemia; research; Race Relations (Amendment) Act 2000

Introduction

This response will use the excellent framework developed by Professor McIntosh but focus in particular on research interests relating to equal opportunities within the health service, nursing and midwifery education together with service policy for sickle cell and thalassaemia disorders. As a result, rather than presenting a more traditional detailed critique, it will present an additional perspective.

Why a multi-ethnic perspective?

Our communities are becoming more and more diverse (Parekh, 2000) and as the following definition illustrates, ethnicity is just one aspect: 'Diversity results from differences in gender, ethnic or national origin, religion, age, physical or mental capability, marital status, sexual preference, social background, organisational role and many other factors which cause people to have different perspectives on the same set of facts or issues' (Kandola and Fullerton, 1998). Kai (1999), in describing the iceberg model of diversity, notes that the following more visible aspects are above sea level: gender, age, ethnicity and nationality. Below sea level and less visible are socio-economic status, occupation, health, previous health experiences, religion, education, social groupings, sexual orientation, political orientation, cultural beliefs, expectations and behaviours. It is to be hoped that community healthcare researchers, in any part of the world, could routinely integrate diversity into their day-to-day planning of studies.

Within the Faculty of Health and Human Sciences at Thames Valley University, our academic centre leads on the development of a multi-ethnic strategy for nursing and midwifery recruitment, education, practice, management and research (www.maryseacole.com). The Centre was deliberately named after Mary Seacole in order to honour this black Victorian nursing heroine, now an icon to many minority nurses. This is due to both the significant nursing contributions she made

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during the Crimean War as well as the determined way she overcame multiple rejections in her attempts to support the work of Florence Nightingale (Alexander and Dewjee, 1984).

Current and future influences on practice

Professor McIntosh identified a variety of influences in this section of her framework. Those that will be explored from a multi-ethnic perspective concern some of the changes occurring at the demographic, political and professional levels. The focus in this paper will be on service delivery rather than employment issues; useful recent references on the latter include equal opportunities and nursing employment (Beishon *et al.*, 1995; Culley, 2001; National Nursing Leadership Programme, 2002 (www.nursingleadership.co.uk/pubs/odds.pdf); recruitment of black and minority ethnic students to preregistration nursing and midwifery programmes (Chevannes, 2001; Mahoney, 2001); and racism affecting health visitors (Culley and Leatham, 2001) together with a general overview of how racism impacts on nursing (Culley and Dyson, 2001).

Demographic changes

A decade ago the 1991 census identified that the England and Wales population of 50 million included approximately three million (6%) from minority ethnic groups (Balarajan, 1997). Scotland, Northern Ireland and Republic of Ireland have also witnessed an increase in the range of diverse groups within their countries. Community nurses involved with families and children need to be aware, however, that these statistics also revealed that approximately 11% of births were to mothers from black and minority ethnic groups. This has important consequences for delivery of appropriate health care (see Bowler, 1993; Schott and Henley, 1996; MacLachlan, 1997; Henley and Schott, 1999 and Hellman, 2000).

Many factors have resulted in significant demographic changes over the last 10 years and these will become evident in the findings of the April 2001 census which should be made available in 2003. Asylum seekers and refugees are one cause of change and this is a factor common to many other parts of the world as seen from recent media coverage of the people in two boats who were attempting to enter Australia. While this is currently an extremely contentious issue, the UK has a long history of receiving political and economic refugees. Their countries of origin will be influenced by wherever there are civil wars, invasions, persecution and other political, environmental and economic upheavals.

The introduction of the refugee dispersal programme within the UK (following the 1999 Immigration and Asylum Act) has had an important impact on community nursing practice in many areas that had previously no significant experience of such diverse populations. Issues are many and complex – some include interpreting and advocacy requirements, psychological trauma of those fleeing political, religious or ethnic persecution, poverty, stigma, racisms, isolation, uncertainty of the outcome of applications for refugee status as well as cultural issues related to health beliefs (see Levinson and Coker, 1999; Trafford and Winkler, 2000).

