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Community Nursing: The Ethical Issues

Rosie Tope and June Smail

Introduction

During recent years many of the countries forming the continent of Europe have become more closely integrated in terms of health and social policy. Inevitably this integration of policy has influenced the mode of management, organization and delivery of patient care. Most European countries have adopted the WHO philosophy of 'Health for All by the Year 2000' and have been working with varying degrees of success towards achieving this aim. In 1993, the Council of Europe concluded that the adoption of a common strategy in the fields of public health and welfare would achieve a greater unity between its members. The adoption of this strategy enabled professionals involved in health and social care to train and work throughout Europe in the country of their choice.

Most countries now boast pluralistic societies in which a diversity of people live. Many different ethnic, racial, religious and social groups can be identified, all of whom wish to maintain independent lifestyles and retain their own values while living within a common civilization. Recognition of and respect for the rights and views of others enhance the quality of health and social care. Ethnocentricity has no place in society if Health for All is to remain an achievable target.

As a result of the 1993 Council of Europe recommendations, most European countries are formally adopting the concept of collaboration in health and social care on both

national and international bases. Furthermore, a great emphasis is placed on the contribution made by effective teamworking. The White Paper *Caring for People* (DoH, 1990) laid out plans for 'community care in the next decade and beyond'. The main aims were identified as promoting individual choice and independence by:

- Enabling people to live as normal a life as possible in their own homes or in a homely environment in the local community
- Providing the right amount of care and support to help people achieve maximum possible independence.

The primary health care team (PHCT) has a vital role to play in helping the general population to achieve these aims. General practices are the focus of community provision and there are clear implications for teamworking as a mechanism for co-ordinating community care.

Structure and organization of primary health care in Europe

The core members of primary health care teams vary considerably throughout Europe. In many countries registered nurses work solely within the primary health care centres and do not visit patients in their homes. Instead, patients are expected to visit the health centres for consultation and treatment. Most countries do not have the equivalent qualification of health visitor and most tend to use the generic term 'community nurse'. In addition, many of the primary health centres fulfil the function of a small hospital by providing in-patient beds. In some countries the health centres are the first port of call for all emergency and urgent care, rather than the model adopted in the UK of accident and emergency departments located in district general hospitals.

Within the confines of this chapter, it is not feasible to examine the organization and delivery of community care in every country in Europe, but opinions have been sought from experts in primary health care in Greece, Finland and Sweden. These

individuals have considered the ethical dilemmas commonly faced by nurses and the other professionals working in the community within their own countries. In our analysis of their comments it will be seen that common beliefs and aspirations emerge, along with a recognition of the effects of current circumstances and limitations within which all primary health care teams currently function.

Each of the countries discussed supports the notion that it is preferable for people to be cared for in their own homes wherever possible and that the core value of health care should be the worth, dignity and individuality of every patient. There are similar concerns about the cost of institutionalized care and the need to secure adequate funding for chronically ill and elderly people. Most of all, there is concern about the seeming inability of the various organizations and authorities to work collaboratively and harmoniously for the good of the patient. There is a similar recognition that acute sector care has always attracted, and for the foreseeable future will continue to attract, the greatest amount of financial investment. There is great concern that these apparently insurmountable problems will continue to impede progress in enhancing the quality of community care.

Political, historical and cultural influences all play a part in the philosophical interpretation which each country applies to its planning and implementation of health care and it is these differences upon which this chapter focuses. Therefore, before considering the most prevalent ethical issues, the structure and organization of primary health care within the four selected countries will be described.

Ethical issues concerning professional accountability, autonomy, advocacy, clinical judgement and competence are considered in conjunction with the rights and expectations of patients regarding confidentiality, informed consent, compliance and invasion of privacy. A central tenet of the discussion is that ethics is not just a matter of personal opinion, and therefore any decision reached about a particular ethical issue is bound to raise some controversy.

When caring for patients in the community, nurses and health visitors are confronted by many conflicting needs and interests. For example, the prevailing social factors may not only conflict

with the existing economic and political limitations, but also test the personal integrity of individual practitioners. The difficulties for practitioners lie in justifying what is right and good and in using their insights gained from systematic, reflective study to influence the development of ethical health policies.

How the ethical issues are addressed has been analysed and described by community health professionals in Greece, Sweden and Finland, so that the similarities and differences can be highlighted and compared with UK practice.

The United Kingdom

In the UK the roles of all nurses working in community settings have evolved rapidly over the last few years. Frequently, they are based in the same premises as, and work in collaboration with, general practitioners as core members of the primary health care team. In 1996, the Department of Health indicated that there were 8999 general practices and health centres in England and 532 in Wales (DoH, 1996a).

A primary health care team is generally accepted as being an association of different professionals whose aim is to provide the patient with comprehensive care (RCGP, 1991). The roles of individual team members may vary, but the purposes and goals of the team should be clear and shared. Effective care delivery requires that nurses and health visitors co-ordinate and plan care with the involvement of clients, patients and other professionals.

In the UK, health visitors provide a service to families, especially those with young children, across all social classes and age groups. The four guiding principles of health visiting which remain relevant today are:

- The search for health needs
- The stimulation of awareness of health needs
- The influence of policies affecting health
- The facilitation of health-enhancing activities (CETHV, 1977).

Community nurses work predominantly in people's homes, with the elderly, those who are chronically sick or those who

are terminally ill. Many of their patients, therefore, are those whose problems 'defy precise definition, do not have readily available cures and are often prolonged' (Knopke and Diekelman, 1981). Although community nurses work as independent practitioners, they are managerially accountable to nurse managers and are usually employees of an NHS trust.

In the main, practice nurses are employed by general practitioners (GPs) and work in health centres and GP surgeries. In recent years, their numbers have increased dramatically in response to the 1990 GP contract. This new contract, imposed on GPs by the government, not only includes a number of new controls on GP activities, but also extended the services which GPs are expected provide to include more health promotion and illness prevention. Practice nurses represent approximately 20 per cent of all nurses working in primary care (Atkin and Lunt, 1993) and their role includes investigative procedures, screening and health promotion activities, family planning, chronic disease management, childhood immunization, travel health and advising on minor ailments.

These three groups of community nurses, health visitors, district nurses and practice nurses, make up the 'core' nursing component of primary health care teams. In addition community midwives, community psychiatric nurses and school nurses increasingly work as team members in GP practices. Midwives are responsible for the total care of women during pregnancy and the postnatal period. The community psychiatric nurse's skills are particularly helpful to people who have depression, mental stress and/or dementia and school nurses liaise with the practice, schools and families on child health issues.

When the organization of community nurses in the UK is compared with that of other European countries, different patterns emerge.

Greece

Greece has been trying to implement a national health service for the past 15 years, with varying degrees of success. The latest reform occurred in 1992 when Greece was divided into a number of district health services. The geographical size and

patient population of each district vary considerably, depending on whether it is in an urban or rural location. Each district health service has a director who represents its interests at the Central Health Committee which is directly answerable to the Ministry of Health. According to Greek law (Law No. 2071), the Greek state secures the right of every citizen to seek and gain access to primary, secondary and tertiary health care, while at the same time enabling each individual to retain freedom of choice and dignity. The Central Health Committee comprises several doctors representing the clinical sector, a doctor and dentist who represent the university medical and dental schools respectively, a representative (usually a doctor) from the schools of nursing, one senior nurse who represents all the secondary and tertiary care nurses of Greece and finally the Director of Social Services.

Primary health care for 10 million people is provided by 185 health centres situated throughout Greece. Each health centre serves at least four communities and has at least four peripheral clinics. The centres develop their own policies which reflect the needs of their respective populations (National Statistical Office of Greece, 1993). Halandritsa health centre, situated 22 kilometres from Patras, for example, was opened in its present form in 1991. It serves 27 villages located over a wide geographical area with a total population of 25,000 people. Five peripheral clinics are run by the staff from the health centre which is autonomous.

Organizational policy is developed by the core team consisting of the medical director, other doctors, nurses, midwives, social workers and administrative staff. The health centre is managed and organized by an innovative, enthusiastic and committed medical director and staff and as such, serves as an exemplar for many other health centres. Great emphasis is placed on health education and health promotion for all patients, as well as the provision of innovative in-service continuing education programmes for trained staff and students from a number of professions. The health centre acts as the focal point for the population. Social activities take place within the centre with people from many different villages attending. There is an integral link between many of the health and social activities and a clear health education message. Lack of resources, however,

impedes further developments which the Halandritsa team are keen to implement.

In some areas of Greece, additional primary health care may be provided by out-patient clinics in the district hospitals providing this is approved by the hospital council. Efstathiou (1997) suggests that after almost 15 years of an established primary health service in Greece, the following general conclusions can be drawn:

- Curative services are still in high demand
- There is no national strategy regarding primary health care
- There is a great shortage of qualified nursing staff and social workers
- There is a chronic lack of resources which impede progress in primary health care
- Many of the professions retain a traditional orientation towards curative rather than preventative care.

Finland

The central tenet of Finland's health policy is to 'encourage people to adopt healthier ways of living, reduce preventable health problems, and refine and elaborate the health service network' (Ministry of Social Affairs and Health [MSAH], 1996, p. 5). Priority has been given to the community sector and the organization and delivery of health care have been modified accordingly. Staff who originally worked in acute hospital settings are being transferred to newly created posts in the community. All patients with non-urgent problems are assessed by a medical practitioner within three working days and, if necessary, are referred to a hospital for further investigation within one or two weeks of the initial consultation.

Finland's health policy has meant that 'the health of the population has steadily improved even though disparities between sectors of the population still exist' (MSAH, 1996, p. 1). Generally, however, people have adopted healthier lifestyles in recent years, although there tends to be a higher number of deaths through accidents, suicides and acts of violence in Finland than in most other European countries. Conversely, the number of

deaths from cancer tends to be lower although the reasons for this are not clear.

In 1994 there were 243 health centres in 455 municipalities serving a total population of just over 5 million people. In order to ensure continuity of care, the local populations served by the health centres are organized into 'cells' of between 4000 and 10,000 people. Each cell is assigned to a team which comprises doctors, public health nurses and other professionals. Each doctor has responsibility for approximately 2000 patients. The system is comparable with that in the United Kingdom as each patient registers with an individual general practitioner in a health centre. In normal circumstances, the patient makes an appointment to see his or her own doctor, but anyone requesting an urgent referral is able to see the first doctor available.

The total number of in-patient beds in the health centres is 23,000 or 451 beds per 100,000 inhabitants and only 13 centres are without in-patient beds. Arrangements for home visits by community nurses are the responsibility of the health centres and the majority of these visits are to patients over 65 years of age.

Sweden

Sweden has a population of almost 9 million people, with 85 per cent living in the southern half of the country (Svenska Institutet, 1994). Health and social care are viewed as crucial to the overall welfare of the country and both are financed through a national social insurance system. There are 10 regional hospitals, 80 district or county hospitals and 900 health centres serving the entire population and approximately 300,000 people are employed in the health care sector (Svenska Institutet, 1995). In general, Sweden's population enjoys a relatively high standard of health when compared with international standards. Life expectancy is rising with 18 per cent of the population over 65 years of age and infant mortality is one of the lowest in the world. Cardiovascular diseases account for more than half of all deaths. In common with other Scandinavian countries the incidence of suicide is relatively high,

although this has decreased significantly during the last decade. There are, however, considerable and growing differences in the level of health attained by different social groups (Svenska Institutet, 1995).

The primary health care centre is the first point of contact with the health service for the population. Individuals have the right to choose their own family doctor who treats all diseases and injuries not requiring hospital admission. Many different health professionals are employed by the health centres. All patients pay a fee for each consultation and this has recently been increased to 125Kr which is approximately £12.50. After a total fee of 800Kr is paid in any one year any additional consultations are free. In 1997, however, there is emerging evidence that people cannot afford to seek treatment and care and it is anticipated that the gap will widen still further between the different levels of health experienced by the different social classes. In addition, there are a number of private schemes available and many people consult a doctor and receive treatment through this route.

Patients do not have access to health centres 24 hours a day. If someone is ill during the night or at weekends the district hospital is contacted for advice. An established community nursing service provides home visits when required and a number of clinics within the health centres are nurse or midwife led.

In a pattern reminiscent of other Western countries, the largest proportion of financial resources, 58 per cent, is allocated to the acute care sector with only 5 per cent being spent on long-term care and 17 per cent on primary health care. In total 7.5 per cent of the gross national product is spent on health care (Svenska Institutet, 1995).

In 1992, as a result of lengthening waiting lists, a guarantee was introduced that no patient should wait more than three months for admission to hospital. If the patient's local hospital is unable to meet this criterion, then arrangements must be made to admit the patient to an alternative hospital. During the same period, the number of beds in acute, psychiatric and long-term care facilities has reduced considerably with the introduction of policies to enable individuals to remain in their own homes wherever feasible. It is reported that many patients

have been discharged from hospital into the community without appropriate support or funding and, in common with the United Kingdom, this has caused an additional strain on the under-funded primary health care sector.

Ethical issues

Policy development and allocation of resources

In a truly pluralistic society, effective community care raises a number of ethical issues. Questions about what constitutes a priority are being increasingly debated by health and social service personnel in the UK, Greece, Finland and Sweden, as well as in numerous other countries. Strategic planners, policy-makers and managers may differ significantly in their perceptions of need from those of clinical staff who are at the sharp end of patient or client care. Although limited financial resources are still widely perceived as the most crucial limiting factor in primary health care, issues of quality and safety are increasingly entering the equation. Ways are being sought to ensure that the same priority is given to caring for chronically sick and elderly people in the final stages of their lives, as to those with acute illnesses or injuries who require life-saving treatment.

There is a significant cultural difference between some of the southern and northern European countries as far as caring for frail elderly people is concerned. In northern Europe the nuclear family is in much greater evidence, while in southern Europe it is commonplace for three or even four generations of a family to live together. There it is usual for younger family members to care for frail, elderly relatives in the family home. There is, therefore, less demand on both health and social service sectors to care for and financially support elderly people. Although this may be of great psychological benefit to the elderly person concerned, it may also disadvantage them as there is less opportunity for health professionals to assess and treat their physical needs. Caring for a dependent relative on a 24-hour basis also places a heavy burden on the carers. In Greece, for example, many women forgo the opportunity to pursue a

career because it is expected that they will care for all their dependent relatives. This burden is compounded even more by the lack of qualified community nurses able to visit patients in their own homes.

Balancing interests

Many ethical issues can be attributed to the need to balance the rights and quality of life of an individual against the need to use limited resources appropriately. This means that patients wishing to exercise their autonomy in relation to treatment decisions may not be able to because of a lack of resources. Dines and Cribb (1993) argued that autonomy is an integral part of human health and well-being. In some instances, however, the health and autonomy of an individual may conflict with the health and economic well-being of the community in which he or she lives.

Downie and Calman (1987) queried what restrictions, if any, should be placed on individuals who represent a potential danger to the health of the community in which they live. Furthermore, they asked whether infringing the liberty of an individual in order to improve the health of others can ever be justified. In some instances the answer would appear to be quite clear. In the United Kingdom, a person who is deemed to be severely mentally ill and is thought to be a danger, either to himself or to others, can be compulsorily detained in a secure place. An individual who is known to have salmonella and who handles food intended for consumption by the general public will be forbidden to work on health grounds, until he is clear of the infection. People who refuse to practise safe sex while knowing that they are HIV positive have been identified publicly. Similarly, in Scandinavia strict controls are placed on individuals representing a danger to the public. In Sweden, for example, an individual who is HIV positive is required by law to give the names of any sexual partners and to inform them that they are carrying the virus.

In Greece the situation is less clear. As far as the person with salmonella and working in the food industry is concerned, the law forbids that person to work until the infection is cleared.

The problem, and therefore the ethical dilemma, is that employers may not enforce this even if they are aware of the situation. The only people who may be aware that a person has salmonella are the health professionals and, if they protect patient confidentiality, they put members of the general public at risk. In reality, it is left to the patient to decide. The question of identifying individuals who are HIV positive but who do not practise safe sex is a subject of current debate in Greece. As yet no conclusions have been drawn.

In other instances the situation may be more confused, for example parents refusing to have their children immunized or women refusing cervical smears or mammograms and wishing to be removed from call and recall programmes. It could, for instance, be argued that as patients or clients have the right to agree to or refuse treatment, a health professional is accountable only for ensuring that the person is in possession of all the facts to enable informed decision-making which reflects personal choice and preferences. In Greece, parents who refuse to have their children immunized are prosecuted. Parents are legally responsible for their children's health until they reach 18 years of age. This is similar to Finland, where 'a child's parent is not entitled to refuse treatment that would avert a health risk or save the life of a minor' (MSAH, 1996, p. 8). With regard to personal choice, however, a woman can refuse to have a cervical smear or a mammogram as she is not deemed to place anyone but herself at risk.

