

Haemoglobinopathies and health-care provision for ethnic minorities

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Abstract

The level of training and competence in dealing with haemoglobinopathies (which mainly affect ethnic minorities in the UK) may not be totally adequate among nurses. Nurses indicated that they received little or no information in their teaching for working from a multiracial perspective and what they had learned was through experience and personal research since qualifying as nurses. Knowledge of the biological basis of inheritance, methods of acquisition of thalassaemia and sickle-cell anaemia and the ethnic profile of people affected by these conditions may not be totally adequate among nurses. Many nurses wanted more training, including those who had already received instruction, since this was described as 'far too vague', 'not constructive', 'minimal', or 'embarrassingly insufficient', recommending that instruction be given by a sickle-cell anaemia/thalassaemia counsellor with a contribution from patients. A combination of poor quality, or lack, of instruction, together with time and resource pressures, is responsible for this limited understanding, resulting in insufficient awareness of the health needs of ethnic minorities leading to inequalities in healthcare provision.

Key words: Biological sciences ■ Nursing education ■ Ethnic groups

As the number of people diagnosed with haemoglobinopathies increases in parts of the UK (Centre for Health Service Studies, 1999), it is becoming clear that nurses working in some departments are having to deal increasingly with patients who present with thalassaemia and sickle-cell anaemia (Table 1). The reduction in teaching time for biological sciences in nurse education at both pre- and post-registration levels in the last 10 years may have led to insufficient knowledge and awareness of the health needs of ethnic minorities which could lead to inequalities in health care provision (Khattab et al, 2001; Courtenay, 1999; Jordan et al, 1999). The aim of this article was to review training and awareness within the nursing profession of haemoglobinopathies, which mainly affect ethnic minorities in the UK (Atkin and Ahmad, 2000).

Biological sciences in the nursing curriculum

The vital contribution of the biological sciences to a nurse's practice was recognized by the General Nursing Council back

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in 1922 when they were included in the training syllabus for student nurses (Courtenay, 1999). The governing body that replaced the Council in the 1980s also emphasized the central role of these sciences (UK Central Council, 1986). Recent commentators continue to highlight the crucial need for nurses to have some mastery of biological subjects (Courtenay, 1999; Jordan et al, 1999; Jordan and Reid, 1997; Waters and Thomas, 1995). Courtenay (1999), in referring to specialist nurses in such diverse areas as, for example, intensive care, diabetes and incontinence, points out that a sound grasp of biological sciences is essential. She states:

'Without it, they will be able to extend their role only by learning discrete skills or tasks. They will be unable to demonstrate advanced practice, which should reflect the academic rigour of the education they have taken.'

Jordan et al (1999) argue that there is an increasing need for application of biological knowledge as nursing work becomes more autonomous. Allied to this growth in autonomy is the increasing interest in interprofessional education and practice. The need for less distinct boundaries between the caring disciplines, especially in relation to nursing and medicine, must surely equate with an even more pressing need for nurses to have a greater expertise in the biological sciences than previously possessed by many of them.

This assertion can be seen in the context of views held by Leininger (1974) who argues that the task of selecting key constructs and principles for curriculum in order to learn about the cultural needs of patients is an important activity of schools of nursing and students.

Nursing training and ethnic minorities needs

Although institutions seeking approval to provide nurse training programmes are required to demonstrate commitment to antidiscriminatory/equal opportunities policies (Baxter, 1997), the reduction in teaching time for biological sciences in nurse education may have led to insufficient knowledge and awareness of the health needs of ethnic minorities which could, in turn, lead to inequalities in health care provision. One such need is haemoglobinopathies which mainly affect ethnic minorities in the UK (Atkin and Ahmad, 2000). A report from the University of York (Centre for Health Services Studies, 1999) identified a projected 44 births per year affected by thalassaemia in England alone. The report suggested that 500 people per year require treatment for this disease. The York report also referred to a projected 129 potential births per year affected by sickle cell disease

(SCD) in England, indicating that 5000 patients per year will require treatment.