Of interest is that even established cosmopolitan cities such as Manchester experience difficulties. A recent survey identified a low level of awareness of general practitioners about services that asylum seekers can access (Manchester Community Health Council, 2001). Examples included paid interpreting services via the then Health Authority (HA), the £300 maternity grant (requiring a support letter from their GP), and that asylum seekers should be registered with GPs as permanent residents so that they can access the usual screening and immunization services. Much of the GPs confusion was due to the HA failing to distribute guidance at the time that the dispersal programme commenced. The Community Health Council subsequently produced leaflets that primary care staff have found particularly useful, especially practice nurses and health visitors. More recently the NHS commissioned a training resource for health professionals (Burnett and Fassil, 2002) that is also available online at: http://www.london.nhs.uk/newsmedia/publications/Asylum_Refugee.pdf.

Legislative changes

Various recent legal enactments in respect of human rights, disability and race relations will impact on community nursing practice within diverse communities. This section will focus on some aspects of the Race Relations (Amendment)

Act 2000 that came into effect in April 2001. Useful information about the Act can be obtained from the Commission for Racial Equality (CRE) (www.cre.gov.uk). NHS Trusts and Higher Education Institutes are examples of public bodies that will now be legally subject to the general duty to promote race equality. By the end of May 2002 all NHS Trusts were, by law, required to produce their Race Equality Scheme encompassing a 3 year action plan on how they will undertake the ethnic monitoring of staff, users, complaints, promotion and disciplinary procedures. The CRE and the NHS have published detailed guidance for NHS Trusts (see for example: http://www.cre.gov.uk/duty/pdfs/pg_health.pdf and http://www.doh.gov.uk/race_equalityresource/index.htm). Failure to respond could ultimately result in the CRE taking legal action against an NHS Trust.

Professor McIntosh stresses that social inclusion embraces minority ethnic populations and that this is extremely relevant to health services (see Graham, 2001). Equitable access to care is a cornerstone of the NHS Plan (Department of Health, 2000) raising important research questions for community nursing services. The findings of a study by Nazroo (1997) suggested that minority ethnic respondents, except for Caribbeans, were less likely to be using health visitors or district nurses. Gerrish (1999) in her analysis of the allocation of district nursing resources to different general practitioner (GP) practices identified marked inequalities in the district nursing provision which impacted upon the services to minority ethnic patients. She concluded that although nurses at an individual level did not appear overtly to disadvantage minority ethnic patients, institutional forces conspired to perpetuate the disadvantage experienced by minority ethnic communities.

An increasingly powerful institution in respect to being able to address the needs of minority ethnic groups are the Primary Care Trust (PCTs), (preceded by Primary Care Groups (PCGs) (see Arora *et al.*, 2000). Thus the findings from a survey of annual reports from HAs and PCGs in English districts with a high proportion of minority health populations (between 10 and 45%) provide cause for concern (Menon *et al.*, 2001). Of the 13/20 responses received from HAs, one made no mention of the health of black and minority populations compared with a lack of reference in 10 of the 22/64 PCGs. More than 75% of HAs cited

initiatives for ethnic minorities compared with only 36% of PCGs.

The implications of the Race Relations (Amendment) Act 2000 will require all NHS Trusts to implement ethnic group monitoring. This will necessitate training of staff, information for users, analysis of data, developing a strategy to address any gaps identified and continually reporting in their annual reports on the progress that has been made (Aspinall and Anionwu, 2002). Aspinall (2000) has identified the inadequate progress of HAs since mandatory collection of data on inpatients commenced in April 1995. There were high levels of incompleteness and invalid ethnicity coding and nine tenths of HAs made no use of the data. While ethnic group monitoring within primary care has not been as widespread, recent studies paint a more optimistic picture concerning feasibility (see, for example, Pringle and Rothera, 1996).

Nursing accountability for the quality of patient and client care

The experience of those affected by, or at risk of having a child with a sickle cell or thalassaemia disorder (haemoglobinopathies) will be used to illustrate this theme. It has been noted that while common illnesses and diseases are the main problems for ethnic minorities the specific importance of these conditions is 'that they provide us with useful bench marks to assess the willingness and ability of the NHS to respond to specific needs of ethnic minorities' (McNaught, 1987: 8). Until recently such evidence has been sadly lacking (Anionwu and Atkin, 2001; Department of Health 1993).

