

taking on a wider range of responsibilities and are often designated as the key worker.

In the United Kingdom, key worker responsibilities are presently defined within a legal framework, that is, the Care Programme Approach (Department of Health, 1989). Such responsibilities confer greater autonomy on the nurse, in the sense of more powers of decision-making and a wider brief for implementing a number of interventions without deferral to a psychiatrist. Not all key workers are nurses, however, and a recent national review, commissioned by the Sainsbury Centre for mental health and chaired by Rabbi Julia Neuberger (1997), has recognized that mental health nursing roles overlap considerably with those of other professions.

This review has noted that the case manager or key worker role for people with a serious mental illness being cared for and treated in the community may be undertaken by any mental health professional or indeed non-professional. To emphasize this point, Filson and Kendrick (1997) recently reported a considerable overlap in the roles of occupational therapists and nurses working in the community. In the United Kingdom, key workers in the community usually come from a nursing background, while in the United States, such key workers usually come from a social work background. In Europe, case manager roles are increasingly developing, although the level of responsibility and autonomy given to key workers varies tremendously, not only between countries but also within them. Case management models, such as the one in Verona in Italy, have been common in European countries for many years and these are now being applied in former Eastern bloc countries such as the Czech Republic (Pfeiffer, 1993). As previously mentioned, these case managers may have a greater level of autonomy with considerable responsibility for organizing and delivering treatment programmes. Thus, with this responsibility comes a need to be aware of the ethical issues.

In many countries mental health nurses have developed very specific psychotherapeutic roles. The first preparatory training programmes in behavioural psychotherapy were established at the Maudsley Hospital in London in 1972 to enable nurses to undertake this element of care (Marks *et al.*, 1977; Marks, 1985). These programmes explicitly set out to train nurses as

autonomous therapists in a range of anxiety disorders such as agoraphobia and obsessive compulsive disorder and as therapists for common sexual conditions, such as premature ejaculation, anorgasmia and vaginismus. More controversially, nurse therapists were trained to deliver the treatment of sexual problems where the behaviour can be viewed as 'abnormal', for example, exhibitionism, paedophilia and fetishism. These nursing roles are now commonplace in some parts of Europe, for example in the Netherlands and Scandinavia, and training in these therapeutic techniques is now beginning in former Eastern bloc countries such as the Czech Republic.

A recent and similar nurse educational development in the treatment and management of serious mental illness is that of the Thorn Initiative (Lancashire *et al.*, 1997). Although this programme was originally designed for nurses, it is now open to other mental health professionals, including psychologists, social workers and occupational therapists. The aim of the Thorn programme is to train case managers working in community settings in an array of research-based treatment techniques appropriate for people with schizophrenia. These include: cognitive behavioural interventions for psychotic symptoms; the use of family management techniques emphasizing family stress management and problem-solving; as well as a range of skills connected with case management. This programme is currently only available in the UK, although there are similar, but less extensive, training programmes in Australia (O'Halloran *et al.*, 1995). Within a few years, however, it is likely that similar programmes of training will be established in Scandinavia and the Republic of Ireland.

It is evident, then, that mental health nurses may work in a variety of settings, with people who are experiencing a wide spectrum of mental health problems, for which a wide range of interventions can be used. In addition, mental health nurses have acquired various levels of autonomy. There is no simple way of examining all of the ethical dilemmas faced by nurses within the limits of a single chapter and therefore, in order to capture many of the issues involved, five key areas have been selected. These have been chosen as they represent some of the most difficult problems encountered by mental health nurses in trying to balance the interests of people with mental health

problems with those of the wider society. Also, these issues reflect the vulnerability of this client group. They are:

- Confidentiality
- Sexual and personal relationships
- Treatment against the patient's will and the use of legal measures
- Continuing professional development
- Issues connected with the elderly with mental health problems.

Confidentiality

Mental health nurses face particular problems in connection with this aspect of their practice. Clause 10 of the UKCC's *Code of Professional Conduct* (1992) requires nurses to 'keep confidential any information obtained during the course of professional practice and to make disclosures only with the consent, where required, by the order of a court, albeit she/he can justify disclosure in the wider public interest'. On one hand, when the nurse is acting as a therapist, for example treating someone who suffers a very intimate sexual difficulty, there is both an implicit and explicit understanding that whatever the patient discloses to the nurse is in the strictest confidence. However, in other circumstances, nurses have a duty to disclose certain information to professional colleagues, carers or others. In these cases it can be argued that such disclosure is necessary for the patient's care or to protect the patient or others from possible harm.

Let us examine some of these issues. First, nurses often look after people with serious and enduring mental illnesses such as schizophrenia. As a consequence of that illness, a person may develop a wish or plan to commit an act of violence. While we know that the media portrayal of the seriously mentally ill as violent is generally unfair, there is no doubt that rates of violence among the seriously mentally ill are higher than those found among the general population and such phenomena are common enough to affect most community nurses. Indeed this problem has achieved formal recognition in the establishment,

by the Department of Health, of the Confidential Inquiry into Homicides by People with a Mental Illness. There are, of course, notable examples of violence by mentally ill people and perhaps the most widely reported case was that of Christopher Clunis who stabbed a complete stranger, Jonathan Zito, to death on Finsbury Park tube station in December 1992. The subsequent inquiry (Ritchie *et al.*, 1994) showed that Christopher Clunis's care was very poorly co-ordinated and that communication between all the agencies involved in his case, namely the police, social workers, psychiatrists and nurses, failed repeatedly. One of the key issues in this failure of communication was that of workers in the various agencies not reporting to others, information which suggested that Christopher Clunis had a propensity to cause serious harm. In such cases, nurses have a clear duty to disclose information which they may have obtained within the context of their professional relationship so as to prevent harm befalling members of the general public. To whom then should this information be transmitted? Clearly there is a duty to convey this information to all other members of the multidisciplinary team. However, in many cases there may be grounds for reporting such information to the police. Many European countries are now following the example set by Scandinavian countries and are developing police/mental health services liaison schemes to deal with such difficulties. Italy has a number of these schemes in place, as does the United Kingdom.

Liaison schemes facilitate co-operation with the police and help to ensure that the patient's problems are dealt with as sensitively as possible. Mental health services across Europe are all developing more sophisticated information systems so that care can be properly co-ordinated. However, there is also a world-wide trend towards specifically identifying patients who are at particular risk of harming themselves or others by using mechanisms such as supervision registers. Without doubt, there will be many cases where disclosure of information to the police is very reasonable, as the central reason for disclosure is the protection of the public. Normally, if the nurse feels that there is a danger of the patient coming to some harm or harming others, this information should be shared with the psychiatrist who bears the ultimate responsibility for the patient's care and treatment. In some circumstances, however, as in the case of

community psychiatric nurses working 'on call' duties at night, the nurse may have to exercise discretion and contact the police immediately. Wherever possible, such disclosure should be the responsibility of the psychiatrist in charge.

Gradually, mental health services have begun to recognize that working with people with serious and enduring illnesses poses problems concerning confidentiality and increasingly staff are guided by a range of locally developed policies. The nurse has a moral, as well as a professional, duty to understand these policies before embarking on any autonomous actions. As a corollary of this, nurses are becoming increasingly aware of the need to have good clinical supervisory frameworks in place so that ethical and clinical problems can be discussed with a supervisor. In mental health services, this supervisor need not necessarily be a nurse and in many, a multidisciplinary supervision model is employed, with one specific individual acting as a facilitator. Any breach of confidentiality is serious and striking a balance between maintaining patient trust and safeguarding the public's interest is one of the most difficult issues faced by mental health nurses.