As the incidence of haemoglobinopathies increases in parts of the UK, it is becoming clear that nurses working in some departments, such as Accident and Emergency (A&E), are having to deal increasingly with patients who present with painful SCD crises. Level of training and competence in dealing with haemoglobinopathies may not be totally adequate among nurses as indicated in a number of studies. In a study, which was aimed at discovering the levels of knowledge, skills and information of health personnel involved in the provision of services and care to black and ethnic minority people in four health authorities, Higham (1988) and Khattab et al (2001) indicated that many of the nurse respondents gave the impression that they received little or no information in their teaching for working from a multiracial perspective and what they had learned was through experience and personal reading since qualifying as nurses.

Furthermore, many of the nurse tutors who participated in Higham's study (1988) noted the lack of training materials and resources on this subject and felt that information on the health needs and health care of ethnic minorities should be incorporated in a structured way as part of nursing training or as part of training of all NHS staff. Lawrenson et al (1998) also found that none of the North Thames A&E departments had formal training in place for staff to gain an appreciation of issues facing patients from ethnic minorities, even though that particular area has one of the most diverse ethnic populations in England. These findings are consistent with the findings of Khattab et al (2001) which showed that only 15% of the nurse respondents had received instruction on sickle-cell anaemia or thalassaemia (mostly during their pre-registration training at large teaching institutions in London). The majority (85%) of the nurses who participated in the study of Khattab et al (2001) had had no training in haemoglobinopathies.

Nurses' knowledge of the biological basis of haemoglobinopathies

Khattab et al (2001) showed that knowledge of the biological basis of inheritance, including methods of acquisition of thalassaemia and SCD as well as the ethnic profile of people affected by these conditions may not be totally adequate among the group of nurses included in their study. There appeared to be poor understanding of aspects of acquisition of the sickle cell trait. Furthermore, there was evidence of limited knowledge surrounding matters such as acquisition of thalassaemia, in particular, the level of knowledge concerning the ethnic origin of affected individuals was a great cause for concern as respondents seemed to know only about the Mediterranean origin of the disease.

Although thalassaemia is more likely to be found among people of Mediterranean, South Asian or Chinese origin, the thalassaemia gene can also be found in people of African-Caribbean origin and White British people (Atkin and Ahmad, 2000).

The findings of Khattab et al (2001) were similar to other studies (cited below), which revealed a lack of knowledge of the pathophysiology and pharmacology of the subject within the health care professions. Waters and Thomas (1995) found that,

among 12 qualified nurses, 7 of them felt adequately prepared to deal with such patients, yet their average score on SCD knowledge testing was 3.1 out of 10. Anionwu (1996) attributed the negative attitude found between many nurses and SCD patients to those nurses perceiving such patients to be drug-dependent because of analgesia requirements. Alleyne and Thomas (1994), in obtaining similar findings, noted that patients interviewed were concerned about the nurses' approach to pain management in SCD patients. It appears that many nurses were reluctant to give opioids in high doses to patients suffering acute painful SCD crises. This reluctance stemmed from a fear of bringing about or enhancing addiction. There is, however, no evidence that opioid dependency is a problem in the SCD population (Newcombe, 2002).

Another indication of uncertainty on aspects of SCD amongst A&E nurses comes from the work of Thomas and Ellis (2000). They describe how, by incorporating education about SCD and its possible serious sequelae, a support group for A&E nurses helped them to gain deeper insight into the reasons for the difficult and challenging behaviour of many SCD patients.

Table 1. Definitions of terms

- Haemoglobinopathy: disorder or disease caused by or associated with the presence of abnormal haemoglobins in the blood.
- Sickle cell disease: an inherited haemoglobinopathy, characterized by sickle-shaped cells which are stiff and can block blood vessels resulting in pain episodes, anaemia, infection and organ damage.
- Thalassaemia: any of a group of inherited haemoglobin metabolism disorders which impairs the synthesis of one or more polypeptide chains of the protein, globin resulting in anaemia of varying severity, depending on the form inherited.

This increase in knowledge of the pathophysiological aspects of SCD enabled nurses to not only offer enhanced psychosocial care but also undertake 'better nursing assessments' (Thomas and Ellis, 2000).