Table 1 provides a summary of these two autosomal recessively inherited red blood cell disorders (see Anionwu and Atkin, 2001).

Community nursing practice relating to these genetic disorders can be divided into 1) screening and genetic counselling and 2) care management of children and adults affected by either of the disorders. With respect to the first point, it is important to realise that there will be 17 to 100 times as many healthy carriers as there will be affected children and adults. It has been estimated that each year there are approximately 3000 babies born who are healthy carriers for a sickle cell

Table 1 Overview of sickle cell disorders and thalassaemia

Sickle cell disorders ~ 12,500 UK cases	Thalassaemia major and intermedia ~ 800 UK cases
Main consequences and treatment Red blood cells sickle causing:	*Main consequences and treatment*
• Painful crisis	• Inadequate production of haemoglobin. Require blood transfusion every 4–6 weeks of their life
• Damage to various organs in the body: e.g., spleen, lungs, hips, eyes, brain (stroke) leading to possible disability and early death	
• Vulnerability to serious and life threatening infections	• Body unable to excrete excess iron from transfusions requiring chelation therapy. Storage of excess iron in liver, heart and endocrine glands causing life-threatening damage
A variable and unpredictable illness:	
• Early diagnosis to reduce risk of life threatening infections by use of prophylaxic penicillin	• Additional complications: diabetes and osteoporosis
• Avoidance of sickling triggers (e.g., dehydration, fever, low O_2 tension, changes in temperature)	• Improved survival but early deaths due to nonadherence to chelation therapy common
• Pain management	
• Education of practitioners	• 25% on UK register have had bone marrow transplants
• Socio-psychological support	
• Newer therapies: hydroxyurea, bone marrow transplantation. ? future role for gene therapy	• Future therapies: ? hydroxyurea and gene therapy

disorder and the same number who are healthy carriers for thalassaemia (Hickman *et al*., 1999).

Positive news is that screening and genetic counselling is now on the health service agenda so current gaps in service provision such as inadequate language provision, ad hoc, inequitable and culturally inappropriate services (Atkin *et al*., 1998a; 1998b) may at last be addressed. The NHS Plan stated that there will be a resourced nationally linked antenatal and neonatal screening programme by the year 2004 (Department of Health, 2000; see also www-phm.umds.ac.uk/haemscreening/). Herein lies a significant number of research questions that could be posed relating to the implications for

community nurses, midwives, practice nurses and health visitors.

Unfortunately, care of affected individuals remains a neglected area particularly pain management in sickle cell disorders (Maxwell *et al*., 1999) and coping with the burdensome iron overload treatment for those affected by beta thalassaemia major (Atkin and Ahmad, 2000). The role of community nurses may well increase due to the encouragement of greater management within primary care rather than in the acute sector as currently prevails. Health visitors are already involved with children and parents who may be affected with the disorders. One area that has been overlooked is the possible disabling nature of sickle cell disorders (SCD) and beta thalassaemia syndromes. Examples related to SCD include strokes in young children, visual and hearing impairment and mobility problems due to sickling in the hips and shoulders. Those associated with beta thalassaemia syndromes include complications related to osteoporosis and diabetes.

There are really an enormous number of research questions that can be pursued by community nurses in respect to issues that have an impact upon minority ethnic communities in addition to sickle cell and thalassaemia (Anionwu, 1996a).

Current knowledge and skill base for practice

This section will focus on the degree to which nurses are adequately prepared to practice within a multi-ethnic society. An ENB commissioned study involving colleges of nursing and midwifery throughout the country identified that 'The case studies have confirmed the expectations that might reasonably have been drawn from the national survey; namely that very many current practitioners are not currently equipped to provide appropriate intercultural care to minority ethnic clients' (Gerrish *et al*., 1996: 127).