Confidentiality in child sexual abuse

As highlighted in Chapter 7, concern about the sexual abuse of children is rising across Europe. Mental health nurses often work with children who may have experienced sexual abuse, and during the course of their work nurses may not only become aware of continuing abusive practices but also be in a position to identify the perpetrators of such actions. In England, the Children Act 1989, and the associated guideline Working Together under the Children Act 1989 (1991) make it clear that the prime responsibility of the worker is towards the interests of the children involved. The guideline emphasizes that if a worker becomes concerned that a child is being abused, then that worker needs to share that concern with other professionals in the team. This sharing of concern may of course involve breaking confidentiality with the child concerned so as to ensure that the abuse is brought to an end. In the case of children, the potential loss of trust that

the child may experience is an extremely serious concern which must be carefully balanced.

As an extension of this problem, nurses may find themselves working with someone who is a perpetrator of sexual abuse, a situation which is most likely to confront nurses working as behaviour therapists who are specifically trained to treat such sexual problems. What happens, for example, if a paedophile is referred for treatment by a nurse therapist and then, during the course of treatment, the paedophile discloses that he has once again commenced paedophilic activity? There is no specific guidance based on any nursing codes of conduct which can be used by such nurses. However, the professional practice guidelines of the British Psychological Society for Clinical Psychologists (1995, p. 33) do provide some guidance for psychologists, although these materials stop short of giving clear, unequivocal advice. For example, the guidelines cite the following: 'a particular example of this balance of risk might involve the disclosure of a perpetrator of prior sexual abuse who is currently in contact with children, against the strong wishes of an adult survivor who is in therapy. There are no statutory requirements for psychologists to disclose in such situations.'

In summary, therefore, mental health nurses are faced with a range of very difficult situations involving confidentiality and the disclosure of information. Although there are several mechanisms for assisting nurses, such as locally developed guidelines and legal mechanisms, nurses must ensure that they use the multidisciplinary team to share particular problems and that they are able to access appropriate expertise for the purpose of clinical supervision.

Sexual and personal relationships

Although at first sight this seems to be a clearly defined area, it is one where there are potentially a number of problems for nurses. There is no doubt that at one end of the spectrum the issues are unambiguous. For example, in the United Kingdom it is a criminal act for a nurse to enter into a sexual relationship with a patient who is receiving in-patient psychiatric treatment. Similarly, a community nurse who is caring for a patient with a

serious and enduring mental illness and who is, by definition, vulnerable, would be in clear breach of the professional code of conduct if he or she commenced a sexual relationship with that person. Suspicion that such acts are taking place may cause difficulties, however, for other members of the team. For example, all mental health nurses working in hospital settings will have experienced patients who make false claims against members of staff, for reasons connected with their mental illness. Such cases may include patients with paranoid illnesses who may claim, *inter alia*, that a member of staff is poisoning them, is in love with them and so on. Although such allegations may be made either maliciously or as part of the patient's illness, every allegation concerning possible abuse must be treated very seriously.

The central principle in such cases is that, unless there is an extremely good reason, allegations must be investigated properly. This must involve informing the police so that the matter may be investigated thoroughly and independently. It may be that information comes to light which suggests that abuse may have occurred, but the patient does not wish to make a complaint. In this case, there is still an obligation to investigate the matter properly, although considerable sensitivity will be needed by mental health staff and the police. Patients who have experienced sexual abuse by a member of staff may be reluctant to complain because they fear that the complaint will interfere with their treatment or, in some cases, the abusing member of staff may have used threats to ensure silence. In such cases, nursing staff must be prepared to act as an advocate for the patient. From an ethical standpoint, the nurse needs to keep in sharp focus that protection of the patient is paramount and all other considerations, in a sense, become secondary.

In recognition of these problems, many countries are becoming much more aware of the need to provide gender-sensitive intervention. Italy is perhaps the best example of innovation. For example, the Trieste mental health services now operate a service which focuses specifically on women and this service is provided by women mental health professionals. For more detail, the reader is referred to Ramon (1996). Another example can be found in Naples, where a 'women only' service is provided within the public sector. In the UK, there are pockets of good practice in provision of gender-

sensitive services; however, most of these are provided within the voluntary or private sector. Within public sector provision in the UK, mixed wards are the norm and as a recent study showed (Johnson *et al.*, 1997), women users of mental health services are in great danger of sexual abuse and assault while in hospital. In the UK the Royal College of Nursing has campaigned for separation of the sexes in mental health facilities and also for users to have the opportunity of using the services of a nurse of the same gender.

Another dimension which is worth noting, but which has not received specific attention in this chapter, is that of ethnicity and the particular problems faced by people from ethnic minorities who use mental health services. Across Europe there have been major changes in the racial and ethnic mix with migrations from Africa and the Indian sub-continent into many countries. It is worth noting therefore that steps to make services more sensitive to gender issues should also be accompanied by moves to consider the ethnic diversity which now maintains across all European societies. As highlighted in the opening chapters, this obviously brings with it a diversity of spiritual and philosophical views which in turn have major implications for ethical frameworks.

Treatment against the patient's wishes

A recent report on London's mental health services showed that up to 50 per cent of in-patients may be detained under the Mental Health Act (Johnson *et al.*, 1997). In Europe as a whole, legislation varies widely and, in all countries, nurses are faced with the problem of detaining and treating some patients against their will. By definition these patients are in hospital when they do not want to be there and this may be for a period of assessment. However, in a majority of cases patients will be receiving some form of treatment. This treatment may involve medication or, in some cases, electro-convulsive therapy. The framework suggested by Tingle and Cribb (1995) for organizing ethical thinking and discussion is helpful in considering some of the issues. This framework contains four commonly defined key principles:

- Autonomy (the principle of respect for person's and others' right to self-determination)
- Non-maleficence (the principle not to do harm)
- Beneficence (the duty to do good)
- Justice (the principle to consider fairly the interests of all those affected) (Beauchamp and Childress, 1994).

With detention under the United Kingdom's Mental Health Act, all four of these principles need to be considered, both separately and in various combinations. The Mental Health Act 1983 has been framed in such a way that patients' rights are protected as much as possible, and there are considerable safeguards attached to the working of the Act which prevent abuses of power. Patients' rights include access to both an independent review and an appeals procedure. However, nurses, more than any other professional group, have to face the brutal reality of detaining someone in hospital who does not wish to be there. In turn, this may involve using physical restraint to prevent him or her leaving and administering injections of tranquillizing drugs against the patient's will.

Although the power of detention under the Mental Health Act lies mainly with doctors and social workers, nurses have, under Section 5 (4) of the Act, the power to detain a patient who is already receiving treatment for a mental disorder while a doctor who will consider formal detention is found. The Act makes it clear that the nurse can exercise this prerogative if he or she considers that such detention is necessary for the health or safety of the patient or for the protection of others. In addition to this formal holding power, nurses may, in many circumstances, have an important role as their view of the patient obviously influences the decision of the responsible medical officer to continue detention of a patient, to allow them to become informal, or to place another order on them. Deliberations as to whether patients are competent to make decisions about their treatment are compounded by the fact that challenges to patients' competence are often provoked when patients disagree with professionals about what is in their best interests. Nurses need to be very careful, therefore, that decisions about patient competence are kept separate from judgements about whether or not to override their decisions. In other words, would the person's

competence be challenged if he or she concurred with the professional's opinion? Thus, nurses always need to ensure that the information which they provide to those responsible for making a decision is thorough, detailed and objective.

Sometimes, this will mean that although the nurse may have built a sound, trusting relationship with the patient, he or she will need to pass across information which was received in the course of that professional relationship, if it is at all relevant to the decision-making. To take one example, the patient may have confided information regarding doing harm to another person and the nurse therefore becomes duty bound to divulge that information. Thus, it may be that the principles of autonomy and non-maleficence are somewhat in conflict.

There may be occasions when nurses feel that decisions to give medication or a treatment such as ECT is wrong. Nurses should, of course, assert their view at the appropriate time, for example within a ward round or a multidisciplinary team meeting. However, in the UK, nurses have no right to conscientiously object and withdraw their services in such circumstances. Under the UKCC guidelines, nurses are obliged to take part in the treatment process.