Seedhouse and Lovett (1992) argued that clinical and ethical analysis and decision-making are inseparable in health care. They suggested that clinical analysis entails identifying the patient's or client's problem, making the correct diagnosis, deciding the appropriate treatment and determining how the treatment should be organized and managed. Ethical analysis, on the other hand, involves the identification of the role and duties of the health professional in clinical analysis, what the preferred outcome should be for the client and how much time a health professional should devote to achieving that preferred outcome. A further critical consideration is the extent to which a patient's or client's ability to be self-governing should be respected. This decision must be made in conjunction with deliberations about how much informa-

tion should be given and how authoritative a health professional should be.

While there appears to be little doubt that clinical and ethical analysis are inseparable, it is the interpretation and application of the latter which presents the major challenge in primary health care. Professional ethics and the ethics of daily living are not radically different and it is argued that the ethical issues which arise within the confines of community care cannot be minimized through devising clinical protocols.

Patients' rights

In Europe there appears to be a general consensus of opinion regarding the overall clinical diagnosis, treatment and management of patients, but here the similarity ends. The way in which patient and client care is organized and delivered, how much information is given and the degree of patient participation in care differ significantly between the various countries. To a large extent these differences depend on the historical development, policy decisions and the ethnic, racial and cultural influences which have evolved in the individual countries. Since the beginning of this decade a number of countries have introduced Patient Charters (DoH, 1996b) or Bills of Rights. In essence many of these documents say the same thing. For instance, a patient must consent to treatment and should do so after a full explanation of their state of health. The diagnosis, the extent of treatment and care needed, the risk factors involved and any feasible alternatives to the recommended course of action should form part of any such explanations if they are to qualify as ethical and demonstrate respect for the individuals concerned.

In Greece, however, no such Bill of Rights exists. Although many patients in Greece may be aware of their diagnosis, it is by no means certain that everyone asks or is told the nature of their illness or the expected outcome. This is particularly true if a person has cancer. Culturally, people tend to avoid using the word 'cancer' and several authors suggest that cancer is still regarded as a stigma. Many Greeks refer to cancer as 'the bad disease'. All patients are given the opportunity of being

informed of their diagnoses but many prefer being kept in ignorance. Patients also have the right to refuse recommended treatments and, in common with most other countries, are then held responsible for the consequences. Community nurses are seen as having an essential role in helping patients recognize and understand the treatment they are receiving.

In all four countries patients are entitled to read their personal health records and, with the exception of Greece, are able to amend any information they believe to be inaccurate. Complaints procedures are explicit and personal health records are deemed to be confidential with access only allowed to those capable of justifying it. In Greece, patients and their relatives are given the relevant information by the doctor. No other health professional is allowed to disclose new information. For community nurses this can prove difficult, as they are not permitted to answer any additional questions asked by patients. On discharge from hospital, most patients receive information pamphlets which are then used by community nurses as a basis for discussion with their clients.

In the UK, professional accountability requires that community nurses have the authority to act with a reasonable degree of autonomy. There are, of course, areas of potential conflict with fellow nurses, other professionals and managerial personnel. The attributes of accountability and autonomy are authorized within the nurses' *Code of Professional Conduct* (UKCC, 1992). In Finland and Sweden, community nurses are also held accountable for their practice. Nurses in Greece, however, do not work independently from the doctor, whether in a patient's home or the health centre, thus their accountability is to the doctor rather than to the patient. It is, for example, a nurse's professional duty to inform the doctor of any confidential information pertaining to the patient's health problem, regardless of how or where this is obtained.

Justice and inequalities

For many community nurses in the United Kingdom, the re-organization of the health service in 1990 and the introduction of the GP contract have raised ethical concerns in relation

to equity. Fund-holding general practitioners carry their own budgets to purchase patient care and this has been criticized for encouraging a two-tier system which benefits these patients to the detriment of others (Harmen, 1996). Similarly, the allocation of scarce resources within a market economy is currently of ethical concern to many community nurses.

It has already been acknowledged by the Svenska Institutet that there is a growing concern in Sweden about the widening gap in the level of health attained by different social classes. Failure to provide adequate financial support for primary health care can only increase the health risks to poorer members of society. This in turn places greater financial demands on the acute care sector which then has to respond to the increasing need for secondary or tertiary treatment and care.

In Finland, exactly the same trends are identified. Fund-holding is a municipal responsibility and currently there are real concerns concerning the equitable distribution of some budgets and resources allocated to the primary health centres. In 1997, the Ministry of Social Affairs and Health itself acknowledged that the health service in general has been subject to major cuts in the money available as well as to inequitable distribution of existing funds. Since 1991, the number of staff employed in health and social care has decreased significantly. There are 46,000 professionals working in the primary health care sector in Finland but there are a further 31,000 doctors, nurses and social workers who are not employed because of a lack of funding. It has been suggested that if many of the unemployed health professionals were given jobs in primary health care, the country would save money in two ways. First, unemployment payments would be reduced and second, the level of health within the general population would improve as a result of more efficient primary health services.

The Ministry of Social Affairs and Health acknowledges, in the same document, that while the policy of reducing institutionalized care and decreasing the number of acute beds has been implemented successfully, there are inadequacies in the present system of care and support for people in the community. The number of psychiatric in-patient beds has been reduced by 35 per cent in five years. The additional demand for the services of the primary health care teams, by those

patients unable to care adequately for themselves, is a cause of great concern and debate among community nurses.

At the beginning of 1997, a new law was enacted which determines minimum standards of care which must be achieved in private nursing homes. In a move similar to that which exists in the UK, nursing home inspectors with statutory powers to recommend closure of nursing homes which do not meet minimum standards have been appointed. Each municipality will be able to withdraw or withhold funding for unsatisfactory nursing homes. There is, however, general agreement that standards in most nursing homes are excellent and that compulsory closure will rarely need to be enforced.

In the UK, community services are criticized for being 'service driven' rather than 'needs led', but services based on need are often difficult to realize. Increasingly, health and social services are working in isolation instead of forming new alliances. Different services, such as needs assessment, treatment and care services, have to be co-ordinated to ensure that all of a patient's or client's needs are met.

In each primary health centre in Finland, the management team, which comprises a senior doctor, senior nurse and administrator, decides how their designated budget is to be allocated. The financial plans are then submitted for approval to a politically appointed council of lay people who approve or reject the proposals. A potential area of criticism is that as the council consists of political appointees, decisions on spending reflect the current political agenda rather than patient or client need. This again can cause major ethical dilemmas for the whole management team, as the need to seek approval may outweigh existing clinical priorities.

Interprofessional working

In the context of the health care team, conflicts and disagreements can arise between nurses and doctors as to who has ultimate authority and control over patient care (Tope, 1996). Thompson *et al.* (1988) suggested that although nurses may be left with the responsibility for patients they have no authority to change doctors' orders. Co-operation in planning patient care

in a practice is essential. Protocols, when they are developed, agreed and used by both nurses and doctors, overcome possible conflicts about care and treatment. Protocols are used increasingly in the UK, Finland, Sweden and Greece and it is generally agreed that they help team members to collaborate more fully in planning and implementing patient care and treatment.

Another potential problem in relation to teamworking is confidentiality. Virtually all general practices in the UK use computers which can be programmed to allow differential access to the various team members. But how much patient confidence should be shared with other team members in order to manage a situation effectively? Decisions about disclosure of potentially confidential information must, by necessity, be a matter of professional judgement. The UKCC (1996, p. 26) states that 'confidentiality should only be broken in exceptional circumstances and should only occur after careful consideration that you can justify your action'.

In Finland, the Patient's Bill of Rights 1991 states quite clearly that under no circumstances can any information given by the patient, in confidence to a nurse or any other health professional, be disclosed. Unlike the UKCC directive, there is no written caveat that states 'in exceptional circumstances' confidential information can be shared on a 'need to know' basis. This presents a major ethical dilemma for Finnish community nurses as it is acknowledged that there are occasions when failure to disclose information may place the patient, or others, at risk. This is the complete antithesis of the Greek approach where all information must be disclosed to the doctor.

In Greece, the introduction of computers for record keeping is perceived to have benefited the entire health care team, as the previous medical secrecy has, to a large extent, been abolished. Nurses are no longer unaware of patients' health problems as the patient's records are available to anyone who has access to the computer. It remains, however, the responsibility of the nurse to maintain patient confidentiality from everyone other than the doctor. The number of health care teams evolving in Greece is increasing, in hospitals, clinics and health centres, and these are always managed and supervised by the doctor. The community nurse's prime responsibility in such teams is that of 'counsellor'.

Confidentiality and adolescents

In the UK, confidentiality relating to those aged under 16 is frequently concerned with issues surrounding family planning, drug and alcohol abuse, and at times these can pose particular ethical dilemmas for community nurses. The House of Lords decision in the Gillick case supported the view that in exceptional circumstances, treatment and medicine can be given to a girl under 16 years of age without the parents being informed (Dimond, 1990).

In Finland and Sweden there is no legal age of consent so that children of 12 are deemed to be capable of making an informed decision about their treatment and care. Theoretically, a girl of 12 could decide to have an abortion without informing her parents although, of course, this would be most unusual. Written consent forms are not common in many countries and therefore the dilemma of treating a child confidentially poses less of a problem for community nurses in Scandinavia than for those in the UK.

In Greece, parents have to be informed by law, if their daughter is less than 16 years of age and requests contraception. Doctors and nurses can offer advice and teaching about the various methods of contraception, but these cannot be prescribed without parental permission. Similarly, if a young person tells a health professional in confidence that they are using drugs, their parents must be informed of the situation by the health professional. From this standpoint there is no ethical dilemma for health professionals, as the law dictates that parents must be informed. The dilemma for community nurses and doctors is that because of the law, many young people do not seek appropriate advice and health care because they know that their parents will be informed. In order to meet the health needs of young people, some health professionals in Greece believe that the law should be more flexible.

Professional duties

Advocacy in health care is concerned with promoting and safeguarding the well-being and interests of patients and clients

(UKCC, 1996). Advocating for others may cause community nurses to compromise either themselves or their integrity as they attempt to uphold both the interests of service users and remain loyal to their employers. Examples of conflict may include complaints about low staffing levels or inappropriate skill mix. A particular problem for community nurses might be the early discharge of a patient from hospital in the absence of acceptable community care arrangements, which, in the UK, is now a social service responsibility. Increasingly, community nurses are taking the initiative and making their own decisions based on their own experience and education. *The Scope of Professional Practice* (UKCC, 1992) rejects the notion of 'role extension' and focuses instead on the autonomous practitioner. Nurses working in the community have expanded their practice and some have developed the nurse practitioner role. The Royal College of Nursing Institute of Advanced Nursing Education (RCNANE, 1989) defines the nurse practitioner as someone who:

- Makes professional autonomous decisions, for which she/he has sole responsibility
- Possesses a repertoire of skills which embraces those with physical, psychological and social domains, especially diagnosing, prescribing, counselling and health promotion.

In Finland and Sweden, the term 'nurse practitioner' is not generally used, but there is clear evidence that community nurses in these countries fulfil the criteria necessary to claim this title. Experienced and expert nurses are permitted to make autonomous decisions, providing they are in full possession of the facts. Most of the skills and knowledge demonstrated by nurse practitioners in the UK are shared by their Scandinavian counterparts. However, in Finland, nurses are not permitted to prescribe drugs of any kind, neither are they supposed to give contraceptive advice. In reality, it seems that most will give informal advice at the request of a patient providing the circumstances are appropriate. In Greece, there is no current provision for the role of nurse practitioner, although there is no doubt that community nurses have a much more significant role than in previous decades.

Examples of the expanding role of the nurse can be seen in the mobile blood donation units which are organized and administered by experienced nurses.

Competence

Unless there is specific statutory legislation which requires a particular professional to carry out certain activities, there is considerable freedom for the development of skills which cross traditional lines of professional demarcation. The current emphasis in nursing is placed upon skills, knowledge and competence. However, Hunt and Wainwright (1994) ask, 'how do nurses know when they are competent, how does the employer determine the competence of an individual employee and how do the profession and the law courts determine competence?'

The problem of defining competence is one that appears to tax the nursing profession in each country under discussion. In common with the UK, the ethical issues surrounding incompetence are ones which are commonly debated in Finland, Sweden and Greece. All seem to agree that incompetence is evident on rare occasions, not only among the nursing profession but also within medicine and the professions allied to medicine. The problem it seems is not in identifying the incompetent practitioner, but is in the immediate 'closed door policy' which accompanies such an occurrence. In each country it is claimed that any investigation into incompetence is usually instigated as the result of a complaint by patients, or their relatives. Interviewing witnesses and collecting written evidence against an individual are fraught with difficulties because professional colleagues perceive their participation as disloyalty. In all four countries, there is a national Central Registration system. If a qualified nurse is removed from the Register, then theoretically, it should not be possible for him or her to gain employment as a qualified practitioner, although there is a suggestion that in Greece, some nurses work in private clinics after dismissal from the national health service. The general position in Greece, however, is that if a nurse does not perform his or her duties competently, the Administrative Council is informed and after due consideration, will decide the penalty that the nurse should pay.

Conclusion

In conclusion, the different approaches to ethical issues in the four countries described indicate the breadth of the area with which community nursing ethics is concerned. All community nurses and health visitors must practise their professions with due regard to the ethical principles which govern them, as well as in accordance with local policies, protocols and the law.

There can be no doubt that the 1990s is a period of enormous change in the organization and delivery of health care in the UK, Greece, Finland and Sweden. There has been a reduction in the length of hospital stays, a dramatic increase in the demand for community care and the boundaries, not only between health and social care, but also between the various professions involved, are being redrawn. There is also increased pressure to demonstrate consumer-orientated cost and clinically effective care within a competitive market.

The WHO regards the development of primary health care as one of the key elements in achieving 'Health for All' (WHO, 1995). The underlying principle is to provide an effective and efficient first-level contact for all families and individuals, near or in their own homes. However, the provision of care in the community is complex. There is a need for comprehensive liaison and collaboration between the hospital, community and social services for many age groups and conditions. Community nurses in all countries need to be aware of the influences of social, economical, political and ethical factors which may not be fully apparent in hospital. As the community health care setting has changed and continues to change, it is important that ethical concerns are identified and confronted in order to promote best practice and high-quality patient care.

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6

Ethical Issues in Maternity Care

Helen Crafter and Cathy Rowan

Introduction

This chapter will address some of the ethical issues in the delivery of maternity services which may have long-term repercussions on the health of women, children and families. In particular, attention is given to fetal screening tests and the issues surrounding the autonomy of both women and midwives during the process of birth. The role of the midwife in the United Kingdom (UK), Italy and Iceland will also be explored. Although the UK and Italy are in the European Union, maternity and midwifery practice in the two countries differ considerably. Iceland is not a member state of the European Union, but is a member of the European Free Trade Association (EFTA) which gives Icelanders the same freedom of movement as members of the European Union. Consequently, the education and training of midwives in Iceland comply with the EU Midwives Directives (see Appendix 1). The similarities and differences in maternity practices will be considered and salient points drawn together.

The ethical issues under scrutiny

The ethical issues surrounding birth have major repercussions for the world as a whole. As all of us are born and have, at least, a biological mother and father, so issues in pregnancy and

birth are also pertinent to men. Half of the world's population are women and most women will give birth or be closely related to someone who does. The control a woman (and her partner) have over their lives, especially at such a monumental time as the birth of a child, must surely influence their feelings about themselves, their children and the world in which their children will grow, develop and perhaps raise their own families.

Fetal screening

Fetal screening tests are now routinely offered to women in Western Europe. The commonest are those for Down's syndrome and neural tube defects such as spina bifida and anencephaly. Many countries in the Mediterranean region or those with multicultural populations also offer haemoglobinopathy screening, particularly for thalassaemia or sickle cell disease, by offering blood tests to the parents.