Level and quality of training

The demand for changes within the structure of nursing education has a long history, and it is clear that nurses perceive the learning of the biological sciences as being difficult and problematic (Wilson, 1975; Akinsanya, 1987; Courtenay, 1999; Jordan et al, 1999). This perception cannot be helped by the abundant evidence that teaching time for this area of the curriculum has been, and continues to be, reduced in many institutions (Courtenay, 1999; Jordan et al, 1999). Khattab et al (2001) suggested that half of the nurses (52%) involved in their study wanted more training, including those who had already received instruction, since this was described as:

'...far too vague', 'not constructive', 'very superficial', 'minimal', or 'embarrassingly insufficient'

Such statements confirm that a combination of poor quality, or lack of instruction, together with pressure on time and resources, is responsible for this lack of understanding and

awareness. These findings are consistent with Higham's study in which over two-thirds of the nurse tutors would like to have seen more information on the subject included in training materials on the health needs and health care of ethnic minorities (Higham, 1988).

The findings of Khattab et al (2001) support those of Anionwu (1988) and of Dyson (1994) on the provision of multicultural education for student nurses and midwives respectively in the UK. Such education, however, will serve little purpose in the context of caring for individuals with haemoglobinopathies unless the nurses experiencing this education have appropriate biological knowledge in relation to these disorders.

Surprisingly, 35% of the nurses who participated in the study by Khattab et al (2001) felt that they had had adequate training. These findings align to the findings of Higham (1988) who confirmed that just over a third of tutors involved in his study said that racial disadvantage and discrimination were covered as a specific topic in nurse training.

Khattab et al (2001) showed that 13% of the participant nurses were unconvinced whether they needed further instruction, with comments such as:

'We don't have time for such things' and 'There is no need, as there is not a significant ethnic population here.'

This failure in acknowledging the existence of a multicultural society combined with the lack of biological knowledge of haemoglobinopathies within the nursing profession may result in an inability to respond effectively to the health needs of people suffering from these disorders within ethnic minorities in an equitable and timely way (Waters and Thomas 1995; Ahmad and Atkin 1996; Khattab et al 2001).

Reduction in teaching time for biological sciences and its impact on nursing care

The insufficient knowledge and awareness of the health needs of ethnic minorities, demonstrated in this review, may be due in part to the reduction in teaching time allocated for biological sciences in nurse education at both pre- and post-registration levels (Khattab et al, 2001; Jordan et al, 1999; Waters and Thomas, 1995). This lack of knowledge and understanding of haemoglobinopathies will contribute to a catalogue of professional errors and judgements (observed in a number of studies) such as:

- Poor pain control; this means that one of the most distressing aspects of the illness remains untreated. France-Dawson (1994) highlighted the decision by many SCD patients to avoid attendance at emergency departments for their crises because of long delays before being seen by medical staff. Such delays could be attributed to lack of understanding on the part of the triage nurses about pain involved in SCD.
- Stereotypes of minority ethnic patients as having a lower pain threshold; this attitude is rife in the health services
- Worries about African-Caribbean patients becoming dependent on drugs
- Lack of information provided to the patients or their carers about the condition.

This attitude of seeming disinterested in the patient's suffering is due, in the authors' opinion, to lack of knowledge and understanding of the condition which will inevitably lead to inequalities in health care provision and could be translated as racism by the clients as suggested in many studies (Khattab et al, 2001; Atkin and Ahmad, 2000; Anionwu, 1996). France-Dawson (1994) pointed out that, to act as advisors to these patients and their carers, nurses must first possess the appropriate biological and psychosocial knowledge about SCD.

The cuts in contact time with lecturers is difficult to comprehend, especially in view of the wide acknowledgment that nursing students find the learning of the biological subjects to be difficult and demanding (Jordan et al, 1999). Moves towards the use of so-called 'more student-friendly' methods of learning, such as worksheets, computer programmes, games, CDs, etc, may form only a small part of the solution to this ongoing problem of acquiring understanding of the biological sciences. Nicoll and Butler (1996) found that students did not want such methods to interfere with the curriculum's taught time, but, rather, be available for library loan or use in lunch breaks. They also found that their students seemed to prefer the use of lectures for the teaching and learning of biological sciences. In addition, Jordan et al (1999) found that:

'For students, bioscience was one of the most valued course components, second only to nursing interventions.'