User groups and patient autonomy

The way that nurses view autonomy has been changed considerably by the user movement within mental health services. In the United Kingdom, the user movement has grown rapidly over the last 10 years to such an extent that the last review of mental health nursing (Department of Health, 1994) published its final report under the title *Working in Partnership*, alluding to the substantial role that users of mental health services played in the review process itself. For a description of user issues specifically connected with mental health nursing, the reader is referred to Campbell (1996). Several European countries have well-developed user movements. For example, in the Netherlands there are two national organizations, the National Foundation of Patients and Residents Council and the Client Union (Baudin, 1993). These organizations have developed to become powerful in changing the attitudes of the public and profes-

sionals with regard to the rights of patients within the mental health system. The movement has certainly given the patients much greater opportunity to say what they feel about the services they are receiving and in turn, this seems to have produced positive changes in the attitudes of the professionals caring for them. Listening to patients' accounts of how they feel both about the illness they suffer and the treatment they receive is now much more central to the assessment process carried out by nurses and their fellow professionals. Indeed, the focus on personal experience has led to many services offering a much more sensitive and psychologically orientated approach to the symptoms of major mental illnesses such as schizophrenia. A Dutch psychiatrist, Marius Romme, from the University of Limburg, collected a large amount of anecdotal information from patients and together with a journalist colleague, Sandra Escher, developed a number of strategies for helping patients cope with auditory hallucinations. This work has led to the development of networks in various European countries for people who experience hallucinations and has certainly influenced the way that mental health professionals approach people with schizophrenia.

In Italy, the user movement is particularly strong and, like other European countries, has developed in parallel with relatives' organizations. Across Europe these relatives' organizations have advocated greater recognition of the carer's role and called for more information and collaboration from professionals.

The growth of the user movement and relatives' organizations across Europe has certainly led to considerable changes in the attitudes and approaches of mental health professionals. Ramon (1996) has noted that there are now user organizations in 13 European countries and the user voice is also being heard in countries of the former Eastern bloc. Prior to this recent recognition of the user perspective, patients were frequently viewed as passive recipients of the treatment process. When treatment decisions were made, the broad ethical position was of the professional adopting a paternalistic stance, making virtually all decisions on behalf of the patient and thereby largely disregarding any autonomy. The user movement has forced mental health professionals to think about the issue of treatment choice and has made them realize that decisions need to be taken from

multiple perspectives, including professional knowledge, the user viewpoint, the opinions of relatives and carers and finally, the prevailing view of society. In Italy and the United Kingdom there are sizeable groups, both within and outside professional organizations, who consider that the process of deinstitutionalization has gone too far and that some patients, currently cared for in the community, should be in residential settings. This is, of course, not the only view, but it serves to emphasize that when considering overall the principle of justice within the wider societal context, professionals need to be aware that there are no simple ways of describing this dimension.

Continuing professional development

In order to provide the most effective care and treatment, continuing professional development is essential. This professional development not only includes continuing education and training but also, where at all possible, accessing skilled clinical supervision. In a sense, much continuing professional development is only made possible by the employer arranging for appropriate study leave and for access to relevant courses. Nevertheless, there is an ethical obligation on nursing staff to keep themselves abreast of developments. Nurses, as members of a profession, are responsible for updating knowledge by reading professional literature and fulfilling the duty to actively seek opportunities for enriching professional skills and knowledge. In some areas of mental health nursing this issue is more complex. For example, nurses who have received specific education and training for advanced specialist roles have a great deal of autonomy. A nurse therapist, for instance, may be referred a patient with a serious mental health problem and the referring agent will assume that the nurse applies the highest possible level of skills and knowledge.

In carrying out any psychological treatment, the individual nurse is obliged to consider issues of treatment effectiveness and, taking into account the individual assessment of the patient, must ensure that the patient is provided with the most effective treatment available. If the nurse does not have the requisite skills, there is then an obligation to ensure that treatment

is available to the patient, if necessary, by another practitioner. For example, a patient may be referred to a nurse therapist for treatment of a phobic disorder which is usually treated by exposure therapy which reviews of evidence suggest is the optimum choice (Craske *et al.*, 1991). On assessment, however, it may become clear to the nurse therapist that the patient is suffering a severe level of depression and, in such a case, the evidence indicates that medication is the optimum approach. The nurse then has a clear duty either to send the patient back to the referring agent or refer him/her to an appropriately qualified person who may make a further assessment and prescribe the appropriate treatment. Clearly, while such situations are common, individual cases may pose difficulties.

An additional and obvious safeguard for nurses working in such a speciality is that of clinical supervision, which is rapidly becoming a universal standard in many European countries. Nurses have an obligation to ensure that they avail themselves of all the necessary supervisory facilities to enable them to discharge their duties in the most effective and ethical fashion and therefore supervision is demanded by the UK Council of Psychotherapy as a prerequisite to registration. In some cases, appropriate supervision may not be in place and in such circumstances nurses should act in the patient's best interests and ultimately their own best interests, by refusing to continue with the delivery of a clinical service until such facilities are made available to them. In addition, resolution of ethical problems can be greatly enhanced through the process of clinical supervision.

Elderly people

In some ways it is a pity that the topic of elderly people needs separate consideration. If society was fair, elderly people would have the same access to services and be treated in the same way as others. The reality is that in many respects, ageism is prevalent in most Western societies. In Chapter 10 Reed explores some of the reasons for ageism which are many and complex. In simple terms, older people are often perceived as less worthy of attention because of the view that their life is over and they are seen as not contributing to society, particu-

larly in the economic sense. In addition, the cognitive decline which often accompanies old age reinforces a pre-existing negative view. Nurses are as susceptible to these negative stereotypes as are members of the general public and the detrimental effects of this are demonstrated by Norberg in her discussion of nurses working with demented patients (Chapter 3).

Nurses are often employed in positions where they have influence over equity of access and their first ethical duty is to ensure that older people are treated with the same consideration as others and that they enjoy the same access to services. There are many older people who have functional illnesses such as anxiety and depression and for whom treatments are available. The various psychotherapies and medications are as applicable and effective in older people as they are in younger age groups. Age, *per se*, should therefore never be a bar to the receipt of such treatment.

Some problems with older people, for example dementia, may lead nurses to consider both the principles of beneficence and autonomy. In the spirit of beneficence care and treatment need to be designed with an overriding concern for the ultimate benefit of the individual and, as far as possible, pay due regard to the person's power of self-determination. Nevertheless, in conditions where the patient's cognitive function is compromised, nurses may have to make paternalistic decisions on the patient's behalf. In situations where patients cannot, because of incompetence, exercise their autonomy, informed consent cannot be given. This does not mean, however, that the process of achieving consent should not be undertaken, nor does it mean that patients should not be given any information at all. Autonomy is not an absolute concept and even when it is severely restricted, there may well be certain areas of daily life about which patients are able to make decisions.

The cognitive impairment which may be present in many cases will affect how much information is given to the patient and in which mode. Those caring for older people should always err on the side of caution and respect for personhood and, therefore, it is always better to give the patient too much information rather than too little, even though some of it may be beyond their comprehension. Unfortunately, there is widespread evidence that some of those involved in the care of

older people err on the wrong side and provide little or no information, assuming that the cognitive impairment is such that the person will not be able to understand anything. Once more, nursing practice should be guided by both the multi-disciplinary team and the process of supervision.

With regard to older people with dementing illnesses who are being cared for in hospital, the same principles apply as to those patients who are detained under the Mental Health Act for treatment of a serious and enduring illness such as schizophrenia. There are many occasions when the nurse may well have to take action which is contrary to the patient's wishes to ensure that either they, or others, are not harmed. To take a common example, the nurse may need to physically restrain a patient from leaving hospital to protect him or her from being knocked over on a busy road.