Screening for fetal abnormalities is non-diagnostic but offers parents a risk ratio on which to consider whether they wish to proceed to more invasive diagnostic fetal tests such as amniocentesis. Probably the most widely used screening test throughout Europe is ultrasound scanning. It may be used to measure nuchal translucency (a measurement taken in the fetal neck region) and together with the fetal size and mother's age, can give a risk ratio for Down's syndrome at approximately 10–14 weeks of gestation. At present nuchal marker scanning will detect from 33 per cent (Nicolaidis *et al.*, 1994) to 86 per cent (Bewley *et al.*, 1995) of fetuses with Down's syndrome. To a large extent, the reliability of the test depends upon the skill and experience of the operator and the quality of equipment available. Slightly later in the pregnancy ultrasound may be used to detect cardiac defects and duodenal atresia, both of which are associated with Down's syndrome. Approximately 40 per cent of babies with this abnormality have a cardiac malformation (Simpson, 1997a, p. 882) and 30 per cent of cases of duodenal atresia are associated with the condition (Simpson, 1997b, p. 914). Ultrasound scans therefore may be regarded as an ongoing screening process for Down's syndrome during the pregnancy.

Maternal serum screening for Down's syndrome calculates risk using a number of biochemical markers, most commonly alpha-fetoprotein (AFP), human gonadotrophin and unconjugated oestriols. The test is carried out between the 14th and 21st gestational weeks and, according to one UK study, will detect approximately 66 per cent of fetuses with Down's syndrome (North Thames West Region Institute for Medical Research, 1995). A risk of 1 in 250 or greater is regarded as 'screen positive' and the mother is likely to be offered a diagnostic amniocentesis. However, the actual odds of those with a positive screen result carrying an affected fetus is only 1 in 43 (Wald *et al.*, 1992). This suggests not only that there are a great many women who are left feeling anxious, but also a large number of amniocenteses are performed on the basis of an unreliable screening test. Furthermore, approximately 33 per cent of affected fetuses will be missed altogether following maternal serum screening, and even following excellent counselling, some couples may feel falsely confident that their unborn child is unaffected.

Alpha-fetoprotein screening for open neural tube defects has largely been abandoned in Western Europe in favour of diagnostic ultrasound scanning, which enables visualization of the abnormality. The AFP test performed at 16 to 18 weeks of gestation measures the protein which escapes from an open neural tube defect in the fetal spine or brain into the mother's bloodstream. A UK study (UK Collaborative Study on Alpha-fetoprotein in Relation to Neural Tube Defects, 1977) demonstrated that the test could detect 88 per cent of cases of anencephaly and 79 per cent of cases of open neural tube defect. However, it has been calculated that for every 15 women having an elevated alpha-fetoprotein level, only one will be carrying a fetus with a neural tube defect (Simpson, 1996, p. 225). Like the maternal serum screening test for Down's syndrome, the anxiety experienced by the large number of women who are given a false positive result can only be imagined.

'Haemoglobinopathy' refers to inherited abnormalities of haemoglobin in the red blood cells. In Europe the commonest of these are sickle cell disease and thalassaemia. Screening is again performed by parental blood testing if the mother carries the affected genes, so that the risk ratio for the fetus can be calculated. Sickle cell disease is seen mainly in people of African,

Caribbean, Mediterranean, Middle Eastern or Asian Indian origin, and thalassaemia in those of Mediterranean, Middle Eastern or South East Asian origin (Boyle, 1994). The practice of 'routine' haemoglobinopathy screening is growing throughout Europe, however, in response to inter-racial parenting and mass population movement.

Although fetal screening tests have been widely accepted as a positive move in antenatal care in many countries, their use confronts parents and health professionals with major ethical dilemmas. In their acceptance of screening tests, parents often see their purpose as confirming normality, whereas in the medical literature, doctors write of 'opportunities to investigate unborn babies for possible handicap' and 'identifying abnormalities early enough in pregnancy for termination to be feasible' (Whelton, 1990, p. 504). These incompatible objectives offer us some insight into the horror for the parents in being told that their risk ratio is higher than average and further tests, which will place their potentially normal child at risk (amniocentesis for instance carries a 1 per cent risk of miscarriage) should be considered.

The issue of informed choice in such circumstances is of great concern and it seems reasonable to ask, 'How can parents best be offered informed choice when they have little or no experience of children with the disability that their unborn child is being screened for?' This question is one of the hardest with which midwives and other health professionals at the sharp end of clinical practice have to deal. Even if a 'screen positive' result is followed up by diagnostic testing, the degree of affliction or disability often cannot be ascertained, especially in cases involving mental capacity.

There are also major concerns about the information and counselling available to parents prior to testing, especially bearing in mind that tests are usually offered at a time when the parents are still celebrating their luck at having conceived. Offering too little information may leave the parents unable to make an informed decision and in great shock if they screen positive. Too much information may frighten them into believing that the health professional considers them to be at additional risk. Either scenario may have negative repercussions on the parents' feelings of bonding with their unborn child

or on their relationship with the health professionals involved in their care.

Women's right to autonomy

During labour and childbirth European women are also subjected to various routines, preferences and practices performed by health professionals in the name of 'safety', although these are often untested. These practices may be far removed from the admirable objectives of respecting women's choices and their right to self-determination and balancing these aims with the demands of evidence-based practice which is sensitive to women's needs and wishes. The publication of *Effective Care in Pregnancy and Childbirth* (Chalmers *et al.*, 1989) brought together the best of the systematic reviews into childbirth practices and makes salient reading for those of us who have subjected women to such unnecessary and unkind indignities as shaving pubic hair, having enemas while in labour and failing to provide continuity of care during pregnancy and childbirth.

Although evidence-based practice is a vital building block for safe and effective maternity care, it must take into account the psycho-social issues related to birth, as well as the rather dry and aloof results of randomized controlled trials which rarely take account of the individual needs of women and their families during the process of giving birth. Central to the debate surrounding evidence-based, humane childbirth are the issues of respect for women's autonomy and the degree of decision-making allowed her by the system in which she gives birth. An interesting measure of such autonomy is the extent to which women are given a choice about the place in which they give birth. In particular, the desire to deliver in the family home is one of the many important indications of who controls birth within a country's maternity service. In many European countries women have little choice in relation to the place of birth but are expected to comply with others' decisions about this fundamental aspect of the birth process.

The role of the midwife in Europe

Although the activities of a midwife, wherever she happens to reside, always involve caring for women and new-born infants at around the time of birth, the amount of responsibility held by midwives is largely determined by social tradition and the involvement of other professionals, particularly doctors, in maternity care.

Historically in Europe up until the seventeenth century, midwives, qualified only by their personal experience of birth, were the primary attendants. Doctors became increasingly involved after the industrial revolution and today an uneasy professional relationship exists between doctors and midwives as to the nature of their respective roles and where the boundaries of their respective professional activities meet.

When studying childbearing and early child-rearing practices in Europe it is readily apparent that the status of women in society and the role of the midwife are closely linked. Where childbirth is firmly under the control of doctors, so too is the practice of midwifery. The medical professional may also control the education of midwives, removing a powerful instrument through which midwifery can develop its own ethic and professionalism. In such countries pregnancy is treated in much the same way as illness. For example, a doctor's presence is considered necessary for antenatal care, the aim of 'care' is to diagnose abnormality and the woman's views are not highly valued in decisions about care management. Birth is conducted in hospital, the administration of drugs to the mother is commonplace, movement in labour is restricted and practices such as episiotomy and caesarean section are widespread. In countries where midwives have secured a more autonomous role, pregnancy is more likely to be viewed and treated as a normal life event. Antenatal care commonly takes place in the community under the jurisdiction of the midwife, the woman's psycho-social well-being is seen as important as her physical well-being and mechanisms are in place for women to give birth at home if they so wish.

However, even within the European Union where directives exist to protect women by formalizing the rules governing the

practice of midwifery, their interpretation leads to a wide variation in the degree of professional autonomy which midwives possess. The European Midwives Liaison Committee (EMLC) (1996) produced a report of a study of the activities, responsibilities and independence of midwives in the 12 countries that were members of the European Union when the study began in the late 1980s. It was based on 3857 completed questionnaires received from chief midwives and midwives in clinical practice from nine European countries (Belgium, Denmark, France, Germany, Greece, the Netherlands, Ireland, Luxembourg and the United Kingdom.) No chief midwives in Italy, Portugal or Spain responded to the questionnaires and so the final report in its referral to these countries relied on data supplied by the few individual midwives who responded. This no doubt has a considerable effect on the reliability of the findings for those three countries.

The study gives a broad, if limited, picture of midwifery practice in Europe. Midwives appearing to have the greatest freedom and autonomy in decision-making were those in the Netherlands, France, Denmark and the UK, while those having the least were found in Belgium, Greece, Luxembourg and Portugal.

Considering that all midwifery practice in countries belonging to the European Union (EU) is controlled by the same European Economic Community (EEC) legislation (see Appendix), the existence of such wide variations in practice must have a complex multifactorial explanation, which is rooted in historical, cultural and political differences within each of the countries.

The value placed on women's autonomy

In the literature search which formed much of the background to preparing this chapter, the variations in midwifery practice, even in those countries governed by the EEC's Midwifery Directives, were staggering. Reading and hearing about women's expectations and experiences of maternity services proved equally enlightening, if somewhat disturbing. Some countries have well-established pressure groups, such as the National Childbirth Trust in the UK, while in other countries resigna-

tion, along with an almost complete trust of the medical model of childbirth, was apparent.

It is difficult to completely disentangle why and how countries, and even areas within them, acquire the maternity structures that exist. Is it because women truly do not care about how they give birth, so long as they and the baby are healthy? Is it because midwives by tradition are professionally weak, or is it because the medical profession is so much stronger? How is it that the psycho-social issues surrounding this most powerful emotional event are so often lost in the race to produce perfect children, at the perfect time, in a room full of strangers, who are more preoccupied with the latest technology than the woman's emotional well-being?

It is in the interests of humanity that children are born to women who are confident in their ability to carry, give birth to and nurture their infants. This is best achieved by listening to women and respecting their preferences in relation to pregnancy and the birth process, and also by not treating them like children by removing their responsibility and decision-making capacity at this sensitive time. All European countries are still recovering, to some degree, from the subordination of midwives to doctors which has been part of a general pattern of the medicalization of childbirth in which women are the recipients of maternity care, rather than active participants within it. To expect a labouring woman to submit to the so-called superior knowledge, expertise and whims of a professional group, most of whom have not experienced birth and motherhood themselves and then emerge as an assured and competent mother, is neither rational nor logical.

However, the autonomy of women during their childbearing and child-rearing periods is not a simple concept. Some women appear to be 'willing patients', happy to undertake whatever procedures their carers recommend for them. Some believe that safety is gained through technology and medical input and they expect these beliefs to be respected. Autonomy for women must begin well before they first become pregnant as truly informed choice is only available to women who are receptive to a broad range of information which acknowledges and deals with psycho-social, emotional and spiritual needs as well as physical ones. Women are, all after, products of their own cultural

background and they continue to be influenced by these values throughout their whole lives.

The value placed on midwives' autonomy

But why should midwives be autonomous? Is it not safer for doctors to oversee the care of pregnant and labouring women and the training of midwives for that matter? Is it not safer to give birth in hospitals with access to emergency equipment in case things suddenly and unexpectedly go wrong?

There is increasing evidence from Europe and elsewhere that autonomous midwives who control their professional practice offer as safe an option for women and babies (Campbell and Macfarlane, 1994) or a safer one (Tew, 1995), as that offered when maternity services are overseen by doctors. Autonomous midwives also provide a service that leaves women more satisfied with the birth experience (Poulengeris and Flint, 1987; McCourt and Page, 1996). No-one would wish to deprive women of obstetric, anaesthetic and paediatric expertise where it is beneficial but, in the words of the Expert Maternity Group established in England by the Department of Health (1993):

A woman with an uncomplicated pregnancy should, if she wishes, be able to book with a midwife as the lead professional for the entire episode of care including delivery at a general hospital (p. 18)... The part which the midwife plays in maternity care should make full use of all her skills and knowledge, and reflect the full role for which she has been trained (p. 39)... The knowledge and skills of the obstetrician should be used primarily to provide advice, support and expertise for those women who have complicated pregnancies (p. 41).

The group also reinforced the finding of a Select Health Committee which reported in 1992:

On the basis of what we have heard, this committee must draw the conclusion that the policy of encouraging all women to give birth in hospitals cannot be justified on grounds of safety (p. 1).

At home births in Europe the midwife is necessarily the lead professional as the birth tends to be uncomplicated and a doctor,

if present, is at risk of being called away to a patient with a medical ailment. The midwife working within the EU is duty bound to stay with the woman for the birth and the period immediately afterwards. It is difficult to imagine how a health worker who has not been entrusted with autonomy could effectively conduct a birth at home ensuring the safety, as well as the emotional well-being, of the family. The practice of Dutch midwives who are some of the most autonomous in Europe may be used here to demonstrate the value of midwives being the lead health care professional at the time of a birth. In Holland, approximately one-third of all births occur in the home yet the perinatal mortality rate is among the lowest in the world (Campbell and Macfarlane, 1994, p. 38). Indeed, a large Dutch study into 'place of birth' has demonstrated that for women having a first baby with a low-risk pregnancy, home birth is as safe an option as hospital birth. The same study also found that for multiparous women with a low-risk pregnancy, home birth was significantly safer than giving birth in hospital (Wiegers *et al.*, 1996). This finding, however, should be set alongside the activities of Dutch midwives who attend an extraordinarily high number of home births compared to midwives in the rest of Western Europe and who are, by experience therefore, extremely competent in dealing with births which occur in women's homes.

Ethical issues in maternity practices in the UK, Italy and Iceland

The EMLC (1996) reported through their survey of midwifery practice that UK midwives have a relatively higher level of autonomy than some of their European counterparts and Italian midwives less so. Icelandic midwives, while not in the EU, are governed by their midwifery rules, and practice is similar to that seen in the UK. Maternity services in Iceland, however, have not received the same governmental backing as those in the UK and concerns exist that the medicalization of childbirth in some areas is increasing rather than abating.

The United Kingdom

Health authorities vary throughout the United Kingdom with regard to the screening tests which may be offered to women. In some areas AFP screening is still routinely offered, while in others this has been replaced by diagnostic ultrasound scanning for open neural tube defects and anencephaly at 16–22 weeks of gestation. Unless a woman chooses private health care through an obstetrician or independent midwife all her maternity care, including screening tests, are paid for through the National Health Service (NHS). However, before its widespread introduction, some health authorities required women wishing to have the maternal serum screening test to pay for it. Part of the midwife's role is to inform women about the advantages and disadvantages of screening tests in an unbiased and non-judgemental way, as well as to support them by listening and providing further information once they have made a decision about availing themselves of the tests. Professional counsellors who may or may not be midwives are also available in some maternity units, particularly to support women who have screened positive and are considering the implications of the results.

The Midwives Information and Resource Service (MIDIRS) together with the NHS Centre for Reviews and Dissemination have recently produced a number of easily readable and understandable leaflets on 'Informed Choice' which provide information for women and health professionals based on the best available research evidence. Unfortunately these leaflets are only available in the English language and their dissemination is dependent upon health authorities purchasing them. To date, however, MIDIRS and the NHS Centre for Reviews and Dissemination have been delighted with the sales to NHS trusts (Rosser, 1996).

In the UK it is common, but by no means universal practice, for women to receive the majority of their antenatal care from a small team of midwives known to them by the time they go into labour. A guideline for future practice in the Department of Health *Changing Childbirth* report (1993) recommended that, by the year 1998, at least 75 per cent of women should know the midwife who delivers them. It seems unlikely,

however, that this recommendation will be reached despite enormous changes to the regional organization of the maternity services (Mayes, 1997). One reason why it will not be achieved is the huge demand on NHS resources which cannot be met in the UK.

Almost all births take place in hospital but a further recommendation of the *Changing Childbirth* report (DoH, 1993) that women should receive clear, unbiased information and be able to choose where they would like their baby to be born may have paved the way for an increase in home births over the next decade as women and midwives strive to rekindle their confidence in choosing and attending home births.

Birth practices in the UK are far from being completely 'woman centred'. It is still common to see obstetricians patrolling delivery suites and managing childbirth as they would a medical ailment, even where women have a clearly written birth plan requesting minimal intervention and a midwife is competently attending the woman in a way that they both find acceptable. Induction of labour before 42 weeks of gestation in normal pregnancy and arbitrary limitation of the duration of the second stage of labour by performing an operative delivery are still not unusual procedures despite being listed as 'forms of care that should be abandoned in the light of the available evidence' (Chalmers *et al.*, 1989, p. 1477).