One approach has been to facilitate cultural competence which has been defined as 'a dynamic, fluid, continuous process whereby an individual, system, or health care agency finds meaningful and useful care-delivery strategies based on the knowledge of the cultural heritage, beliefs, attitudes, and behaviors of those to whom they render care'

(Giger and Davidhizar, 1999: 8). Another concept is the cultural safety model that was developed in Aotearoa (New Zealand) in the late 1980s. A group of Maori nurses developed this concept as a means of analysing nursing practice from the perspective of the indigenous people who are a minority (Ramsden, 1990; 1992). Polaschek (1998) has also provided a useful critique as well as outlining the development of the concept and how, despite controversy within the national media, it was adopted by the Nursing Council of New Zealand. Are there any research questions that we in the UK can pose in relation to the applicability of the New Zealand experience?

Finally a useful contribution to the debate within the UK is a book entitled *Ethnicity and Nursing Practice* (Culley and Dyson, 2001) which offers a comprehensive update with an exploration of many themes that generate numerous research questions relevant to community nursing practice.

Using research in practice

This final theme will draw from the experiences of nursing practice and the haemoglobinopathies. The first sickle and thalassaemia counselling post was established in 1979 and subsequently the vast majority of future appointments were after 1987 with Figure 1 demonstrating that most post holders hold a community nursing qualification.
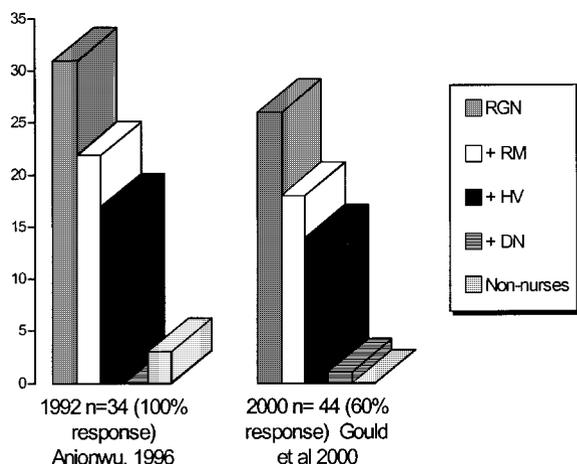

Figure 1 Qualifications of sickle and thalassaemia counsellors

Relevance of the ethnic origin of practitioners

In a survey undertaken in 1992 (Anionwu, 1996b) in which all 34 sickle and thalassaemia counsellors then in post responded, 25 (73%) described their ethnic origin as Black, African, African Caribbean or Black American, four (12%) as Asian, one Mauritian, one Greek Cypriot and two (6%) as White (one of whom described herself as an Eastern European Jew). Ten were able to counsel in various languages other than English such as Hindi, Punjabi, Urdu Igbo, Yoruba, French and Greek. A follow-up survey in 1997 of all 68 counsellors in post identified that 68% were African or African Caribbean, 16% as Asian, 13% as White, 3% as Other and there was one who did not provide details of her ethnic group.

Several research studies have demonstrated that sickle and thalassaemia counsellors represent an acceptable model of care for minority ethnic communities affected by, or at risk of these disorders (Atkin *et al*., 1998a; 1998b; Gould *et al*., 2000). Parents, health professionals and health service commissioners have all identified that these specialist workers were the focus of provision. Parents were particularly appreciative of their cultural sensitivity and, for some, a shared language other than English. There are, however, many research questions remaining about particular areas of their practice (see Anionwu, 1996a; Gould *et al*., 2000).

Conclusion

In conclusion, it is vital to embrace a multi-ethnic perspective into community healthcare and research and there is an ethical imperative to ensure that this is no longer viewed as an optional extra. An example has been drawn from my own interests which commenced when working as a health visitor in north west London. This experience awakened me to the gaps in general health service provision for minority ethnic families. It appeared particularly stark for parents and carers of children affected by sickle cell disorders and in 1979 I became the first person in Britain to be appointed as a sickle and thalassaemia counsellor. Incorporating research activities into my work resulted in a PhD thesis exploring community development and health promotion for sickle cell disorders in Brent. It also triggered many other research questions

such as those explored in *Sickle Cell Anaemia – Who Cares?* (Prashar *et al.*, 1985) and an increasing interest in the politics of health care for families affected by these disorders (Anionwu and Atkin, 2001).

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