Returning to an earlier point, the care of older people should, in the vast majority of respects, be subject to the same ethical principles as that for any other age group.

Conclusion

Mental health nursing is a profession which embraces a wide range of skills, roles and responsibilities. The ethical challenges posed for practitioners in caring for some of society's most vulnerable people are therefore many and varied. New roles in the community, such as those of case managers, are producing new dilemmas, particularly in the area of public safety. It seems likely that mental health legislation will change across Europe, as the provision of compulsory treatment in the community becomes increasingly necessary.

Furthermore, it is likely that nurses will have new powers of detention and treatment at their disposal. The ethical problems which come with these new responsibilities will be great. On account of this, there is a need to strengthen multidisciplinary teamwork, so that nurses may experience and benefit from the necessary support. Recent work (Onyett *et al.*, 1995) suggests that community mental health teams still, by and large, function at a suboptimal level and there may be real problems in achieving best nursing practice. These problems are by no

means confined to the United Kingdom as community teams are a relatively new development world-wide. An additional safeguard for nurses is access to skilled supervision, where ethical problems may be shared and a solution found.

Having said all that, one needs to consider the wide variation in standards of mental health nursing across Europe. Following the 'Velvet Revolution' in the former Czechoslovakia, I undertook a trip to take part in a training exercise held in Prague and in the countryside of what is now the Czech Republic. I was truly taken aback by the way that the mental health services in that country appeared to be out of date, even when compared with the standards which maintained at the beginning of my training in the late 1960s. However, on returning to that country on several occasions in the ensuing five years, the training and the attitude of the workforce have changed beyond all recognition.

The Czech Republic now has a workforce of psychiatrists, psychologists and nurses who are developing innovations in community care and who have made up many of the deficits in education and attitude attributable to the four decades of communist repression. The situation in other former Eastern European countries, however, is still very mixed. While user organizations flourish in Hungary and Poland, countries such as Romania still care for the mentally ill in sometimes squalid and medieval conditions. Although there are many examples of doctors and nurses who are attempting to bring Romania's mental health services to a reasonable level, the nursing workforce is largely ignorant of modern pharmacological or psychotherapeutic approaches.

In situations such as these, some of the more sophisticated ethical considerations referred to above have little or no relevance. Many patients are not receiving the most basic level of care and there are few, if any, resources for education and training. There is currently one training initiative led by a team from the Maudsley Hospital and the Institute of Psychiatry which includes notable figures from British mental health such as Ray Rowden, Victoria Hornby and Jim Birley, but such initiatives need to be replicated. There is, in the author's view, a responsibility for those of us in richer developed countries to do more than offer wise words. Countries such as Romania

do not only need financial aid, but also education and training from more fortunate workforces. Perhaps the final message of this chapter should be that the responsibility for providing ethically sound mental health services across the world is a responsibility that we should all share.

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10

Ethical Issues in the Care of Older People: Difference, Distinction and Division

Jan Reed

Introduction

Ethical debates about the care of older people are extremely interesting on a range of dimensions. They evoke ideas about justice, fairness, personhood and rights, among other things, but one of the fundamental issues which is not often made explicit is the degree to which the concerns that we raise are actually about ourselves. With some of the client groups identified in this book, we can see or construct some clear divisions between these groups and others and between these groups and ourselves. When we talk about children, for example, we can use some legally determined or empirically researched chronological age as a cut-off point. Below this, humans are children and above this, they are not. When talking about people with mental health problems we can use some diagnostic classification system or assessment schedule to say whether or not a person belongs to a particular group. There are, however, problems with these lines of demarcation: individual variations in development make childhood a more elastic concept than we suppose and mental health problems have to be placed in an ever-changing context of cultural definitions and norms. Nevertheless, these definitions are used and part of their function is not only to specify the characteristics, needs

and problems of particular client groups, but also to distinguish them from 'us', the professionals, the normal people.

In the case of older people this will not do. While it is possible to point to legal definitions of, say, 'pensionable age', empirical evidence does not support the idea that there are clear developmental changes once this age is reached. Individual variations and differences are too marked to make this credible. Not only is it difficult, therefore, to demarcate older people, separate them from other client groups and specify their unique needs and problems, but it also becomes difficult to separate them from ourselves. Older people are us, just a bit further on in development and experience. We will become old, we will become them. Being old is not like being young, something you grow out of, it is what everyone will grow into. Being old is not a time-limited condition, like being pregnant, nor is it something for which there might be a cure, like mental illness, it is just being old. When we debate ethical issues in the care of older people, therefore, we debate our own care.

Historically, for professionals such as nurses, the demarcation lines between patient and professional have been an important part of our role and social identity. Menzies (1960) described how much nursing work at the time of her study was based around routines which served to depersonalize care and create a distance between nurse and patient. Armstrong (1983), in his analysis of the nurse-patient relationship, describes how, until the 1970s, many nursing textbooks concentrated almost exclusively on the technical and manual aspects of nursing. When 'psychology' was mentioned, the nurse-patient relationship was often portrayed not as something which was in any way intimate, but instead centred on the nurse as a model of health and efficiency who would inspire patients to comply with their treatment regimes. To some extent, things have changed with the development of more personalized approaches to care, such as the nursing process, patient-centred nursing models and ideas of holistic care. At an official level, at least, nurses appear to be moving towards a more personalized form of care in which emotional closeness is more valued than it was and has ceased to be something to be strenuously avoided.

Distance has also been maintained by language, in the way that this has emphasized difference and has also become pejo-

rative. It is easy to dismiss issues of language as trivial, when in fact they are extremely important because language not only reflects, but also shapes, what we feel (Reed and Ground, 1996). Referring to older people as 'geriatrics', for example, reduces them to examples of a medical speciality, while the term 'the elderly' emphasizes their distinctness as a group. Looking back over the years at my own work, I shudder with embarrassment about the words that I have used. The use of the fairly recent term 'older people', makes the point that there is a group which simply consists of people who are older than others. Critics point out that everyone is older than someone else but in some ways, this is a positive aspect of the term. For instance, it reminds me that I am older than some people, that you are older than some people and that we all share this state of seniority. Most importantly, there is some evidence that older people themselves prefer this term (Walker, 1993).

These issues of difference and distinction are the central themes of this chapter. If ethics is about anything, it is about how we treat each other and how others treat us; put simply, it is about shared experiences and values. Making distinctions and differences is therefore at the heart of ethical debate – do our distinctions allow the needs and problems of our fellow human beings to be addressed more effectively, or do they simply create unhelpful divisions which are ultimately unethical in themselves?

Opinion is very much divided on this. At a pragmatic level, it seems obvious that meeting needs depends on being able to identify them and this is facilitated by being able to classify and summarize the groups of people who have these needs. This process also raises a number of concerns. Many writers have made the point that some policies based on differentiating older people from others result in them being separated from others in physical and social ways, such as receiving care in, for example, care homes or hospitals, or by being excluded from social activities and debates. Retirement policies and pensions for older people are an interesting example of this process. Pensions which are provided simply on the basis of a person reaching a particular age seem to be benevolent mechanisms for ensuring provision for older people. When they are interpreted by employers as a rationale for compulsory

retirement their benevolence becomes questionable as they are then being used as an excuse to exclude older people from the job market. Because pensions are not equal to salaries, older people inevitably experience reduced incomes which affect their activities and participation in social events. Older people become 'hidden' from others, they are not seen around and, therefore, their experiences are not acknowledged in everyday discussions. Another way of hiding the structured inequalities experienced by older people is by portraying them as affluent and emphasizing the power of the 'grey pound'. As Ginn (1993) points out, this process denies the problems that older people face.