The education of student midwives is under the control of the profession but the recent move of departments of midwifery education into higher education, invariably into faculties of nursing, has meant that they are often headed by nurses. All midwifery training establishments must have an 'Approved Midwife Teacher' who formally leads the midwifery programmes, so that the departmental or faculty heads (nurses) tend to fulfil a purely administrative role. Midwives are educated to either diploma or degree level for three to four years. Alternatively, if they are already in possession of a registered general nurse qualification, they can gain a midwifery qualification in 18 months.

Italy

The Italian fertility rate is now among the lowest in the world (Council of Europe, 1996, p. 187). The fall began in the 1970s and in 1993 (the latest figure available) the total fertility rate was equal to 1.26 children per woman, giving a crude birth rate of 9.6 live births per 1000 average population (this may be compared to 17.5 for Iceland and 13.1 for the UK for 1993 [p. 41]). As well as having fewer children, couples are also bearing them at a relatively older age. This seems surprising in a country renowned for its large Catholic following, although it may be explained by Italy's recent modernization resulting in many more women working outside the home. This would not have been possible without access to contraception and the ability to plan a family to fit in with working practice. Although seen as desirable, children place enormous pressure on Italy's nuclear, urban families. The state provides little in the way of child support and child care facilities for working mothers and, as consumerism grows, couples choose to expand their luxury possessions rather than their families (Gumbel, 1997).

Despite the improving social status of women in modern Italy, pregnancy and birth are still heavily controlled by doctors. Fetal screening tests are commonplace and although a national health care system is in place, women pay extra for each test that they have. Ultrasound scanning tends to be offered (and unfailingly accepted) at 12, 20 and 34 weeks of gestation, and sometimes more frequently, to check for fetal viability, abnormalities and growth. Screening for neural tube defects and for Down's syndrome for women over 35 years of age is generally available.

On the Italian island of Sardinia, thalassaemia major is a common inherited disorder with a carrier frequency of 12.6 per cent, which means that one couple in every 60 is at risk of having an affected child. The incidence of the disease among new-born babies is 1 in 250 births (Cao, 1993). The condition has no cure and consequently a programme based on carrier screening, genetic counselling and prenatal diagnosis has commenced. Voluntary screening is offered to young unmarried adults, prospective parents and to couples where the woman is pregnant. Counselling is reported to be carried out according

to internationally accepted guidelines. A large majority of women accept the prenatal diagnosis which is generally very accurate and many opt for termination rather than give birth to a child with a severely limited quality of life and lifespan.

Care and procedures for labour and birth differ greatly in Italian hospitals and birth is often supervised by doctors. Pain relief is rarely administered as the pain of labour is said to be a normal expectation for Italian women. Many hospitals offer muscle relaxants such as hyoscine in early labour and a few hospitals offer epidural analgesia, especially where a resident doctor has recently studied its administration abroad. Inhalational analgesia such as nitrous oxide 50 per cent and oxygen 50 per cent (commonly known under its trade name of 'Entonox' in the UK) is not used and pethidine and other narcotics are not readily available (Fracassi, 1997; Prevedello, 1997).

In 1984, Morrin reported on an observational visit to a maternity hospital near Rome. The labour rooms were communal and procedures such as vaginal examinations were performed with little privacy. Women laboured in a horizontal position and when full dilation of the cervix was diagnosed, the women were moved to their own room and instructed to bear down. A doctor was always present for the birth, episiotomy was used liberally and the infants were delivered by fundal pressure. These procedures are still practised in some parts of Italy (Fracassi, 1997; Prevedello, 1997). In some areas, particularly Tuscany, there is a more liberal approach towards birthing practices. Some hospitals have 'natural birth rooms' which are popular because women can walk around freely. In the maternity unit at Poggibonsi episiotomies are not performed unless strictly necessary and the midwife is responsible for the entire course of labour. Women's partners remain with them and the new-born baby is placed on the mother's abdomen, where the cord is cut only after it has stopped pulsating (Brunetti, 1993).

In theory Italian women have the right to home birth, but in much of the country the mechanisms are not in place for this to be a realistic possibility. Independent midwives exist and are cheaper to consult than their British counterparts. Their numbers appear to be growing as Italian midwives become increasingly concerned about their role in hospital births.

One of the reasons why birth is so medicalized in some parts of Italy may be explained by the role which doctors play in midwifery education. After two years in nurse education, student midwives study for another two years to qualify as a midwife. Throughout the country the midwifery programme is run by doctors who are involved in both developing and teaching the curriculum. The liberal use of episiotomy and delivery by fundal pressure are two major components of the programme and students may not see a physiologically normal birth throughout their whole period of training (Frasca, 1997; Prevedello, 1997). The EMLC Report (1996) expressed concern about the deficient exposure of some student midwives to the full range of activities described in the EEC Directives and the implications for the ability of midwives trained in Italy to assume responsibility for the care of pregnant women, as required by EC statute. The problems of midwifery practice in Italy are compounded by the lack of an independent and competent midwifery authority for the country.

Iceland

In Iceland midwives are trained to an advanced clinical and theoretical level and on completion of their education are awarded both an educational certificate and a professional qualification. Since 1982 a nursing degree has been the level of entry. Eight midwives graduate a year from the 18-month midwifery programme at the University of Iceland which has been running in Reykjavik since January 1996. With the transfer of the programme to the university, midwives, for the first time, gained full control of their midwifery curriculum when a midwife was appointed as the Director of Midwifery Studies. Until this time the post had been held by a doctor (Olafsdottir, 1996). On qualification those who choose to practise midwifery join a workforce of 236 midwives who are involved in the 4500 births a year, two-thirds of which take place at the University Hospital of Iceland in Reykjavik.

Midwives attend almost all pregnant women although most also see a doctor on a few occasions, even when the pregnancy is uncomplicated. Most obstetricians and general practitioners

still insist on seeing women at every antenatal visit and some women choose this medical approach to their care. The usual venue for antenatal care is in hospitals or health centres. There is no routine provision for antenatal care in women's homes. In many hospitals midwives perform and are responsible for routine ultrasonography which is offered to all women at 19 weeks' gestation. The midwives' role includes the provision of explanations and counselling. If a fetal abnormality is suspected on the scan the midwife cannot make a diagnosis or pass her concerns on to the woman. She must refer the woman to a specialist for a second opinion. AFP screening is offered to women who have a family history of spina bifida and those who request it, but it is not performed routinely. The test has, to a large extent, been superseded by diagnostic ultrasound imaging of the fetal spine and brain. The University Hospital of Iceland is likely to start offering maternal serum screening to women from the end of 1997 (Gottfredsdottir, 1997; Olafsdottir, 1997). In addition, women who reach their 35th birthday before the baby's due date are offered diagnostic amniocentesis at 14–16 weeks of gestation.

Iceland has a history of offering 'low risk' women birth centre care, which is characterized by a home-like environment and care by a small team of midwives. Such a birth centre existed in Reykjavik from 1960 to 1995, when, according to the media, it was closed for 'economic reasons'. The delivery rate at the centre declined rapidly following the opening of a large, high risk delivery unit in the University Hospital two miles away. This unit incorporated a birth unit staffed by six midwives with doctors only attending women when problems arise (Sigurdardottir *et al.*, 1996). The closure of the outlying birth centre where doctors had to travel the two miles to attend women and the setting up of the birth unit within the University Hospital have placed midwife-led care closer to medical jurisdiction and made the birth unit more vulnerable to hospital culture than was the community-based birth centre. There are also professional concerns from midwives about the effect that such proximity to medical involvement may have and the implications of this for the empowerment of women and midwives (Gottfredsdottir, 1997; Olafsdottir, 1997).

Continuity of carer schemes are not common and the prevailing policy is to centralize all maternity care. At the University Hospital where the majority of the country's births take place, midwives are department based rather than case-load based so that most women receive care from different midwives in pregnancy, labour and then postnatally.

Home birth is rare in Iceland. There are about 8–10 per year conducted by one midwife who offers these women care in labour and the post-partum period. Sometimes another midwife assists at the actual birth. The primary midwife stays with the woman booked for home birth if she requires transfer to hospital during labour. She has a contract with the state and like all Icelandic midwives is entitled to offer home birth and postnatal care and to claim expenses through the government health insurance system (Gottfredsdottir, 1997; Olafsdottir, 1997). The centralization of birth into hospitals has been the same in Iceland as in many European countries in recent times and the associated influence of a dominant medical profession in this shifting of childbirth from home into hospital has resulted in a transfer of decision-making about the birth process from both women and midwives alike.

The midwife is the leading professional for all normal births in Iceland and, as in most of Europe, doctors are readily available should medical assistance be necessary. In common with much of Europe and the United States, the normal delivery rate is slowly declining and caesarean and epidural analgesia rates are increasing in Iceland (Olafsdottir and Gottfredsdottir, 1996).

Conclusion

In Europe, women's experiences of childbearing are varied and they appear to depend, to a large extent, on the history of the health care professions, cultural preferences and political developments. The social status of women and the role of the midwife share many similarities and, where women are not encouraged to be active participants in decision-making, the role of the midwife also tends to be seen as subordinate to the medical profession.

Fetal screening tests are available in the UK, Italy and Iceland but who they are offered to and how women and couples are informed about their advantages and limitations varies considerably. In the UK screening tests are offered to almost all women and there is a move towards exploring how women can be provided with genuinely informed choices. In Italy screening and diagnostic testing are very popular especially in the large northern cities. The quality of information with which women are provided is, however, variable. The idea of 'counselling' in relation to such tests has different connotations from those that exist in the UK, with Italian counselling being more directive (Fracassi, 1997; Prevedello, 1997). In Iceland fetal screening tests, other than an ultrasound scan at 19 weeks of gestation and amniocentesis for women over 35 years of age, are not routinely offered, although maternal serum screening may be introduced in 1997/98.

Women's experiences of labour and birth are also diverse in Europe, despite the existence of EEC Midwives Directives designed to bring the activities of midwives into line across the European Union. Medical domination is apparent in all three countries in various ways. In Italy doctors preside over normal births in some maternity units and dictate that babies should be delivered by fundal pressure following the routine performance of an episiotomy, whereas this degree of intervention is not seen in the UK or Iceland. The mechanisms for home birth are in place in some areas of each country but the practice is not common and medical resistance continues. This is despite the support for women to have a home birth if they so wish, by governmental health departments, particularly in the UK and Iceland. As the evidence to refute the safety of home birth simply does not exist (Campbell and Macfarlane, 1994), the motivation of the medical profession to maintain control over normal birth must be questioned on the basis of whose interests are being served.

In our conversations with midwives from Italy and Iceland in the preparation of this chapter, we discussed the existence and role of women's groups in providing a supportive voice for the right to self-determination and a reduction in routine medical intervention in physiologically normal pregnancy and birth. The National Childbirth Trust in the UK provides a strong

voice in commenting on these issues and it provided a sustained input during the compilation of the Department of Health (1993) *Changing Childbirth* report. However, our European colleagues explained that such pressure groups barely exist in Italy and Iceland. A group of women had attempted to keep the birth centre in Reykjavik open in the early 1990s, calling themselves the 'Children of Nature', but when the centre was closed despite their protest, the group disbanded. It is not clear why countries should have such varying experiences of pressure groups, but it may be that Italian and Icelandic women are more trusting of the medical profession, or less concerned about the psycho-social atmosphere in which they give birth.

Evidence-based practice too receives variable attention in different corners of Europe. The UK has a strong history of producing research and, as in the USA and Canada, there has been a strong push in recent decades to systematically review the available evidence and incorporate it into clinical practice. With the aim of developing practice that is known to increase good and reduce harm, it is likely that evidence-based care will spread throughout Europe resulting in many of the outdated and harmful practices being eventually eliminated. However, the vested interests of all health professionals must be put aside for this to happen and those of women and their families must finally be placed centre stage.

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7

Children, Rights and Nursing Concerns

Gosia Brykczynska

Introduction

Moral rights

Although philosophers have been commenting on matters of morality for several thousand years, it is only within the last few hundred years that a clear philosophical argument has been developed around the concept of moral rights. Writings on the nature of moral rights, what they are, who can lay claim to them, whom they benefit and what difference their existence makes to social morality – have been the preoccupation of Western philosophy since the time of John Locke (1632–1704). As Almond (1991) notes, although ‘of comparatively recent vintage linguistically, rights belong to a tradition of ethical reasoning which goes back to antiquity. In relation to this tradition the overtones of the notion are legal rather than ethical.’ Needless to say, this interest in rights, be they human, civil, political or social, is neither the sole prerogative of moral philosophers nor their sole interest. The literature on universal human rights has a long and fascinating history, the roots of which can be traced back to the doctrine of natural law, although it is only relatively recently that the rhetoric concerning rights and the popular understanding of them has entered the public domain. Today, therefore, it is not unusual to hear quite unso-

phisticated individuals demanding 'their rights' to parenthood, better housing, sovereignty and such like (Lumpp, 1982; Hart, 1984 [1967]). The fundamental questions remain, however: 'what are rights?', 'what do we mean by fundamental rights?', 'how do they impinge on health care?' and 'can a unique category of people, namely children, lay a particular claim to special rights?' This chapter will attempt to address these issues, within the context of paediatric nursing in Europe.

Rights have been varyingly described as claims that demand respect. Some rights demand more respect than others, such as the right to life, but even this seemingly obvious and uncontentious right is surrounded with qualifying clauses and commentaries. All humans can lay a claim to the right to live, providing, for instance, that they are already living, or that they have not forfeited that right by committing a capital offence, or that they are not deemed to be living in a state which is itself incompatible with life and so on. If the 'right to life' is potentially as problematic as this, it is not difficult to imagine that many other rights of presumably lesser significance will be even more contentious. Any reasonable definition of a right, or rights, needs to acknowledge the relative nature of any set of rights. The definition of a right as a claim that demands respect, while fairly basic and therefore quite useful, has of course the in-built limitation that it does not accord that right any obvious hierarchical standing or make clear the extent or limit of the respect due. Historically, rights were seen and considered as personal or political claims concerning one's freedom (that is, autonomy) which demands the respect of an autocratic ruler. Such an approach was taken in the writings of John Locke (Waldron, 1984).

The first philosophers writing about human rights were, for the most part, concerned with what today would be referred to as political and social rights. They were not particularly concerned with all people, that is, all of humanity, but rather the specific rights of a certain set of people, nor were they particularly concerned that their theories about claims that deserve respect were limited and narrow. Nonetheless, there is a direct line of philosophical argument concerning rights which stems initially from the political philosophies of David Hume and John Locke, through the French and American writers, such as Jean

Jacques Rousseau and Benjamin Franklin, all of whom influenced the course of American and French philosophical history, down to the present day. As a result of this historical legacy, both France and the United States of America, even today, see themselves as custodians and inheritors of the notion of human rights, even though, in recent times, neither country has produced significant new contributions to the philosophical debate on rights. In keeping with the rest of contemporary Western society, these countries are, however, concerned with the implementation of various rights. In the case of the United States of America, while it has a history of producing Charters and Bills of Rights (both specific and general), it has paradoxically a less illustrious history of implementing these rights. The widespread impact of the unprecedented violations of human rights which occurred during the Second World War led to the signing of the United Nations' Declaration of Human Rights in 1948.

The rights in which we are interested as health care workers are those that demand respect in relation to promoting, restoring and maintaining health. Additionally, in paediatric nursing and child health care, these claims will be child centred. Beauchamp and Childress in their highly influential textbook on biomedical ethics (1989) make the additional qualification with regard to rights, that they are justifiable claims. They point out that 'A right is thus analogous to property over which one has control, so that rights contrast with privileges, personal ideals, optional acts of charity, and the like (p. 56).

Health care rights

In the context of health care, one of the most fundamental rights to which a person can lay a justifiable claim, is the right to personal involvement in treatment – otherwise known as a right to autonomous decision-making about one's care, or at least a fairly shared decision-making process and some involvement (Brazier and Lobjoit, 1991; Kultgen, 1995). This right tends to take precedence over other related health care rights because most other rights, such as the right to a particular type of treatment or medical intervention, can be seen as a

form of personal ideal such as the right to bear children, or the right to an organ transplant. The inherent problem with the rights debate is that one person's right is another person's ideal, fancy or act of charity. Rights, therefore, tend to be seen as having *prima facie* considerations, that is, they are only morally binding if no other, more pressing, claim is evident. Similarly, health care rights are only binding insofar as a more morally binding right does not take precedence (Lumpp, 1982; Reckling, 1994). Regardless of the inherent or relative value of a rights claim, it should ideally be something over which an individual can have control or do something about, such as the example of property given by Beauchamp and Childress (1989). This distinction is important and is a source of much misunderstanding as it is nonsensical to demand respect in relation to a claim that, although justifiable in itself, cannot be ordinarily realizable, as for instance, the right to a heart transplant. One can make a justifiable claim concerning equal access to transplant services, but not that a particular organ be provided, since there is no moral or legal way of assuring a guaranteed availability of such an organ. Neither health care workers nor society generally has control over this commodity and, therefore, such a right has no realizable obligation (Emson, 1992). In effect, we have no control over the availability of organs for transplantation. It is interesting to note here that in a case concerning the demand of a leukaemic patient that his cousin be obliged to donate his bone marrow to save his life, the judge commented that although the cousin could not be forced to give his bone marrow, the fact that he refused to help his cousin said much about his lack of moral integrity. In that particular case, the judge, confirming the thinking of much of society, agreed that whereas there is no right to an organ transplantation and life-saving measures, society still has a moral obligation to facilitate life-saving measures whenever it can do so (Beauchamp and Childress, 1994, p. 192).