Furthermore, the study by Khattab et al (2001) showed that the 52% of nurses who requested further training, recommended that instruction should be given by a sickle-cell anaemia/thalassaemia counsellor with a contribution from patients. This finding is in keeping with the results of other, earlier studies conducted among student nurses (Burnard and Morrison, 1992; Sutcliffe, 1993).

Content of nursing curricula

The education of nurses is undergoing considerable change at present in its structural, organisational and ideological approaches. This is an ideal climate in which to introduce innovation. The opportunities now exist more than ever for the profession to address the issue of race equality. There is some evidence that this opportunity is being grasped (Baxter, 1997). In our multicultural society, bodies controlling nursing education should provide guidelines on what needs to be taught, and to what level, to ensure equality in the delivery of health care between ethnic minorities and the rest of the population.

Larbie et al (1987) and more recently Baxter (1997) suggested that the content of teaching on race equality in nursing should have three main dimensions. The first is the antiracist dimension, which is the preconditioning required for effective work on the other two dimensions. The second focuses on the differing concepts and patterns of illness and health within ethnic minorities and the third on the dimension of practical skills needed in order to care for different ethnic groups. These last two dimensions necessarily involve knowledge of biological sciences.

Rohde (1978) suggested that it is impossible to develop and implement curricula which include cultural diversity unless

one breaks down the attitudinal, philosophical and behavioural barriers which prevent it.

The question for the nursing profession, that inevitably arises from such a consideration of the need to embrace and work within cultural diversity, is centred on the knowledge and skills required to offer safe and effective health care to ethnic groups.

In facing up to this kind of question the authors assert that the profession finds itself facing some tensions, mostly of its own making. On the one hand, it is being asserted that the biological sciences are an essential part of any nursing curriculum, and that they form one of the most demanding and difficult parts of the curriculum. On the other hand, there is evidence that curricular time for the biological sciences is being reduced in many educational institutions. In the context of the health problems of ethnic groups, it is unsurprising if nurses are unable to make as useful a contribution as might be hoped. If it is perceived that their biological knowledge of disease in general terms is inadequate then it can be assumed that their awareness of the biology of ethnic diseases is even more so. It is ironic that this realization comes at a time when society is keen to emphasise the concepts of racial equality, multiculturalism and ethnic values. The world of healthcare is not exempt from this emphasis as evidenced by the work of Larbie et al (1987) and Baxter (1997) who, in calling for nurse education to incorporate various dimensions of race equality into its curricula, highlight the need for nurses to become aware of the different patterns of health and disease in ethnic populations.

Conclusion

Although there is a growing interest in the health and social care needs of minority ethnic groups, the impact of ethnic diversity on nursing curricula needs to be acknowledged, and a genuine commitment on the part of bodies controlling nursing education should be made in order to provide guidelines on what needs to be taught, and to what level, to ensure equality in the delivery of health care between ethnic minorities and the rest of the population. Research exploring these disadvantages is in transition, having to incorporate new insights that challenge the orthodoxies of the past (Atkin, 1998). Further research is therefore needed to determine the appropriate content and depth of biological sciences knowledge required by nurses and the links between health inequalities and nursing education (Akinsanya and Hayward, 1980; Akinsanya, 1987; Pearson and Clarke, 1994; Wharrad et al 1994; Jordan and Reid, 1997).

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KEY POINTS

- There is a lack of knowledge and understanding of the pathophysiology of haemoglobinopathies within the nursing profession due to the reduction in teaching time for biological sciences in nurse education.
- This lack of knowledge and understanding may contribute to a catalogue of professional errors, including poor pain control; stereotyping and worries about dependency on drugs and lack of information provided to patients or their carers which could lead to inequalities in health care provision.
- More research is needed to determine the appropriate content and depth of biological sciences and their impact on health inequalities in nursing education.