Often, these issues can be seen most easily at the political and policy levels where issues of distinction materialize into legislation, funding decisions and service provision (Hugman, 1996). When comparing different countries, as in this book, there are obvious advantages in concentrating on this level of debate as policies are more available to scrutiny than individual personal debates. Also, information about professional concerns can be very limited, particularly if, as in the case of the care of older people, the nursing input is not always significant and the professional voice is not always heard. This does not mean, however, that the ethical issues covered in this chapter will only be at a political or policy level. What I hope to explore is the relationship between this form of ethical debate and the delivery of care. Nursing takes place in political and social contexts which shape practice in powerful ways and an awareness of this dynamic is essential if nursing is to understand and develop practice. To see nursing ethics as distinct from the general political and social context in which nurses work, is to miss an opportunity to identify and voice concerns, to challenge prevailing assumptions and to ensure that the care that we give is consistent with our professional values and those of our clients.

Ethical issues at a policy level

The areas of moral and political philosophy are important in this discussion. These areas have often been considered as distinct from each other in general textbooks of philosophy

where, for example, there are separate chapters for each topic. In philosophical writings this distinction is not always clear, however, and philosophers such as Kant or Mill discuss general principles of conduct which they apply to both personal and political spheres. It is useful, however, to make some distinction between the two topics, based on the recognition that there is a great deal of difference between the state and an individual (Reed and Ground, 1996). There is, of course, a relationship between the two – the state acts for or represents individuals, ignores them or oppresses them. Equally, individuals have varying degrees of influence on state activities.

The decisions that are made at a political level, therefore, impact on practice and care. This may be in the way that resources and funding for care are determined, the way that priorities for spending are set, or the way in which goals and aims for services are formulated (Boyajian, 1988). Where state resources are limited, always remembering that the state has already made decisions about what level of resources it should have, through its taxation policies, then the competing claims of various different groups have to be weighed against each other. In this process of weighing, a number of considerations are possible. First, it may be thought that the state does not have a responsibility to meet these needs, that the provision of state support is either demeaning to people because it reduces their independence, or it is unjust to those who have been prudent enough to make their own provision. Second, if some state responsibility is acknowledged, then a number of other considerations come into play about the strength of the claims of different groups.

Cultural and social values influence how decisions between the claims of different groups are made. Societies can, for example, attach merit to certain groups because their dependency arises from an activity which is approved of. War heroes are usually regarded more highly than drug addicts because the former group acquired their disability through activities which were of benefit to others in society, while the latter group can be reviled because their problems are seen as self-inflicted and of no benefit to others and indeed may make others' lives more uncomfortable, unpleasant or dangerous. Decision-making of this type evokes notions of reciprocity, that is, the idea that

the contributions that a group of people make (or have made in the past) should be rewarded and met with equivalent contributions. If this form of reciprocity prevails, older people are likely to benefit as their past military, political and cultural contributions – in a Europe which, in this century, has seen much conflict – will be held up as justification for providing them with support now. If, however, the idea of reciprocity is time limited, so that only current contributions are acknowledged, then the position of older people becomes more vulnerable. If older people are not working or fulfilling active social or familial roles, then they can be seen as parasites on the active, working, money-making, younger population.

Another temporal dimension of reciprocity is the commitment that we might feel to future generations. As Becker (1986) has argued, this is a somewhat puzzling idea which seems to be based on some sort of allegiance to the notion that perpetuating the human race (or at least our own ethnic version of it) is of great importance. Another element of this commitment to future generations is perhaps based on self-interest, in that we look after the young so that they will look after us if we need help when we are old. It may be the case that, when choosing between meeting the needs of older people or those of children and younger people, one conception of reciprocity would lead us to favour future generations. The irony is, of course, that if this is done for reasons of self-interest then we abandon older people in the hope that younger people will not do the same to us in the future.

There are, of course, other cultural values which impinge upon the decisions made about the distribution of resources to different groups. For example, Western society is often described as being youth-orientated, in the way that people see youth as desirable and old age as distasteful. This set of values can make older people an unpopular choice for resource allocation. These negative attitudes to others have been explored by many writers who point to reflections of these aesthetics in both literature and current cultural images (Till, 1993; Blaikie, 1994). As Norman (1987) has put it, 'both as individuals and as members of society, we find it extremely difficult to be honest about our attitudes to old age and old people. There is an ambivalence at the root of our being.' Norman details this ambivalence further

when she talks about feelings which 'cannot with decency be openly expressed' such as '[the] contempt of the young and strong for the old and weak; fear of the mortality which old age represents; guilt which is translated into anger; and resentment over the need to use scarce resources and precious time on people "who have had their life"' (Norman, 1987, p. 3).

The 'unpopularity' of older people in Europe very much depends on them being singled out as a group of people who are different from the rest of us. This demarcation simultaneously creates and reinforces stereotypes of older people and puts in place mechanisms for systematically classifying their needs as being the problems of old age, rather than problems which are shared across society. What seems a reasonable and sensible approach to identifying need can become a means of pigeonholing people and reducing them to stereotypes. Whether we adopt a position of 'compassionate ageism' (Binstock, 1984) where we feel pity for the frailty and problems of older people, or whether we portray them more positively as affluent and therefore less needy, approaching what Arber and Ginn (1991) have termed 'conflictual ageism', where older people are seen as taking resources away from other groups, both of these positions depend on stereotypes.

It was these concerns that prompted the 1993 'European Year of Older People and Solidarity between Generations'. The aims of the year were, by and large, to highlight the ways in which older people in Europe were living their lives and, perhaps more importantly, to foster mutual understanding across generations and identify areas of common or mutual concern, rather than differences.

Ethical issues at a practice level

The above discussion about wide-ranging social and political ethical debates might appear to be about issues which are separate from nursing care. These issues do, however, impinge upon nursing practice in a number of ways. The ethical and political framework of resource allocation and policy development provides the context in which practice takes place.

Perhaps the most obvious way in which this happens is in the way that the value accorded to particular client groups affects the resources that nurses can command. The label 'Cinderella service' is evidence of this and is frequently applied to such client groups as older people and people who have learning difficulties or mental health problems. These resources affect the material state of the buildings in which care is delivered, whether there are carpets on the floor, the quality of the curtains and the equipment available. Resources also determine the number of staff that are available, the degree to which they are trained and, to some extent, the amount that they are paid. Seedhouse (1988) touches on this in his 'ethical grid' through which he develops a framework for making ethical decisions. He includes in one layer of the grid (the black layer in his diagram) a range of external considerations about the law, codes of practice and the wishes of others, which all impinge on ethical decision-making. As Seedhouse argues, 'in many cases, in the real hard world, the black layer contains the most important factors of all' (Seedhouse, 1988, p. 138).

More subtly, political decisions about the importance and value of older people affect the goals and aims of nursing care. Evers (1981) has evocatively described an ethos of care which she called 'warehousing', where older people were 'stored' in geriatric wards until they died. Evers points out the lack of therapy and rehabilitation in these environments and the pervasive view that the function of the care service was to do little more than this. This state of affairs owes much to the negative and pessimistic views of older people which seem almost endemic in many cultures, the way that they are translated into policies which set organizational goals and into the practices which operationalize these goals. While many nursing debates tend to be carried out as if they were separate from the prevailing political and organizational contexts, a number of studies suggest that there is a close relationship between organizational goals and values and the nursing care given to older people (Baker, 1983; Reed, 1989).

Looking at some of the values and goals of nursing, it is evident not only that organizational goals can shape practice, but also where this impetus does not correspond with nursing ethics, then conflicts can arise. Take, for example, the nursing goal of

individualized care with its connotations of respect for persons. This can be operationalized through a range of different nursing activities, such as acting as an advocate for older people. As Kendrick (1997) points out, however, acting as an advocate is an idea with inherent problems surrounding issues of power. Moreover, in an organization or health care system which is not supportive of the wishes of patients, does not respect their autonomy and is simply trying to deliver care as cheaply as possible, the role of advocate is ultimately unsuccessful and may raise expectations only to see them dashed.