Health care rights are often quite complex and multifactorial because, although health and health maintenance can often be seen as a shared responsibility between an individual and society, this is not always that obvious. For example, in the case of individuals with congenital disorders, the right to health *per se* and the right to have health restored is even more

problematic. One cannot respect a claim to health *per se*, since we have limited control over matters of health and there are too many variables and unknowns at stake. We can, however, and indeed do, have a moral obligation to strive for conditions that promote health, allow individuals to stay healthy and so on (Lumpp, 1982; Hart, 1984 [1967]; Emson, 1992).

If society acknowledges, often through legislation, that certain universal rights, namely subsistence rights, such as a guaranteed access to health care facilities, the right to sufficient and appropriate food, or the right to shelter, do exist, then it is also acknowledging that, as a society, it has an obligation to intervene in respecting those rights. In other words, it has an obligation to act in a particular way. Traditionally, the correlativity of rights and obligations was such that everyone benefited from the recognition of certain basic rights and, therefore, the burden of the obligation to respect these rights served everyone's interest. Such arguments were possible, however, only in societies which acknowledged very few rights, for example, the right to vote, to own property and the right to mobility within a country. All citizens can be seen to benefit from such rights. The more a society increases its rights, however, the more likely it is that some of the rights will place burdens or obligations on citizens which are far removed from any obvious secondary benefits. Not only does this put a potential strain on the society as a whole, but members are more likely to object that the additional rights are not justifiable and, since all rights have only a *prima facie* force behind them, these additional rights will be increasingly disregarded or deemed of low significance. In effect, they will be rights on paper only because other, more universally pressing and obvious rights will be taking precedence (Ackerman, 1991). This is not merely an academic debate, conducted for the satisfaction of moral philosophers and social policy-makers, rather these are very serious limitations of the rights approach to social inequities and these same limitations seriously affect the outcome of a rights-based approach to health care ethics (Upton, 1993).

The questions must be posed, 'why engage in a rights-based approach to health care?' and 'why are the affairs of children so closely tied up with children's rights?' Traditional approaches to moral philosophy and ethical conduct tend to emphasize

the moral obligation of the agent to behave in a particular way. Whether following a deontological or consequentialist form of argument, the moral theory ultimately supports a need for increased virtue and an awareness of moral responsibility. Whereas this primary virtue-based approach is necessary for personal moral development, it does not always address the problems and needs manifest through moral injustices, moral distress and ethical dilemmas (Upton, 1993). Some problems seem to be on a large scale or dimension and a purely personal approach, represented by virtue ethics and a particular philosophical orientation, does not seem to resolve them. Some social, political and moral injustices cannot be corrected by a purely personal approach. Thus, moral philosophers commenting on social injustices arrived at the notion that certain ways of human being or human conduct are necessary for universal human happiness and that these ways of being should, therefore, be guaranteed for everyone (Hart, 1984 [1967]; Waldron, 1984). So fundamental were these self-evident truths that to violate or transgress these rights incurred much moral condemnation and, eventually, they were reinforced by legal sanctions.

Rights-based approaches to ethical issues can be seen, therefore, as generalizable forms of accepted moral norms, in circumstances where personal ethical approaches may not suffice and, even if they did, they would relegate moral conduct to the realm of optional choice (Warnock, 1992). Some moral ways of being are simply deemed too important to be left to chance. Additionally, as noted, some social and moral injustices can only be corrected by a concerted societal approach (Rawls, 1971; Leach, 1994). Thus, no one individual can assure access to health care, but a country's legislation reflecting the right of access to health care can begin to address this problem. Perhaps the simplest way to describe the two approaches is that, whereas a virtue-based ethical orientation tends to reflect personal choice, a rights-based approach reflects societal choice or preference. Personally, I may think it important to respect all individuals as best as I know how, but it is a societal norm and expectation that all citizens will be accorded the right to equal opportunities and employment policies. Such examples are not difficult to consider and all rights can be translated into classical ethical

propositions. These approaches complement each other, rather than reflect opposing perspectives.

Children's rights

So far we have discussed rights generally without considering the issue of children's rights. This is quite appropriate as the literature and arguments for children's rights stem from and owe their origin to the general movement concerning human rights. Indeed, some individuals believe that children should not be accorded separate rights as these already exist as general rights accorded to all individuals, including children. There is some merit to this argument, but because of the vulnerable status of children, most countries have felt it necessary to either accord children separate rights or at least to articulate their rights in a special place so that they are not subsumed among general rights (Archard, 1993; Alston, 1994).

The history of children's rights is closely connected with the history of childhood, that is, as the evolving concept of childhood took shape, so too did the concept of children's rights (Stainton and Stainton, 1992; Archard, 1993; Brykczynska, 1993; Matthews, 1994). First of all, however, one needs to 'see' children, before one can accord them any rights. Not only is it important to 'see' children, but one needs to appreciate children in a state of childhood before one can start to consider any rights, obligations or moral norms in respect of this rather heterogeneous group of individuals, who may be united solely by the fact that their respective governments consider them to be politically under age, that is, they are denied the right to vote. Until a few years ago, there was no global unifying definition of childhood; now with the United Nations Children's Convention, there is at least a minimal definition of a child, as an individual below the age of legal and political majority, which can vary from 17 to 21 years.

Philosophers have long considered children as incomplete adults, that is, not only as smaller versions of adults, a concept not unique to philosophy but one shared by society as a whole, but also as adults in the making. This of course is partially true, as in due course children do become adults. The inter-

esting factor about childhood, however, is not that it is a transitional stage between birth and adulthood, but that it is a fascinating time of varying length, worthy of consideration in its own right and hardly a primarily transitional phase (Matthews, 1994). Childhood needs to be experienced and lived through by children as a time appropriate for them. As such, it has intrinsic and not just relational or secondary value.

The importance of childhood cannot be overestimated, the more thoroughly childish and child-centred the childhood, the better prepared the child will be for adulthood. Commentators on childhood such as David Archard (1993), Gareth Matthews (1994) and Penelope Leach (1994) all concur that many adults, by forgetting what it was like to be a child, assume that it was an insignificant time in their life. All the child-centred evidence appears to suggest that as childhood is now and not transient for children, it is of supreme significance for them. Notwithstanding the psychological origins of childhood amnesia, the problem does remain that if being a child is such a difficult and stressful time, how come children seem to grow out of this, and forget the pain? Contemporary child psychologists, developmentalists and health care workers all point out that children do not really 'forget' the pain or joys of childhood, but rather, the trials, tribulations and activities of childhood shape and inform the moral and social integrity of the emerging adult.

Child activists claim that by not taking the child seriously, by for example, dismissing their concerns because they are fleeting and often oddly phrased to the adult's way of understanding, we are not only doing children a disfavoured, if not grave injustice, but we are also denying part of our own personal history. We were all children once, we reacted and spoke like children and we contributed to the adult world like children. Childhood amnesia may have contributed to adults forgetting about their own childhood memories, but children living today need to be accorded respect like all members of society – a respect that overrides the adult's veil of childhood memory. Fortunately, some adults manage to remember what it was like to be a child and they have a passionate interest in helping children to live fruitful and joyful childhoods. These adults are some of the most vociferous campaigners for children's rights.

One of the earliest campaigners for the recognition of children's rights was Dr Janusz Korczak. Korczak (1878–1942) was probably one of the most legendary figures to emerge from the Holocaust, barring the adolescent diary-writer, Anne Frank (Lifton, 1988). Janusz Korczak, the *nom de plume* of Doctor Henry Goldszmit, was a child psychologist, paediatrician, educator, writer (for adults and children) and above all, a believer in children. His ideas concerning children's abilities, their insights and the way we should respect and relate to them, are only now being rediscovered and promoted (Newell, 1989; Alderson, 1993; Leach, 1994). To give final witness to his trust and care for children, he chose to stay with them rather than leave them to their fate in the Warsaw ghetto and, from there, he and the children were taken to be gassed by the Nazis in 1942.

More recently, Matthews in the United States of America and Priscilla Alderson in the United Kingdom, represent concerned individuals who are striving to improve the way adults think about and treat children (Alderson, 1993; Matthews, 1994). According to Matthews, an American philosopher, children have the natural capacity to ask the obvious question and to process the most unusual or uncommon answer, an ability which adults tend to lose. A child will seriously want to know why the world is round or where words come from and steadfastly stay with the answer – as long as they can process it. Matthews' book *The Philosophy of Childhood*, like his previous study, is peppered with examples of children asking philosophical questions and energetically engaging in philosophical debate, as his wonderful discussion on the nature of the universe illustrates (Matthews, 1994, pp. 10–12). Children have the delightful capacity to appreciate explanations, process these and accommodate the answers according to their cognitive abilities. As Matthews states about himself, 'I can't remember asking myself, as a child what time is. But I did puzzle over the beginning of the world' (p. 13). This innate capacity of children to ask fundamental questions about the world in which they live is part of their richness and intellectual wealth – a treasure lost by many adults. As Matthews points out, according rights to children is not a paternalistic or parentalistic act, it is simply acknowledging the debt adults owe children. Children are not only 'takers'. Even at

an early age, children are capable of giving and delighting adults and sharing in the common heritage that is meaningful human interaction (Darbyshire, 1989; Montgomery, 1993; Worswick, 1993; Edwards, 1996).

Priscilla Alderson has long been a campaigner for increased children's rights, particularly in relation to health care. As she points out '... children in hospital have certain autonomy rights, but schools deny basic rights to their pupils and are imposing unprecedented amounts of compulsory tests and curriculum subjects on them. Parents, not children, are perceived as the consumers of education' (Alderson, 1993, p. 31). This observation, that the rights we accord to children are haphazard and in any event are there to serve adults rather than children, is a point which is highlighted by many advocates of genuine rights for children. As a teacher and mother, Alderson began her interest in children's rights and the legal aspects of their status when she was studying parental consent for surgery (Alderson, 1990). This first-hand familiarity with children, like Matthews and Korczak before him, has led these and many other children's rights' advocates to the conclusion that children need to be accorded rights because their interests are not being served by general rights, proclamations and universal laws. Also, children are demonstrating, and probably always have, more rationality and discernment than is allowed by the casual dismissal of children as immature, cognitively unstable or incapable of decision-making and reflection (Montgomery, 1993; Alston, 1994; Dimond, 1996; Hendrick, 1997).

Children's rights began to be seriously debated at the conclusion of the Second World War by the Human Rights Committee – who, in 1959, drew up the United Nation's Declaration of Children's Rights. This declaration was in force until the International Year of the Child, hosted by UNICEF in 1979. In Poland, in order to highlight his contribution to children's rights, 1978 was designated as the centenary year commemorating the work and life of Janusz Korczak. As a (then) communist country, Poland was also keen to make a public statement which would be listened to by Western powers. Thus, the Polish delegate to the United Nations (UNICEF) chose that year to call for a review of the Declaration of Children's Rights, which was neither widely known, nor had any force of

law worth speaking of. From 1979 to 1989, the new Convention of Children's Rights was drafted repeatedly until finally, on 20 November 1989, the United Nations Convention on the Rights of the Child was circulated to countries for ratification. In all, 172 countries have ratified it, the highest number of ratifications of any international human rights treaty. The United States of America was one of the last countries to sign the ratification document, the United Kingdom doing so in December 1991. The conception, wording, acceptance ratification, final declaration and launch of the Convention, at the Children's Summit in New York City in September 1990, was dogged by (adult) controversy, acrimony and infighting. Notwithstanding all of the problems contingent on the production of the Convention, it is now part of the universal heritage of all children.

The United Nations Convention on Children's Rights

The United Nations Convention on Children's Rights is a collection of 54 articles which collectively outline those rights which the universal adult world deems necessary for the maintenance of children's self-esteem and autonomy. The articles are presented in groups related to various areas of a child's life and some have more moral force behind them than others. Probably the single, greatest criticism of the Convention is that although it has the status of international law, national laws concerning children take precedence, at least in the first instance (Alston *et al.*, 1992; Rogers and Roche, 1994). In the United Kingdom, the Children's Convention informs public policy concerning children but it is the Children Act 1989 that actually guides social action and social policy. Complaints of infringements of the Children's Convention can be addressed to the Court of Human Rights in Strasbourg, as can complaints about violations of the Children Act 1989. Even before the launch of the Children's Convention, however, the Parliamentary Assembly of the Council of Europe passed a resolution in 1986, termed the *Resolution of the European Parliament on a Charter for Children in Hospital*, several points of which are

still not adhered to today (Rosenbaum and Newell, 1992). The principles, such as the right of every child to life from the moment of conception, to shelter, to be recognized as needing a nurturing environment, to protection from abuse of drugs, smoking, alcohol and such like, are still not binding in the European community, nor are they part of the 1989 Children Act in the United Kingdom (Newell, 1991). In May 1988, members of 12 European countries formalized a statement concerning children in hospital and drew up a European Charter for Children in Hospital.

Finally, the National Association for the Welfare of Children in Hospital (NAWCH) in the United Kingdom, now renamed Action for Sick Children (ASC), launched its charter concerning the rights of children in hospital. All these charters and documents, however well intended, do not have the full force of the law behind them. Therefore, should it be proven that some other more pressing issues have precedence over a claim concerning a child's rights, there is no power to change or alter this understanding (Rosenbaum and Newell, 1992). Hope for children stems from the monitoring facilities put into place by UNICEF, in relation to implementing the spirit of the United Nations Convention on Children's Rights. The first report, prepared by the monitoring task force in February 1994, severely criticized the United Kingdom government of the day for not doing enough to implement the spirit of the Convention or to publicize its articles (UNCRC, 1995).

As Brigit Dimond (1996) points out, 'even though at present they have no statutory force, the articles should be the basis of the purchase and provision of child health services' (p. 6). The rest of this chapter will focus on the four main articles of the United Nations Convention of Children's Rights which relate to health care work, and using examples from European countries, it will explore how children's rights in this area are respected and put into practice. Even *prima facie* rights have to be enforceable sometimes if they are to be considered as rights and not just pleasant sentiments or desires.

Article 12

The child has a right to express an opinion and to have that opinion taken into account, in any matter or procedure affecting the child.

This is one of the most frequently cited articles in the Children's Convention and is reflected in a similar point made in the United Kingdom's (1989) Children Act. It is difficult to appreciate just how fundamental this right is, given that adults assume that it is their prerogative to have an opinion and to voice their concerns. In fact, it could be seen as a definition of adulthood that an adult is a person who can voice his or her opinion and that this opinion will be respected. Adults do not need to refer to someone who is older or even wiser. Adults are deemed mature enough, unless proven otherwise, to state their opinions and make their own private and public choices. As Mary Warnock (1992) comments, 'one of the major factors which can inhibit our freedom and diminish our power to choose is not age or poverty, but simply the role bestowed on us by other people who wish us, puppet-like, to play the scene their way' (p. 231). According to many child developmentalists and advocates of children's rights, the reason why we do not hear what children have to say is that we accord them a voiceless role in a play where adults write the script. Since children traditionally have been considered voiceless on matters that counted, children were never consulted. Decisions were made in the best interest of the child, according to the prevailing paediatric theory at the time. Since children's opinions were not solicited, no-one knew for sure how children felt about decisions. They were, like the old adage, literally seen but not heard. This position has changed recently with the ratification of the Children's Convention. Now it is public social policy that children's views are solicited. Whether this will result in a major change in our attitude towards children it is too early to state definitely, but certainly, children are to be consulted, their opinions noted and, wherever possible, their statement of preferences appropriately acted upon.

Priscilla Alderson (1993) in her brilliant study on children's capacity to consent to surgery, notes that, 'young patients suffer double discrimination as patients and also as children. The qual-

ities attributed to adult patients: ignorance, inexperience, too much emotion, too little rationality, helpless dependence, are also attributed to childhood' (p. 9). The voice that is now given over to children is not only the frightened cry of an infant, a cry usually of meaningful protest, as Ulla Fasting (1995) the Danish paediatric nurse notes. It is, as Alderson (1993) identifies, the more rational protest of the school-age child and the active participation and co-operation of the adolescent. That children should have a say in matters that concern them is now a universal requirement contingent on implementing the articles of the Children's Convention. In Europe, different countries approach this point in different ways.

France

In France, child lawyers recognize the need to work with children and gain their co-operation as a defensive move lest children start to demand their right to be consulted and heard, if not in France itself, then at the Court of Human Rights in Strasbourg. Jacqueline Rubellin-Devichi (1994), a French lawyer who specializes in child and family law, in an interesting essay on the understanding of the principle of best interests of a child, enshrined in Article 3 of the Convention of the Rights of the Child, comments that 'the [French] legislature was well aware of the need to pass implementing legislation quickly so as to avoid the humiliation of a moral sanction and even a possible legal sanction by the European Court of Human Rights on the basis of a violation of the child's human rights'. In France, the National Assembly is in the process of addressing itself to the passing of child-centred laws covering three main areas related to childhood, children and family law, namely – issues of parentage, inheritance and divorce. According to Rubellin-Devichi (1994), some progress has been made but the main obstacle to according children the rights acknowledged in the Convention, especially the right to be heard, is that 'the French, convinced that parents know best what is good for their children, tend to consider that parents are better placed than the children themselves to discern their aspirations, their interests, as well as to defend their rights' (Rubellin-Devichi, 1994).

This deep-seated parentalism is not unique to the French, but as Rubellin-Devichi's essay clearly illustrates, it is national and cultural norms that are challenged by the insistence that age-old customs be waived in preference to new ideologies, however commendable the new ideology. In France, up until recently, the problem in upholding Article 12 of the Convention was that children could not initiate a legal case, in fact, they could not appoint their own lawyer. As recently as 12 June 1992, the Court of Appeal of Colmar (Jurisdata No. 41760) threw out of court the case of a child who wished to challenge the decision of a lower court on the grounds that there is no child-centred 'specific implementing legislation'. However, as of 8 January 1993, the new French children's law will allow for a child to have a formal voice in legal affairs concerning its own welfare. As in the United Kingdom, paediatric nurses in France need to understand the spirit of their new national laws and the spirit of the Children's Convention with which the French laws are trying to comply. As is often noted, the United Nations Convention on Children's Rights takes precedence over local laws and local laws must try to comply with the Convention!

In health care practice in France, as in the United Kingdom, allowing or even encouraging a child to have a say about treatment modalities, agreeing and consenting to medical interventions, as well as assenting to various health care protocols, are all expected under the Children's Convention. However, as Alderson (1993) comments, it is not legislation that is holding children up, but the attitude of adults towards children. She states, 'the key to respect for children's rights is respect for their rationality' (p. 40) and respect for a child's rationality is more an ethical and cultural value than something primarily enshrined in law (Montgomery, 1993).

Article 19

The state has an obligation to protect children from all forms of maltreatment perpetrated by parents or others responsible for their care, and to undertake preventive and treatment programmes in this regard.

It is customary to regard maltreatment of children as something that other people do to youngsters. It is difficult for health care workers to imagine that they may be contributing to a child's distress. Apart from the obvious instances where health care workers physically harm children, such as female genital mutilation, male circumcision or the sad case of Beverley Allitt, a British-born enrolled nurse, who within a four-month period managed to kill four children in her care and harm several others (Department of Health, 1994), there are many examples of psychological harm and harm inflicted on the maturing psyche of the child, of which sexual abuse is one example. The maltreatment that is focused on less frequently and one that is quite topical in Europe, especially Central Europe, is the harm inflicted on children by the way that they are treated in hospital. According to Ulla Fasting from Denmark, however, the crime that health care workers perpetrate on children is much more pervasive and much more subtle, but it is possibly just as devastating for the child (Fasting, 1995). The 'new' iatrogenesis she refers to is the infringement of the child's physical and psychological integrity by modern medicine and biotechnical prowess. She is especially concerned about the consequences (as yet only poorly researched) of *in vitro* fertilization techniques on the developing embryo and the effects of technology on the premature infant. Ulla Fasting, a paediatric nurse from Vyborg, Denmark, has for many years campaigned for a more child-centred approach to intensive care units. For a number of years at Danish conferences, she has outspokenly defended the right of a child not to be constantly prodded, pricked, turned, naso-gastrically fed and so on. The very technology that was set in place to save small children is now the cause of much of their distress. In fact, if health care workers do not heed the warnings of activists like Ulla Fasting they will be guilty of knowingly inflicting harm, a point emphasized by English neonatal nurse colleagues (Whyte, 1989; Crawford and Morris, 1994). This essentially iatrogenic understanding of harm perpetrated on children is a concern occupying the hearts and minds not only of physicians and nurses in the United Kingdom, but also of those in the poorer, new democratic countries of Europe, where only now are health

care workers reading the relevant literature on psychological damage to children in hospitals.

Poland

The state is obliged to protect children from harm. The mandate here includes health care workers increasing their sensitivities regarding potential abuse of children and the state putting relevant bodies and mechanisms in place to deal with the consequences of abuse. If child abuse is not recognized and there is no reporting agency or laws to deal with the maltreating adults, then Article 19 has little local significance (Newell, 1991; Alston, 1994). The recent widely publicized scandals of paedophile rings in Belgium, Holland and England serve to highlight the pervasiveness of sexual abuse of children. If paedophile rings are so widespread and involve so many men (and women), it is not surprising that some nurses will also be paedophiles – as will some physicians (Long, 1992). These examples occur in all countries and certainly it is the declared aim of all European countries to curb and eradicate such organized crime.

In Central Europe, in addition to any harm inflicted as a result of abuse, or the 'new' iatrogenesis spoken of above, is the deep psychological trauma experienced by children who have to go to hospital, usually for long periods of time, without the support of parents or relatives. Although some more progressive centres are inviting parents, especially mothers, to stay with a child in hospital, this is still a relatively rare phenomenon. The greatest obstacle to changing the status quo is not necessarily entrenched positions of paediatricians, who often travel abroad and read foreign medical journals and would not mind changing set ways, but the inflexible position of Ministries of Health which produce directives concerning these matters. All too often objections are also raised by paediatric nurses themselves who are poorly and inadequately trained and feel threatened by parents staying on the wards. Needless to say, this is not the position everywhere and centres of paediatric excellence exist all over Central Europe. However, until more nurses are educated in a holistic fashion with input from child psychol-

ogists, child developmentalists and play leaders, it will be very difficult to change the fate of children in hospital wards. In Poland and Romania, paediatric nurses not only have newly founded organizations wherein to voice their concerns, but in Poland they now have a special three-year, part-time, post registration programme in paediatric nursing running at two sites.

Recently, Polish paediatric nurses pushed for the translation of several child development and child psychology textbooks, including a book on ethical issues in paediatric nursing. Brykczynska's (1989) text on ethical issues in paediatric nursing is now compulsory reading on the new nursing programmes. Similarly, the Hungarian nursing centre for continuing education in Budapest has helped publish the translation of Benjamin and Curtis's (1992) textbook on nursing ethics. Such concerted activity in the spirit of Article 19 can only bode well, even if there is still a long way to go in recognizing that health care workers themselves may be contributing to the fears and distresses of children.

Article 23

Handicapped children have a right to special care, education and training designed to help them to achieve a greater possible self-reliance and to lead a full and active life in society.

The United Kingdom

In the United Kingdom, children are considered, at least theoretically, sufficiently equal that neither ethnic origin, genetic predispositions, chronic disease nor infirmity should make a difference with regard to the treatment they may require. In practice, however, children with handicapping conditions, whether they are all embracing, such as severe multiple handicaps, or confined to only one or two areas such as dyslexia, visual or hearing impairment or chronic diseases such as diabetes or cerebral palsy, find that access to comprehensive child-centred services is neither easy nor automatic and equitable. The United Kingdom has several laws in place guaran-

teeing access to health, education and appropriate social services for children. The problem is not the lack of good intention and understanding of the need for better services for children, but the lack of adequate resources.

Although children comprise approximately a quarter of the United Kingdom population, they do not have a quarter of the available health care budget. Child-centred services, which are highly specific and therefore expensive, are both more costly per child patient in proportion to similar treatment for an adult, but are often inadequate or overly compromising and scarce. This was one of the contributing factors operating behind the scenes that made Beverley Allitt's conduct possible (Department of Health, 1994). In effect this means inequitable distribution of paediatric services over the country as a whole. Even if a child can have relatively good in-patient care, there is no assurance that the child will have appropriate community care. The advent of internal markets, the separation of community and acute service trusts, along with a jostling for increased funding from local services, has resulted in social and community health services working with separate budgets, and therefore the child in the middle often loses out on comprehensive co-ordinated care. It is too early to state whether this situation will be resolved, certainly the idea that government monies will follow the child has not materialized and there is much evidence that the available services for handicapped children are piecemeal rather than part of a comprehensive service. Most disturbing of all is that the type of care and care package a child gets depends on where a child lives. Geography seems to determine the availability of services rather than basic health needs. Perhaps this was always the case, but now it is much more blatant and the differences far more obvious. Presumably, some children always had better access to hospitals, paediatric consultants or nursing homes, but now some children have no access to community paediatric nurses, paediatric nursing homes or certain aspects of paediatric social services as these services do not exist in certain areas because they are not seen as a sufficiently high priority to be guaranteed for all children who might need them. The result of such inequity is that some children have a disproportionately better start in life, despite their handicaps, than other children. There is also evidence

that some ethnic groups are simply not engaging in the paediatric services, even when they are available (Slater, 1993).

Central Europe

On the continent of Europe, for the most part, finances follow the child and paediatric services are, at least theoretically, more co-ordinated. Countries of the old communist bloc had highly developed child-centred services and children with handicapping conditions had access to specialized provisions. As in the United Kingdom, these services were dependent on finances, but there were less regional variations within the country because the funding, whatever the amount, was far more centralized.

In Poland, there has been a long tradition of care for children with all forms of disabilities who have always enjoyed access to specialized services (Brykczynska, 1991). In some instances the care might have been seen as overly protectionist, but in the context of Central Europe, it is difficult to assess the extent to which this was overly patronizing and the extent to which it was a realistic necessity. Thus children did, and still do, attend special schools for the blind, deaf, physically disabled and such like. Mainstreaming is the exception rather than the rule. On the other hand many of the youngsters, in the spirit of Article 23, are prepared increasingly for meaningful work and life in the adult world. There are now quite effective self-help groups that speak for the concerns and needs of children and young adults with various disabilities. Perhaps the biggest problem area is in care for and co-operation with children with multiple handicaps and their families. With health care and social budgets ridiculously low, the care of this group of children is indeed inadequate and noticeably severely underfunded. Philip Darbyshire (1989), commenting on the Ten Whys (Whyns) of society and health care workers with regard to multiply handicapped children, could have been speaking of the prevailing attitude towards such children in Poland and in most of Central Europe (Figure 7.1).

This is not an unusual attitude, but where resources are low, equity and just allocation of resources seem to take low priority.

Indeed, as Darbyshire notes, it is not just a matter of resources, it is also a moral stance. To echo the Ten Whys (Whyns) sums up much of society's attitude towards these children. The resolution to the problem will have to come from an increased ethical awareness among social workers and nurses and others working with children.

The Polish Nurses' Association, with the help of moral philosophers and nurses, runs various workshops and seminars during the year on ethical issues in practice using the humanities to increase sensitivities. Additionally, senior child advocates, lawyers and politicians call for more understanding for this group of children. Hopefully, this will lead to a marked improvement in the way that these profoundly handicapped children are regarded and treated and hopefully, in the long term, they will be accorded those human rights to which they can lay legitimate claim. The children have a right to security, warmth, adequate food, nurture and where appropriate, as Article 23 notes, education and training that will help them achieve the greatest possible self-reliance and an active life, in a more considerate and morally responsive society.

Ten Whys (Whyns)

1. Why talk to them – they can't hear;
2. Why listen to them – they can't tell us anything;
3. Why ask them – they can't choose;
4. Why teach them – they can't learn;
5. Why show them – they can't see;
6. Why give them food – they can't taste any difference;
7. Why change them – they'll only wet and soil again;
8. Why give them toys – they can't play;
9. Why take them out – they don't notice anything;
10. Why bother?

(Darbyshire, 1989)

Figure 7.1 Darbyshire's Ten Whys (Whyns)

Article 39

The state is obliged to ensure that child victims of armed conflicts, torture, neglect, maltreatment or exploitation receive appropriate treatment for their recovery and social integration.

This article of the Children's Convention is perhaps the most paradoxical, since it is often state-inflicted harm, in the form of torture and exploitation, that prompts the necessity to ensure that the child victims of state terror have 'appropriate treatment for their recovery and social integration'. Even if the government of countries or local councils are not to blame for harm inflicted on children, they often turn a blind eye to the illegal conduct of its citizens or appear powerless in the face of organized crime.

Amnesty International recently produced a booklet highlighting the plight of children around the world who are victims of armed conflict, torture, societal neglect, maltreatment or exploitation (Amnesty International, 1995). Some of the harm done to children is deliberate and callously targeted at this vulnerable group, for example recruiting children into prostitution, 'buying' kidneys from minors, enlisting boys into the army and so on. Some of the harm is aimed at children, because children represent a dispensable commodity. Exploitation of child labour, killing of street children in South America are prime examples. Finally, there is the harm done to children because they just happen to be in the way. Caught up in adult wars and the conflicts of adults, children, and often their mothers, become trapped in the middle, suffering physical, mental, psychological and spiritual damage. There are more orphaned and displaced children in Europe at this time than at any other since the conclusion of the Second World War. Although Western Europe is relatively free of state violence, bearing in mind that the children of Northern Ireland and the Basque region of Spain may disagree, Central Europe and the Russian Republic are experiencing ongoing massive social upheavals with resultant social chaos and lawlessness. The long drawn out war in the Balkans has resulted in a whole generation of youngsters becoming displaced witnesses of incredible violence and cruelty. Exploitation of children by organized

crime, in the form of drug abuse, is prevalent in the whole of Europe and the recruitment of the street children of Moscow into organized criminal gangs by Mafia-style bandits is a growing problem. Closer to home, in the United Kingdom, the increase in homeless adolescents is of great concern, while the noticeable rise in child suicides and instances of serious bullying demonstrate the effects that societal stress and violence have on young impressionable individuals. The list of contemporary society's faults in respect of children is growing and the question is, 'to what extent is this of concern to health care workers generally and to paediatric nurses in particular, working in Europe?'

Certainly, the noticeable rise in the levels of stress and aggression in children is worrying and common throughout Europe. Children are appearing at schools, clinics and hospitals with stress-related disorders such as depression, anorexia, addictive behaviours, aggression and the like. Increasingly, children are acting out their fears and anxieties on each other, and the rise of serious death-inducing bullying in the United Kingdom is both distressing and alarming. The solutions to these problems will not be found by simply treating the children as passive recipients of 'bad luck', but as Amnesty International (1995) noted, by treating children 'as real people, like grown-ups (p. 1). The implication of this is that just as we would listen to the concerns, anxieties and fears of adults, so we should pay attention to the concerns of children. Under the terms of the Children's Convention, it is a child's right, not only to be 'rehabilitated', but also to expect to live through a 'childhood' free of exploitation and societal abuse. Signatories to the Convention need to look at what they are doing nationally to minimize harm and damage to children by adults. Harm of course is a loose concept and comes in a variety of forms. It might include physical punishment, which is still legal in the United Kingdom, trade in infants and young children as a response to the demand for adoptable children which is a huge problem in parts of southern Europe, or toleration of racial inequalities in health care provided to minority groups, a problem in much of Europe especially the United Kingdom, France and Germany.

Paediatric nurses are in a unique position to gain the trust of children and collectively to have a powerful voice which can demand change, as and when appropriate. The rights of children entail the duties of health workers involved in their care to stand up for the minimum securities needed to ensure an appropriate childhood for all children. The fact that for most European nurses their wages will be paid, directly or indirectly, by the state government, means that campaigning for social reforms to ease the fate of children may call for much courage and commitment on their part. This does not, however, absolve them from their responsibilities. In fact, as Amnesty International (1995) notes: 'Governments now have a duty, which many fail to carry out, to make the principles and provisions of the Convention widely known to adults and children alike' (p. 12).