Linking policy and practice debates

Macintyre's (1977) analysis of policy for older people provides a useful framework in which to examine these connections more closely. She points out that the idea of old age as a social problem which needs to be addressed through policy and provision is a relatively recent phenomenon in the UK. Throughout early policy developments for dealing with the needy such as the Elizabethan Poor Laws, older people were not distinguished in any way from other groups of people needing support or 'relief'. Macintyre argues that they only became 'officially' recognized in policy formation towards the end of the nineteenth century and there is some evidence (see Troyansky, 1996 for an overview) that this was the case in other European countries.

When older people were distinguished as a special group of the poor and needy, Macintyre argues that this was tied up with ideas about 'deserving and undeserving' poor. Some of the strategies for dealing with need, such as 'indoor' or workhouse relief, were partly designed and administered as ways of discouraging people from applying for help and as a means of motivating them to provide for themselves. As such, the strategy was based on the assumption that many of the poor were able to fend for themselves, but were too lazy or dissolute to do so (Longmate, 1974). Older people, however, could not be accused of such moral degeneracy as even the most vigorous detective of abuses of the public purse could see that older people were simply not capable of providing for themselves, particularly in a world where the Industrial

Revolution had put a heavy premium on hard manual labour in factories.

Macintyre further discusses how, after the identification of older people as a social problem, the problem itself is open to different formulations. The first formulation is that the problem is a humanitarian one, in other words 'a perception of old age as bringing problems of various kinds to individuals, problems which the community should attempt to ameliorate through increased provision' (Macintyre, 1977, p. 49). She goes on to argue that the humanitarian view was the one which predominated in the UK at the beginning of this century. It stimulated the separation of older people from other needy groups and set policy goals as being the appropriate and adequate provision of support.

Macintyre then goes on to describe how the problem of old age was reformulated as the century progressed. This was particularly evident as the debates in the UK about the new Welfare State took place and plans for this were developed. Beveridge, for example, more than once cautioned against too-liberal provision for older people as the Welfare State that he envisaged would be funded through the contributions of young working people, and therefore their welfare was paramount. The problem of old age became one of how to reduce their demands on others, or how to meet their needs at a containable (and reduced) cost. Macintyre describes this as the organizational perspective, 'consideration of how best to reduce the social costs imposed on the community by the elderly population' (p. 44).

If we use this framework as a way of exploring the impact of policy on practice, then we can look at three sets of implications. First, if the policy formulation is a humanitarian one, then the goals of care are to meet need and address problems in as effective a way as possible. The concern is primarily that older people are not receiving enough care, or care of an adequate standard. The expectations of such a formulation, therefore, would be that resources would be made available, or at least efforts would be made to provide them. There would also be concerns about the quality of the care that was delivered and that it was provided in the right way and at the right time. Because this would, hopefully, entail some concern for the views of older people themselves, then it is also reasonable

to expect that the autonomy of older people would be promoted, as would the nurses' role as advocate.

If, however, the policy formulation is an organizational one and the central concern is to minimize cost, then practice is very different. Not only are the resources for care limited, but the whole goal of the service is to provide minimum standards of care within these minimum resources. Practice becomes a matter of scrimping and saving, with few staff and little equipment. To use Evers' phrase, the goals of care are about 'warehousing'. Ethical practice, which might include the promotion of autonomy and the development of advocacy roles, becomes extremely difficult to establish and nurses who adopt these values find them difficult to put into practice.

We must not forget, however, the other state of affairs that Macintyre describes which is the state where old age is not identified as a social problem at all. While the humanitarian formulation can be seen as a positive approach and the organizational one can be regarded as a negative approach, both depend on making a distinction between older people and everyone else. If we accept the argument that such distinctions inevitably create barriers between people and foster stereotypical thinking, then we are coming close to arguing that they are inherently unethical in a way that erodes respect for persons as unique individuals, reducing them to stark demographic characteristics. If this line of reasoning is followed, the conclusion that making distinctions is inherently a bad thing if we want to practise ethically, must be drawn.

Alternatively, not making distinctions may lead to other ethical problems. Treating older people just like everyone else fails to delineate the particular issues that face them and that may require specific action. In that case, one must conclude that not making distinctions is inherently a bad thing if we want to practise ethically.

Ethical issues in the care of older people: a European perspective

So far, this chapter has tried to explore ideas about the ways in which political and policy decisions are ultimately based on

judgements of value and therefore are inescapably linked to ethical debates. In particular, there has been some debate on the ethical consequences of distinguishing between older people and everyone else. This distinction can be the basis of problematizing older people in ways that can be broadly regarded as either positive, or negative, in their consequences. These consequences arise from the way that solutions are posed and by the impact that these solutions have on practice.

From this we can begin to postulate some ethical dilemmas and issues for nurses and we can now extend the discussion to an examination of the issues from a European perspective. In the introduction to this chapter I suggested that one way to explore ethical issues in the care of older people in other countries was to look at the policies that they have. This is because policies are often more accessible than professional debates, especially where professional input into the care of older people may be minimal or difficult to identify. Using Macintyre's useful framework, I now want to concentrate on the idea of distinguishing between older people and the rest of society as a fundamental ethical debate. To do so, it is necessary to identify, as far as possible, countries where this distinction is not made. Under these circumstances it is impossible to identify professional debates as there can be no professional debate specifically about the care of older people if older people are not identified as a specific group of people needing care.

The following discussion, while it draws where possible on material which is directly about the ethical debates facing nurses caring for older people across Europe, also makes significant use of the available information about general policies and political philosophies in these countries. The connection between practice and policy, therefore, is made as much by deduction and postulation as by empirical evidence.

Denmark: the humanitarian formulation

Denmark is, perhaps, one of the European countries that comes closest to a strong humanitarian formulation of the 'problem' of old age. The chief concerns of provision and practice seem to be to provide the best possible care for older people. Johansen

(1986) charts the history of welfare provision in Denmark which in many ways is similar to the UK history. A series of Poor Laws and workhouse systems did not distinguish between older people and other needy groups until the end of the nineteenth century when the Old Age Relief Act was enacted in 1891 (Johansen, 1986). Early in the twentieth century, however, a series of reforms, such as the 1922 Old Age Pension Reform and the 1933 Social Reform, which introduced universal benefits, established welfare provision for older people in advance of UK developments.

Denmark has also been quicker than the UK to move towards community care and the provision of care for older people in their own homes. Indeed, Jamieson (1990) notes that there is no equivalent term for 'community care' in the Danish language, which she suggests indicates a lack of ambiguity about the nature of care. It is assumed that it will be community based and hence needs no further qualification. While standards of care in institutional settings are high, no additional care homes have been built since the Housing for the Elderly Act of 1987 and the emphasis has been on providing care to older people in their own homes. To this end, the building of specialized accommodation has been encouraged as have a wide range of facilities and home-based services, including gardening and snow-clearing (Wilderom, 1991). This move, which Giarchi describes as in some ways resembling the 'brave Italian decision to close down its psychiatric institutions' (Giarchi, 1996, p. 99), seems to have been prompted less by overt concerns about the cost of provision than by the desire to respect the wishes and preferences of older people (Abrahamson, 1991). Nevertheless, as predictions for population growth suggest that by the year 2025 the proportion of older people will be 22.2 per cent, which is the second highest in Europe, issues of cost and the sustainability of provision are raised.

With this long history of well-established provision it is not surprising that suggestions for reductions in provision and/or dismantling of the Welfare State have been met with great unease (Giarchi, 1996). The welfare system in Denmark, as Jamieson (1990) describes it, is almost completely state-managed, with very little voluntary or private sector involvement. There is little desire to change this or to put more responsibility on to family networks as state provision is seen

as a right of citizens and no stigma is attached to using these services (Jamieson, 1990; Giarchi, 1996).