Conclusion

Paediatric nurses all over Europe have a legal, as well as a moral, obligation to familiarize themselves with the content and spirit of the Children's Convention. Wherever possible they should work to implement the various articles and should join forces with other concerned adults to improve the lives of children.

From a concern for improved education of paediatric nurses across Europe to a united stand on physical punishment, child abuse or media exploitation of children, child health nurses have much to engage and occupy their social consciences. Perhaps the biggest change in paediatrics and the associated ethical issues in Europe over the last few years has been the realization that health concerns which affect children may have their roots outside of diseased and distressed bodies. In order to better answer the needs of children it has become necessary to approach the child in a broader, far more systematic, holistic fashion. Just as the political boundaries in Europe are coming down, so too are the Cartesian body-mind divisions of traditional approaches to health care. Shakespeare noted in *The Rape of Lucrece*, that 'if children pre-decease progenitors, we are their offspring, and they none of ours'. We must ensure the existence of a healthy generation of Europeans or we may

find that our successors are unfit to survive us. Working towards ensuring that children's health rights are respected is one way that paediatric nurses can contribute to a future generation of healthy Europeans.

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8

Ethical Issues in Integrating People with a Mental Handicap

Ruth Northway

Introduction

It would be nice to say that so much time and effort does not need to be made just to allow people to be a part of the society in which they live. But it never really works out like that does it? (Souza with Ramcharan, 1997, p. 7).

Within every country in Europe there are people who are labelled as having a mental handicap. The word 'labelled' is used here deliberately as labels are seldom neutral. Moreover it draws attention to an important ethical dilemma which must be discussed, namely, which term should be used to refer to the group of people who form the focus of this chapter. This concern might be simply dismissed as a preoccupation with political correctness but the label which is applied to groups is one of the things which marks them out as 'different' and hence in need of integration.¹ As such, it is central to the debate within this chapter.

Terminology has varied throughout history and as one term becomes viewed as derogatory an alternative is advocated. At any one time, therefore, the choice of terms might vary both within and between countries. From the chapter title it can be seen that a decision to refer to this group as 'people with a mental handicap' has been taken. It is acknowledged that such terminology is viewed negatively by some people to whom the

label is applied, preferring instead to be referred to as 'people with learning difficulties'. This preference is noted, respected and would be the preference of the author. However, as this volume is intended for a European audience, the use of 'people with a mental handicap' is defended on the basis that the term is the one which, at present, is most widely understood.

Once a group is perceived as 'different' this usually influences the manner in which they are treated by society. In the case of people who have a mental handicap their difference has often been viewed negatively, frequently resulting in their segregation² from wider society. This state of affairs is at last beginning to change and, throughout Europe, movement towards integration is being made. While this general trend can be observed, its implications inevitably vary from one country to another as a result of prevailing societal values, existing patterns of service provision and the economic resources that are available to effect change. Similarly, differences may be observed at both local and individual levels. Integration is therefore a complex process that requires both considerable time and effort (Souza with Ramcharan, 1997) and one which raises a number of ethical concerns.

Nurses, both specialist and generalist, have a role to play in this process. The exact nature of integration is closely dependent upon both the societal context in which it takes place and the social policies which promote or inhibit it. This chapter will discuss the nature of integration and provide an overview of the current situation in three European countries – Albania, the Republic of Ireland and the United Kingdom. Three broad aspects of integration which raise ethical concerns will be examined: the question of whether community living is a universal right; the issue of choice; and that of integration into health care systems. In each of these areas the implications for nursing practice will be considered. In conclusion, the key similarities and differences between the countries will be highlighted and the consequent challenges which face nurses and nursing identified.

The nature of integration

Meanings of integration

Integration means different things to different people. This is particularly true when adopting a European perspective as it may have different implications in each country. For the purposes of this chapter, however, it is necessary to arrive at a working definition.

The *Concise Oxford Dictionary* (Allen, 1991) defines integration as 'the intermixing of persons previously segregated' and to 'bring or come into equal membership of society'. Therefore, in relation to people who have a mental handicap, the movement towards integration involves not only a recognition that previously these people have not been viewed as part of society, but also a commitment to changing this situation. This is necessary as historically people who have a mental handicap have been segregated for a number of reasons, some of which might be viewed more positively than others. These include a lack of alternative facilities, the belief that specialist provision is the most appropriate form of support and societal prejudice.

Integration has gained momentum as a result of widespread acceptance of the principles of normalization which seek to promote 'an existence... as close to normal living conditions as possible' (Bank-Mikkelsen, 1980, p. 56). Wolfensberger, one of the key proponents of normalization, suggested that integration was the opposite of segregation (Wolfensberger, 1972). He does, however, make a distinction between physical and social integration where the former means that people who have a mental handicap are in the physical presence of others. He makes this differentiation to stress the fact that mere physical presence, while it may promote social integration, does not in itself constitute full social integration which is the ultimate aim. Clearly then social integration has two components. As well as the use of community facilities it also involves relationships with others (Szivos, 1992). Integration therefore becomes a much broader issue than simply moving people out from segregated service provision.

Souza with Ramcharan (1997), speaking from personal experience of the 'separations' to which people who have a mental

handicap may be subjected, discuss how, immediately a label is applied to children, they instantly become 'separated' from society as they are seen as different by their parents and others. This highlights one of the paradoxes involved in integration, as in order to change the situation, clear identification of those who have been segregated, and therefore need to be integrated, is necessary. However, this often involves the application of a 'label' which, while it identifies the group as requiring additional support, may have negative consequences as it further marks the group out as different and unfortunately, difference is often viewed negatively.

Integration is a concept which has been widely discussed at a European level and the European Union has since the 1980s had a programme which has sought to promote the integration of disabled people (the HELIOS programme). It is difficult, however, to speak of integration without placing it in a specific societal context as it is only by doing this that it is possible to determine its implications and hence the ethical issues which may arise. The current situation of people who have a mental handicap in three European countries, Albania, the Republic of Ireland and the United Kingdom, will therefore be examined.

Albania

Prior to the overthrow of the communist regime in March 1992, few details regarding life in Albania were known outside of the country. Swinburne (1994) provides some insight into the situation faced by people who have a mental handicap whose families were often ashamed to admit to their existence. As family support was virtually non-existent these people were left with the prospect of either coping alone or being sent to an institution. The location of institutions in the larger towns resulted in minimal family contact due to the distances involved and poor transport systems. Furthermore, conditions inside these children's homes were often poor; with bare rooms, little stimulation, staff who were not trained to meet the specific needs of the residents, heavy use of sedation and little emotional care (Swinburne, 1994). All of this suggests a very bleak picture

and there is no reason to imagine that conditions for adults living in institutions were any better.

In theory, people in Albania who have a mental handicap have the same rights as other citizens. Educational law states that each mainstream class should be ready to accommodate at least two children who have a mild mental handicap and employment legislation states that every employer of more than 25 people should employ at least one disabled person. In practice these provisions are rarely enforced. As previously mentioned, one of the things which influences successful integration is the availability of economic resources to develop the necessary support systems. Similarly, integration has to take account of the prevailing societal conditions and attitudes at any given time. Both of these factors have had a significant impact on developments for people who have a mental handicap in Albania.

Things have begun to change since 1992 and, while there are still people with a mental handicap who find themselves in institutional provision, some progress has been made. Non-governmental organizations from within the country, such as the National Association for People with a Mental Handicap, along with external aid agencies such as the East European Partnership, have begun to work with the government to effect change. Specialist nurses and health professionals from other countries have been key members of these project teams.

As there was little societal understanding about the needs of people who have a mental handicap and those of their families (Swinburne, 1994), work to raise public awareness has been undertaken. In some areas support is being offered to families, projects to integrate children into mainstream classes have begun and some small group homes have been opened. Work is also under way in the institutions, although this has tended to focus on the provision of education and training for staff in an attempt to avoid the resentment caused by the provision of material aid, in a country where families are often so poor that they have difficulty in providing for their families' basic needs (Swinburne, 1994). Nurses are obviously key members of the staff teams within the institutions but, until recently, they were offered no specific training in relation to this client group. These educational developments have therefore increased both levels

of understanding and the quality of care provision. Some restructuring of the institutions has also taken place.

Nurses also have a role to play outside of the institutions. For instance, health visitors provide advice and direct families to appropriate services, although this is obviously restricted by the limited services available. While progress has been made towards both integration and improving the quality of life for people who have a mental handicap within Albania, it has been slow and patchy. This is not meant to decry the progress that has been made, nor is it to argue that it should be halted. It does, however, illustrate how a legacy of underresourced services, together with a lack of societal awareness and restricted financial resources, limits the speed of change. It is perhaps significant that the project established by the East European Partnership, due to end in 1994 (Swinburne, 1994), is still operative in 1997. At the time of writing, Albania is once more in a period of civil unrest which has forced many foreign aid workers to leave and has prompted appeals for humanitarian aid. It is with some concern, therefore, that the situation of people with a mental handicap in Albania must be viewed.

The Republic of Ireland

The principle of community care for people who have a mental handicap has been broadly accepted within Ireland since the mid 1960s, although it was felt that community living would not be possible for everyone. A range of service provision was advocated which included accommodation within psychiatric hospitals, the development of smaller residential centres, some day services, educational provision and very limited family support. Present services are based primarily on the recommendations of the *Needs and Abilities* report (Review Group on Mental Handicap Services, 1990).

This document suggested that with the provision of appropriate services, the majority of people would be able to live in the community. While this may be seen as a statement of generally positive intent, it is important to note that it also raises the possibility that some people would not be able to live in the community and also that the ability of others to remain

there is clearly linked to the availability of suitable support services. Nonetheless, it did advocate a number of key service developments, such as the need to ensure education for all children regardless of their disability, the need to provide a range of day, respite and other family support services and it also recognized the need for appropriately trained staff.

In relation to residential provision it was recommended that new residential centres should be as home-like as possible. The need to relocate those people who were inappropriately placed within psychiatric hospitals to more appropriate facilities was also identified as a priority. Placement in residential centres was identified as the 'least favoured option' except for certain groups of people (Review Group on Mental Handicap Services, 1990, Sect. 9: 5), including those with a severe or profound level of disability and those who have 'additional handicapping conditions'. The nature of these conditions, however, is not specified.

Progress towards these aims appears to be somewhat varied. Residential centres have become more home-like with the development of smaller living units. Although the level of funding has increased, enabling more residential places for emergency and respite care to be provided together with an expansion of home care provision, there is still a significant level of unmet need. For example, in 1994 there were said to be some 1300 people waiting for residential services and 1500 people waiting for day services (Department of Health, 1994).

The picture in relation to the accommodation of people who have a mental handicap within psychiatric hospitals is also unclear, even though their resettlement remains a priority (Department of Health, 1994). Estimates of the numbers of people involved vary between 942 in 1992 (Department of Health, 1994) to 1200 in 1996 (Commission on the Status of People with Disabilities, 1996). This may reflect both the difficulties and differences in classification, particularly of people who have a mild mental handicap. What is clear, however, is that a significant group of people continue to live in inappropriate and segregated settings. This is of particular concern when it is noted that the Commission on the Status of People with Disabilities (1996) found themselves to be 'greatly shocked by the poor standards of the physical accommodation' in some of

these hospitals (Sect. 23: 18). While they recognized that financial constraints have been a major factor in inhibiting progress, there appears to be a gap between espoused policy and reality, and therefore the Commission called for the *Needs and Abilities* policy document to be reviewed as a matter of urgency.

Within Ireland there are specialist nurses for people who have a mental handicap (registered mental handicap nurses) working in a range of settings, such as hospitals, residential and day care centres, with people with varying degrees of disability and across all age groups. In addition, a small number of nurses are beginning to work directly with families in the home. Thus, specialist nurses are currently working in both segregated and integrated settings and appear to have a central role to play in promoting integration.

United Kingdom

While the majority of people who have a mental handicap have always lived in a community setting, the United Kingdom has a legacy of large-scale institutional provision. Official policy since the late 1950s has been to shift the focus of care from hospitals to community-based provision, but this has been a slow process. Prompted by concerns over conditions in the long-stay hospitals, the 1971 Government White Paper entitled *Better Services for the Mentally Handicapped* (Department of Health and Social Security, 1971) gave a renewed impetus to community integration. Its agenda for change involved both the improvement of conditions within existing institutions and the development of a range of community-based support services. In 1981 the Education Act made provision for children with special educational needs to be educated within mainstream educational provision. However, certain preconditions were set out before this could happen, namely that the education of the child should not suffer, the education of other children should not suffer and finally that it should make best use of available resources. Thus, while at one level there is a policy commitment to integration, a number of obstacles to its realization still exist.

In the mid 1990s a mixed picture has emerged. Current policy states that the priority is to support people to live in community settings through the development of an appropriate range of support services designed to complement existing patterns of family and community support. Some very good, innovative services exist, such as early support schemes, integrated placements within mainstream schools and supported employment schemes, but they are not available in all areas. Community-based services, for example day services, group homes, multidisciplinary community support teams and respite care services, have been developed, but again, there is a lack of uniformity and variations of both quantity and quality of service provision. Some long-stay institutions have been closed and many which remain have active resettlement programmes which are seeking to relocate residents into small-scale community living developments. It is likely that institutional care will remain part of service provision for a number of years and concerns have been expressed that the community services which have been developed are 'inadequate' (Cooke, 1997).

The United Kingdom has specialist nurses for people who have a mental handicap, although there has been an ongoing debate for a number of years as to whether such nurses are required. Interestingly, this debate has arisen partly because if the principles of normalization and integration are taken to their logical conclusion, then people who have a mental handicap would utilize ordinary community services, including health care facilities which employ generalist rather than specialist nurses (Cooke, 1997). Currently, specialist nurses work either in residential settings such as hospitals and small-scale group homes or in a domiciliary capacity, visiting families and clients who live independently or in group homes. Additionally, a number of qualified nurses are employed by social services or voluntary agencies in day and residential services. It would appear, however, that while many of them are employed because of their nursing experience they are not employed as nurses.

Ethical aspects of integration

From the preceding discussion it is evident that while there are variations between countries there are also similarities which will be of concern to nurses. Although it is clearly impossible to discuss all of these, some key areas will be explored.

A right to community living?

Stanton (1994) suggests that initial moves towards deinstitutionalization were primarily concerned with establishing the 'right form of care' rather than with concern for individual rights. Times have changed, however, and most services tend to view the concept of integration into 'normal community living' as a 'right' of people who have a mental handicap (Kay, 1994). Indeed, in this chapter it has been seen that in each of the countries, explicit policies exist which seem to support this goal to varying degrees. It has also been seen that gaps exist between policy and practice and that many people remain in segregated services. For nurses there appear to be three important areas to consider. First, the question of whether community living is a universal right. Second, the nature of the support required and lastly, the impact of the changes on conditions in any remaining segregated provision.

Kay (1994) argues that many of the assertions concerning the rights of people who have a mental handicap centre on the recognition of the personhood of the individual and as such involve moral rights rather than legal ones. It is interesting to note, therefore, that in Ireland admission to residential centres is viewed as the 'least favoured option' except for those who have severe or profound disabilities and those who have additional handicapping conditions (Review Group on Mental Handicap Services, 1990). Similarly, in the UK these are the groups who have often been the last to be considered for resettlement from hospitals and for whom some form of continuing health care provision is often thought necessary. This seems to suggest that some groups of people are viewed as having less of a right to live in a community setting than others. As

it is these groups with whom nurses most often work, the issues involved require further examination.

It has often been argued that the level of need for people who have a severe or profound mental handicap can only be met within an institutional setting. This has been challenged by Tossebro *et al.* (1996) who stated that the necessity for institutions began to be questioned in Scandinavia in the 1980s and, while it was accepted that these people needed a high level of support, the link between this need and institutional care can be broken. What is vital in this debate is that the rights of people with multiple and profound disabilities to live in a community setting are not advocated at the expense of ensuring that both the individual and his or her family have the appropriate range of support services available. Clearly, it is possible for people living in the community to remain isolated because of unmet needs for support. However, it is also essential that a lack of services is not used as an excuse to limit the extent to which a group of people are integrated. That is to argue, as has happened in the past, that they 'need' institutions. The issue seems to be one of resource availability, rather than the ability of the individual who has a mental handicap, and nurses may find themselves placed in the position of advocate for their patient or client. The extent to which nurses can perform this function may be limited by the fact that they are often employed by the agency providing the services, and therefore the nurse may need to ensure that the client has access to an independent advocate.

A further group of people whose rights to live in a community setting are often questioned are those whose behaviour challenges. One widely quoted definition of challenging behaviour, as well as that referring to behaviour which may harm the individual or others, refers to behaviours which may limit or deny access to ordinary community facilities (Blunden and Allen, 1987). The extent to which a behaviour segregates or threatens to segregate an individual is, therefore, one of the key factors in defining whether or not the behaviour challenges.

Kay (1994) argues that if people have a right to live in the community they also have an obligation to behave in a manner which is in keeping with societal expectations. Clearly there are some behaviours which cannot be tolerated such as extreme

physical violence. In such cases it may be necessary to provide some form of intensive support service for a specific period of time. Such examples are rare, however, and on a day-to-day basis the nurse is more likely to be concerned with clients whose behaviour, although it does no physical harm, may serve to segregate them from wider society. The focus of concern therefore should be on what constitutes acceptable behaviour and who decides this (Kay, 1994). Should the nurse ensure that individuals acquire socially acceptable behaviours or should society be expected to be more tolerant? Clearly, in the short term, society is unlikely to change and therefore the reality is that people who have a mental handicap will continue to be excluded if they do not conform to the prevailing standards (Cooke, 1997). Consequently, the nurse has to work with individuals to determine which is the most appropriate course of action for them. There is also an important role for nurses in raising public awareness of the needs of people who have a mental handicap and the importance of this has been recognized in Albania. While this may be a long-term strategy, it may increase understanding and perhaps lead to greater tolerance of individual differences.

The above examples highlight the role of support services in realizing the integration of people who have a mental handicap. In Albania it was noted that many parents had no option but to admit their child to institutional care because of the lack of community-based services (Swinburne, 1994). Such a scenario is not confined to Albania, however. In Britain, institutional closure has resulted in 'inadequate provision for many and no service for some' (Cooke, 1997) and, in Ireland, it is not clear how many people on the waiting list for residential care could be supported in the community if adequate services were available (Department of Health, 1994). Nurses working in community settings are an important part of such support services both in terms of the direct service which they offer and the co-ordinating function which they perform. If institutional care is to be reduced, an adequate range of community-based services are required, both to alleviate the need for admission to residential care and to promote integration.

This highlights a further area of potential concern. The analysis of the current situation in each of the three European

countries has identified that, along with public attitudes, one of the major factors inhibiting progress towards integration is the limited availability of financial resources. The essential question which arises relates to where resources can be used to best effect. One possible solution is for money to be spent only on new developments rather than on improving existing segregated provision. This, however, raises ethical concerns for nurses who, as the main care providers in these segregated residential settings, have a concern for the quality of life of the people they support.

It has been seen that while some improvements have been made in standards of care, concerns about the physical conditions within psychiatric hospitals in Ireland (Commission on the Status of People with Disabilities, 1996) and in institutions in Albania (Swinburne, 1994) have been expressed. Similarly, in the United Kingdom, moves towards integration were prompted by anxieties about the quality of institutional care. Nurses appear to be in a difficult position here, as by arguing for the improvement of institutions, they may be criticized for seeking to defend their continued employment. However, tolerating poor physical conditions for their patients and clients could also leave nurses open to criticisms of neglect. Clearly, nurses must be accountable for their actions and the consequences of their decisions and they must be prepared to defend their judgement (Kay, 1994).

Choice

The decision to move away from segregated forms of service provision is usually one that is based, in part, on financial considerations but also on the belief that such a move would improve the quality of life for people who have a mental handicap. Although this line of reasoning is accepted by many people, inevitably there will be individuals who feel that such a view is not right for them and is paternalistic.

Wolfensberger (1972) argues that devaluation is compounded when people who are devalued by society mix with other people who are similarly devalued. He suggests instead, that if these people wish to avoid devaluation, they should associate with

valued people and shun the company of devalued people. Such a position ignores the benefits which some people may derive from such associations and there is a danger that, in accepting such a philosophy, integration will be imposed rather than chosen. This could raise some dilemmas for nurses working in a system which seeks to promote integration with individuals who do not wish to integrate.

Disregarding the views of people who have a mental handicap about their day-to-day lives might be viewed as treating them as 'less than human' (Chadwick and Tadd, 1992, p. 128). However, it could also be argued that if there is a policy of integration, then the individual has no real choice in the matter. Indeed while most people expect to be offered some choice, a completely free choice is seldom offered as options are limited by a lack of goods, time or resources (Cooke, 1997). In this instance there is a clash between a policy which is believed to be of benefit to a group of people and the wishes of the individual. This represents a clash between the moral principle of beneficence and that of autonomy. In relation to people who have a mental handicap this is further complicated by the fact that they are frequently not viewed as being capable of autonomous decision-making (Chadwick and Tadd, 1992). Moreover, a lack of competence in one area of life is often taken as inferring generalized incompetence (Brown *et al.*, 1992). The challenge for nurses therefore, is to facilitate informed decision-making wherever this is possible. This means that nurses need to work with individuals, to develop decision-making skills, to enable them to clarify the extent of their options and identify the possible consequences of the various courses of action, as well as to support them in their decisions.

Integration into health care

The sections discussed above might be viewed simply as representing the concerns of specialist nurses who work solely with people who have a mental handicap. However, if people who have a mental handicap are to be integrated into society, it follows that they will need to be integrated into the existing health care systems to ensure that their health needs are met.

The integration of people who have a mental handicap therefore becomes the concern of every nurse.

All people who have a mental handicap have the same health needs as the rest of the population, although these are sometimes obscured by their disability. Some, however, have additional health needs as a result of their underlying impairment (Welsh Health Planning Forum, 1992). If these needs are not met, additional restrictions are imposed on the individual, compounding their underlying impairment and limiting the possibilities for their integration. It is essential, therefore, that people who have a mental handicap have access to health care.

In each of the countries chosen for discussion, people with a mental handicap theoretically have the same rights of access to health care as other citizens in their respective countries. In Ireland there is a policy commitment which states that they have the same rights of access to government services as other citizens (Review Group on Mental Handicap Services, 1990). In the United Kingdom it is stated that:

People with learning disabilities (mental handicap) have the same rights of access to National Health Service services as everyone else (National Health Service Executive, 1992, p. 1).

However, simply stating that people have equal access does not take account of their varying needs and may result in unequal outcomes. The National Health Service Executive (NHSE, 1992) recognizes that people who have a mental handicap may require additional assistance to use health services. As Kay (1994) suggests, 'if justice means that unequals should be treated unequally then someone needs to be concerned with the unequals' (p. 87).

There would appear to be a gap between policy and practice. In gathering the information for this chapter, one area of concern common to each of the countries was the difficulties in accessing health care which people who have a mental handicap experience. There may be a number of reasons as to why this is the case, such as communication difficulties on the part of both health professionals and the person with a mental handicap, inadequate training and support of carers and societal prejudice. While each of these

has implications for nurses, it is the latter which perhaps raises specific ethical concerns.

Where resources for health care are limited, then health services tend to be targeted or rationed. This raises particular concerns in relation to people who have a mental handicap, as they may be excluded from health care by virtue of their disability. The issue at stake here is that of respect for personhood, for if we argue that all people by virtue of being human have a right to be valued, then it follows that they also have an equal right to appropriate treatment.

Nurses and other health care professionals are members of society and as such, may have the same prejudices towards people who have a mental handicap. A key factor in promoting better access to health care for people who have a mental handicap is, therefore, the improvement of nursing education. In Albania, training is being provided by non-governmental organizations and within the UK, all student nurses undertake theoretical and practical experience in relation to people who have a mental handicap within the Common Foundation Programme. Similarly, in Ireland, there are calls for disability awareness training to be provided for all health service staff (Commission on the Status of Disabled People, 1996). While awareness may be an important and necessary first step, it is important that it is translated into positive action. This needs to include action at both the level of individual practice and at service and policy levels to ensure that the health system is receptive and responsive to the needs of people who have a mental handicap. Nurses have a role to play at all levels.

Conclusion

Each of the countries examined in this chapter is seeking to promote the integration of people who have a mental handicap and, while much remains to be done, some progress is evident. In each country nurses play a major role in this process. While variations, due largely to differing historical legacies and the level of resources available to effect change, are apparent, some common areas of concern have also emerged between the countries.

One central issue is the question of choice. In each of the countries people have been admitted to institutional care as a result of inadequate community-based services. There was no choice. Similarly, there are those clients who may prefer not to integrate, but find themselves in a situation where policy dictates that this is not an option. The challenge is therefore to provide a range of services capable of meeting both the needs and preferences of individuals, while recognizing that these needs and preferences may change over time.

Another common theme that has emerged is the role played by economic support in bringing about change. Difficulties exist in each country and just as the nature and extent of these problems vary, so too does the impact on nursing practice. There is a difficult balance to be struck between ensuring that appropriate community-based facilities are developed before institutions close, while at the same time ensuring that material conditions within institutions do not deteriorate to unacceptably low standards. As nurses work in both institutional and community settings they may find themselves at the centre of such debates, and inevitably this will impinge on their practice.

A particularly disturbing commonality between countries, which surfaced while researching and writing this chapter, is the difficulty which people who have a mental handicap face when seeking access to health care. Consequently, all nurses must examine their practice in this area, as a matter of urgency, if the situation is to improve.

One overarching challenge is the need for nurses to work at a variety of levels. The importance of working with the individual to ensure that his or her needs and wishes are taken into account has been highlighted. However, by definition, integration means that the individual has to be integrated 'into' something. What this means for nurses is that, although their primary focus may be on their patient or client, they cannot disregard the other part of the equation, namely society. Indeed, a number of the ethical issues which have been highlighted will not be resolved simply by working with the individual. Nurses must have a thorough awareness of the communities and societies in which they work, of the social policies which shape them and of how power operates within them. In short they must be politically aware.

It is not possible in a chapter of this length to explore all of the ethical issues which can arise for nurses when seeking to promote the integration of people who have a mental handicap. This is particularly true as the exact implications will vary from country to country and from individual to individual. However, as Kay (1994) suggests, one of the problems which we face when we encounter ethical dilemmas is finding a 'way in'. It is hoped that, in examining some common dilemmas, this chapter will promote discussion between nurses, helping them to find a 'way in', and thereby contribute to the provision of more positive support for people who have a mental handicap, regardless of where they live.

Notes

1. The process through which people with a mental handicap become recognized as full members of society. Integration may be physical, whereby they are physically part of their community, or social, whereby social relationships are developed.
2. The process through which people with a mental handicap become separated from wider society. This may be physical, for example in specialist services, and/or social, when they are subjected to negative discriminatory attitudes.

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9

Ethical Issues in Mental Health Nursing

Kevin Gournay

Introduction

Mental health problems are so common that at some point in our lives all of us will be affected either by personal experience or the experience of those close to us. Thus, for example, the lifetime prevalence of schizophrenia, the most severe and enduring of mental illness, is 1 per cent and of depression more than 20 per cent (Department of Health, 1994). We know that roughly one in three of us will have a panic attack or panic attacks during our lifetime (Gournay, 1996) and up to 40 per cent of all general practitioner (GP) consultations concern medical problems for which no physical cause is evident. Mental health problems range from discrete episodes of anxiety and depression which last no more than a few days, to the most serious and enduring forms of illness such as schizophrenia and bipolar affective disorder. There is no simple spectrum covering the positions between these two extremes; mental health problems are best conceptualized as being multifaceted and multidimensional. Problems often present themselves somewhat paradoxically. For example, people with the most severe obsessions and compulsions may spend literally hours a day washing their hands while at the same time lead a very productive life in one of the professions and also have major familial and parental responsibilities. Similarly, victims of bipolar affective illness, more commonly known as manic depression, may have periods when they are unable to make any rational deci-

sions and may need to be detained in hospital against their will. However, in between episodes of illness, this person may occupy a position of great responsibility in society.

The nature of mental health nursing reflects the above complexity of mental health problems and the practice of this branch of nursing cannot be easily defined. While mental health problems have remarkably similar incidences throughout both the developed and underdeveloped world, the disparate views of mental illness held by various cultures have led to great differences in approaches to care and treatment. As we will see below, in Europe at least, there are a number of common characteristics of mental health services present in many countries. For example, the care of the mentally ill is now firmly located within the community in many (though not all) Western countries and institutional facilities are, to a large extent, being closed.

The most radical deinstitutionalization policies were enacted in Italy in the 1970s (Battaglia, 1987). However, although there was a great upheaval in services at the time of the legislation, the country now boasts some exemplary initiatives. These include work co-operatives for the mentally ill and a number of innovative accommodation programmes (Mosher and Burti, 1994). In the Netherlands, people with a serious and enduring mental illness are often 'fostered' within the community and such schemes have undoubtedly helped to reduce the stigma associated with such problems (Decker *et al.*, 1995).

Throughout Europe, many mental health nurses are increasingly required to adopt new roles in the community which are very dissimilar from those previously occupied in hospital settings. However, service provisions are by no means homogeneous either across Europe or even within countries. Recently a national research project carried out by the Clinical Standards Advisory Group of the United Kingdom (Department of Health, 1995) showed a great diversity of service provision and quality of care across the four home countries.

This chapter can only provide a starting-point for thinking about the ethics of mental health and mental health nursing. In order to provide context, some of the different nursing roles are described in more detail. Following that, a review will be undertaken of a number of areas of particular importance to mental health nurses which should together provide a basis for

considering ethical issues in theory and practice. As previously mentioned, there are a number of similarities among services across Europe and the areas chosen for consideration are those which are most commonly found in many European countries.

Overview of mental health provision in Europe

In order to understand some of the issues connected with the ethical aspects of mental health nursing, it is important to understand the context. Unlike other forms of nursing, mental health nursing need not be completely located within the health sector. In the United Kingdom most mental health nurses are employed either within the National Health Service or increasingly, within the private sector – either in private hospitals or nursing homes. However, in other parts of Europe the situation is different. In the Netherlands, for example, mental health care in the community is largely located within ‘not for profit’ foundations which combine health, social services and other personnel, with local government providing some facilitative functions. Italy, on the other hand, has placed greater emphasis on the social aspects of mental health care and the country has a network of social care co-operatives. Many countries are now deriving funding for health services from insurance schemes and within these systems care is more medically, rather than socially, dominated. These insurance schemes may be private, as in the UK where the percentage of the population with private cover is rising each year. Or they may be a mixture of state-funded and private schemes, as found in Germany. Although the level of cover provided varies considerably, it is rare for continuing or long-term mental health problems to be covered by health insurance.

The deinstitutionalization referred to above is a complex and extremely variable phenomenon. The greatest decline in bed numbers has taken place in Italy and the United Kingdom, while the numbers of people in hospital beds in France, the Netherlands and Greece has declined at a much slower rate.

Another principle which is important to consider in understanding how services are being delivered and how ethical thinking may be formed is that of normalization. As Ramon (1996) notes, normalization is a much clearer concept than

community care, as it focuses on the rights of people with any kind of disability to an ordinary life; on the provision of opportunities for such a life; and the removal of material and attitudinal obstacles to it. Ramon also notes that normalization has become a much more important issue in the UK, Italy and Scandinavia than in the countries of southern, Central or Eastern Europe. As we shall see below when considering the issue of treatment against the person's wishes, the importance of considering the perspective of service users in treatment decisions is crucial. The reader should therefore bear in mind that in some European countries normalization is not a principle which applies to mental health care. In these countries, therefore, the issue of giving patients treatment against their will is obviously viewed in a very different manner than it is in those countries in which a more liberal atmosphere maintains.

The nature of mental health nursing

Despite deinstitutionalization, mental health nurses work in hospitals, of both the large asylum type and in smaller psychiatric units in district general hospitals. Increasingly, however, they also work in various community settings including patients' homes. Nurses working in hospital settings have functions which are in many ways similar to their general nursing colleagues. Treatment in these settings is clearly prescribed by the responsible medical officer and nursing tasks are usually fairly well defined. Nurses are responsible for giving medication, running therapeutic groups and observing patients. Nurses are responsible for planning programmes of nursing care for in-patients, but there are clear definitions of the areas of responsibility. In community settings, these responsibilities are much less clear. For example, community psychiatric nurses may function in a number of different ways. At one end of the spectrum they may, like their hospital counterparts, have clearly defined roles, such as the giving of medication and the monitoring of symptoms. Indeed, this was the original basis on which the first community psychiatric nursing service in England started from Warlingham Park Hospital in 1954 (Moore, 1961). Currently, community psychiatric nurses are