In accordance with these beliefs and principles, the most frequently voiced criticism of the system is the degree to which it provides a high quality of service which meets the needs of older people – the humanitarian formulation of the problem of old age. Jamieson (1990), listing some of the concerns which have been voiced, identified that some people are being hospitalized needlessly and that professionals tend to exclude them from participation in decision-making. Jamieson also indicates that social aspects of care, such as social contact and integration, are also missing from Danish care, a situation which she suggests may be seen as 'inherent in the professional approach which characterises the public services' (p. 13).

For the practitioner, the ethical issues of caring for older people in Denmark are not centrally concerned with establishing and maintaining rights to care or equity of provision, at least not at the moment. The ethical concerns are, by and large, about how this care can be improved. One particular area of concern seems to be the degree to which older people are empowered and their autonomy supported and respected. Ramhoej (1992), for example, has described how in nursing home care, 'great importance is attached to attitudes towards elderly people living in homes. The old person should not lose their civic rights when moving to an old people's home. His room is his residence and should be regarded as sacred' (p. 17). The rights of citizenship, which convey entitlement to services, need to be extended to rights within the service such as rights to shape care, to have some say in how it is given and what form it should take. Ramhoej also goes on to describe how personnel should not 'undertake responsibility' for the older person but 'the person himself decides which offers [of help] he wishes' (p. 17). This may involve some form of advocacy at an individual rather than at a societal level, but nurses need to make an effort to find out what it is that older people want and then establish how and if it can be managed.

The United Kingdom – the organizational formulation

The UK situation comes closest to the organizational formulation than to any other, although none of these forms is 'pure'. Macintyre (1977) points out that there has always been some ambivalence in UK attitudes towards provision for older people, and this is evident even in policies which are generally felt to be humanitarian. Beveridge, for example, in the Report of 1942 which paved the way for the Welfare State, sums up the problem thus: 'On the one hand, the provision made for age must be satisfactory otherwise great numbers may suffer. On the other hand, every shilling added to pension rates is extremely costly in total... It is dangerous to be in any way lavish on old age, until adequate provision has been assured for all other needs, such as the prevention of disease and the adequate nutrition of the young' (Beveridge, 1942, para. 236).

This ambivalence continues to the present day, although more recently the concerns being voiced about the care of older people seem to be more clearly organizational, as the demographic time bomb is predicted to explode in the near future, showering the UK with older people who will be a drain on resources. Debates about resources often involve discussion of people's responsibility to provide for themselves through, for example, personal pension plans. Recent pension scandals where people have been misled about the returns from schemes, or where funds have been misappropriated, have raised some questions about this move. Similarly, moves to encourage the participation of families in the care of older people may reduce the burden on the state, but in practical terms, many families may not be able or willing to provide this care, nor may older people be happy to accept it.

In this climate of encouraging individual responsibility, the state has not remained completely inactive, on the contrary, a wide-ranging review of health and social services for everyone has been undertaken in recent years. There has been an explicit encouragement of more voluntary and private sector involvement in provision, for example through stipulations that local authorities spend a certain proportion of their budgets purchasing services from this sector (Giarchi, 1996). This idea

of creating a 'welfare mix' so that the state, the private sector, voluntary organizations and individuals combine to provide services is an attempt to move away from what is often seen as a rigid and bureaucratic state-controlled system which fails to meet clients' or consumers' needs. The other side of the coin, however, is that consumerism can only work if consumers have the power to purchase, that is, they have resources at their disposal. For those who have been unable to save money or accumulate wealth, or who have only minimum pensions, purchasing power is just a dream.

The ethical issues for nurses in the organizational formulation are mainly concerned with maintaining equity and justice in the allocation of resources. If the organizational solutions that are proposed are to move responsibility from the state to the individual, as seems to be the case in the UK proposals, then the ethical issues facing practitioners are about rights to services. Whereas one view would be that these rights should only be dependent on the ability to pay for services, this is not the only view and nurses need to explore and articulate other rationales such as respect for persons, the idea of basic human rights and the ideas of justice.

Bosnia and the former Yugoslavia – no formulation

It is difficult to imagine a society or culture in Europe which has not identified the 'problem' of old age in one way or another, or which has not at least marked out older people in some way. The ideal of a society where age does not matter in the way that people are regarded is one that may seem attractive to those who have seen or experienced the harmful effects of ageism. Reading accounts of workhouse life prior to the 'official' recognition of old age, where everyone was treated alike regardless of the reasons behind their destitution and need, does suggest that making a special case of old age may well have some benefits. To do otherwise is to revert to a horrendous form of 'jungle law' where older people are accorded no concessions in the struggle for survival. Before older people were formally recognized as different from other groups of needy people, they were required to work alongside other

fitter inmates at what were sometimes arduous tasks and were given no concessions in the provision of food or accommodation (Longmate, 1974).

Trying to explore the ethical consequences of non-discrimination in contemporary European culture is a difficult task because the idea of age as a primary means of describing people is such a powerful and pervasive one. There is some evidence, however, that in some European cultures the notion of age as an important way of categorizing people is relatively weak and this raises questions about how this translates into care.

A research study carried out in Bosnia has suggested that the category of 'elderly' is not a meaningful social category. 'There is a simple absence of such a cognitive category in many Bosnian people's understanding of their society' (Vincent and Mudrovic, 1993, p. 98). In response to the authors' questions about the problems older people had in Bosnia, the frequent reply was that they had the same problems as everyone else.

This does not mean that the life course is not conceptualized in any way in Bosnian culture, but rather that chronological age is not the foundational idea. Instead, Vincent and Mudrovic identify the recurring idea of *snaga*, which they translate as power or vigour, so that old age involves a loss of *snaga*. When older people were asked about how they felt about ageing, their response was often that they had lost their *snaga*.

The cultural context of *snaga* is explained by Vincent and Mudrovic in relation to established lifestyles in Bosnia, particularly in the rural areas. Work, mainly consisting of farm labour, is synonymous with life for many people. As Vincent and Mudrovic describe it, 'work in this sense is not the British concept of paid employment but rather the activities in the house, on the land, in the factory or workshop necessary for survival' (1993, p. 99). This integration of work and life is perhaps a reflection of the stage of industrialization which Bosnia has reached. As Vincent and Mudrovic point out, migration from rural to urban areas has only been a significant feature over the last 30 years and in rural communities the pattern of life is built on shared family households and agricultural activities. In this environment formal retirement ages mean little and the integration of generations in collaborative working means that *snaga* is more salient than age. With the movement

to urban areas, such patterns, while remaining strong cultural templates, have shifted and increasingly younger people are moving to towns to new forms of work, leaving older people in rural areas. The differences between generations are therefore inextricably linked to differences in work and location.

Nevertheless, the notion of *snaga* rather than chronological age being a more important marker of life is an appealing one in many ways. The loss of strength, while it may occur mainly in older people, is not unique to them and this opens up the possibility of solidarity across generations between all those with debilitating conditions. Similarly, for those older people who do not experience a loss of *snaga*, the social stereotypes of older people may not be applied to them in a draconian and inflexible way. In this way, physical condition becomes more important than age as a social category, a situation which seems more fair, logical and helpful.

When the translation of this into policy and service provision is considered, however, some problems arise, particularly in the context of the violent upheavals in the former Yugoslavia. The communist regime, with its superficial motto of 'brotherhood and unity' espoused by the totalitarian leader Tito, collapsed with his death. This collapse and the ensuing ethnic conflict resulted in the demolition of the centralized communist policy-making machine (Giarchi, 1996). In such an environment, if the needs of specific groups are not acknowledged and their importance reinforced, they can easily be forgotten.

Giarchi (1996) argues that many older people in the former Yugoslavia are experiencing great deprivation. Pensions, for those that have access to them, are not always paid in full or on time because of war conditions. Ruzica *et al.* (1991) suggest that the poverty of older people receiving pensions is partly due to their low level in an economic climate where inflation at one point in 1989 was 1365 per cent, leading to a situation where at least half of the older people were below the poverty line. It is not surprising, then, that significant numbers of older people stay at work. In 1985 the figure was 20 per cent, with half of this group working full time, but with internal wars, opportunities for employment are likely to be very much reduced.

Services for older people are very difficult to evaluate, particularly since the wars began. Giarchi's summary of discussing

nursing services and nursing homes illustrates this well when he states that 'little has been published regarding the numbers involved, eligibility and the extent and quality of the work' (1996, p. 420). In discussing mental health care, Giarchi simply states that there are 'no reports available regarding mental health services for older people in the territories of the former Yugoslavia' (p. 421). Nevertheless there is some information available which gives some indication about the level of provision. Ruzica *et al.* (1991) state that institutional care, when provided at all, is based in a small number of homes (less than 200 across the former Yugoslavia), each with between 150 and 200 residents and, at the time of publication, at least 5400 people on the waiting list.

There is some evidence that even before the wars this provision was being cut back (Giarchi, 1996) and the care of older people was being returned to the family sphere, alongside the movement towards decentralization and away from traditional state institutions (Milosavljevic and Ruzica, 1989). This reliance on family care echoes the recent rural past where families tended to work and live together with the general expectation that the family, rather than the state, should bear this responsibility. Giarchi quotes Article 124 of the Law of Marriage and Family Relations in Slovenia as an example of this: 'Children of age are obliged to maintain their parents who are incapable of work or do not have enough means for their care' (Giarchi, 1996, p. 426). While this emphasis on family values may seem right and proper to some, it must be remembered that if society as a whole does not take responsibility for older people and families break up, as in the case of war, older people are left to fend for themselves or to receive help from voluntary agencies, such as the Red Cross (Giarchi, 1996). With the extreme form of decentralization found in the break-up of the former Yugoslavia where a centralized communist regime has been replaced by a range of warring factions fighting over territory and resources, a 'rather anarchic' political scene ensues with 'enterprises... becoming increasingly exposed to open markets [and] there is no special protection by the state, close downs are more and more frequent' (Svetlik, 1992, p. 221).

For nurses in the former Yugoslavia, a central ethical challenge is to ensure that the particular experiences and needs

of older people are recognized and addressed in a way that does not stereotype them as passive, dependent and pathetic creatures, but instead in one which respects their abilities and strengths and preserves their dignity. Achieving this, particularly in a situation where there are so many other priorities, is an extremely difficult task and requires well thought through arguments rather than emotive appeals. It requires that the different arguments for and against making distinctions are weighed up and the consequences of policies are evaluated. The question is not so much about ensuring the quality of services, but about ensuring that they are provided at all.

Conclusion

This chapter has tried to identify and explore some core ethical issues in the care of older people. These issues involve the distinction and differentiation between older people and others in society. The ethical issues which arise from making these distinctions are complex and they can lead either to stereotypes and ageism, or to a more sensitive understanding of the particular experiences of older people. The ethical and moral impact of making distinctions has to be seen against a range of political and policy contexts and examples have been drawn from three European countries where these contexts appear to be very different and where the central ethical issues facing nurses become subtly, or not so subtly, different. Where the political context is humanitarian, there is no dispute about access to services; instead, the focus is about quality of services and issues of choice, autonomy and empowerment. Where the political context is concerned with cost containment, the nursing task is to try to ensure that access to services is maintained and that provision is at least adequate. Where the political context does not firmly identify older people as a specific group, the nursing task is to ensure that the situations in which older people find themselves, and the problems that they face, are made apparent to others. This can be illustrated by Figure 10.1.

All of these ethical tasks involve some form of advocacy, either by articulating the needs of older people or by empowering them to direct service provision by articulating their needs

<i>Formulation</i>	<i>Ethical task</i>
Humanitarian formulation	Ensuring quality of services
Organizational formulation	Ensuring access to services
No formulation	Exploring and communicating the needs of older people, so that services can be provided

Figure 10.1 Formulations of the problems of old age and their associated ethical tasks

themselves. This advocacy, however, needs to take many things into account: the ageism inherent in so many cultures; the imbalance of power between professional and client; the reluctance of some older people to voice their wishes; and the ever-present danger of marshalling public support through appeals to pity which demean older people and reduce them to passive recipients of care. There is also some degree of hierarchical structure in these tasks. Where the political context is primitive, as in the case where the needs of older people have not been formulated, then the corresponding ethical tasks are very basic and are about establishing the need for care. Where the political context is more sophisticated, then the ethical tasks are qualitatively different and are about issues of access and quality in care. What is central to all of these ethical tasks, however, is that nurses take a wider view of ethical issues and see them not only as part of the day-to-day business of giving care, but as being inextricably linked to the political and policy contexts in which care is given.

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11

Ethical Issues in Critical Care Nursing

Kevin David Kendrick

Introduction

The thrust of this chapter is to explore research findings about issues that cause ethical concern for critical care nurses in Europe. Comparisons between the experience of critical care nurses in Sweden and the United Kingdom will be made for the simple reason that these are the only two European countries that have, to date, published research papers related to the way that nurses deal with, or feel about, the moral dimensions of critical care practice. The first stage in this process will be to explore the preparation of critical care nurses to deal with ethical issues and to identify the nature and essence of nursing ethics in relation to the delivery of critical care.

Ethics: a common concern

Recent decades have seen major scientific and technological advances in the care of critically ill patients. Conditions that once would almost certainly have caused death are now confronted by a broad range of complex interventions (Margotta, 1996). The essential elements in this type of care delivery and management may be defined as follows:

Critical care is optimally delivered to patients by a team of highly trained personnel who are provided with the physical facilities,

equipment and organisational structures that will enable them to fulfil their life-saving and life-preserving function and to do so effectively and efficiently. The intensive care unit has therefore been looked on as the 'hospital's hospital' (Noc and Weil, 1996, p.3).

Meeting and dealing with situations that have an ethical dimension is an intrinsic part of working in this sort of demanding environment and such situations always create a challenge to those involved with them. Facing difficult moral scenarios can cause doubt, anxiety and turbulence among those working in critical care areas and can also contribute to staff burn-out and high turnover (Fenton, 1988; Kendrick and Cubbin, 1996).

To some extent, education is culpable for this situation as it has been slow to offer critical care nurses the opportunities to engage with the 'tools' of ethical analysis (Melia, 1996). This deficiency was largely the result of the cursory attention paid to the place of ethics in post-basic courses in critical care; an omission that has only recently been revisited and addressed (Kendrick, 1994a; Leavitt, 1996). Thus, although nurses across the European Community are drenched with educational opportunities leading to technical competence and, ultimately, expertise (Timmermann, 1996), their ability to engage with the moral demands of critical care delivery has traditionally been left wanting. This is a point upon which some commentators have cogently commented: 'what is technical competence worth when shackled by moral incompetence?' (Hunt, 1991, cited in Tschudin and Marks-Maran, 1993, p. 77).

Summarizing these themes, it can be said that European critical care nurses are faced with the moral dilemmas involved in working in an environment that is technologically advanced. However, there is little educational or practical support to help them confront and frame ethical concerns which can lead to angst, disillusionment and low morale (Bertolini, 1994).

Beyond medical ethics

Many of the published papers dealing with the moral concerns associated with critical care have traditionally been subsumed

under the umbrella term 'medical ethics'. The following list highlights some of the subjects that frequently arise in the literature:

- The ethics of organ transplantation (Blackwell, 1989; Anaise *et al.*, 1990)
- Considerations of age and the allocation of medical resources (Levine, 1989; Dimingo, 1993)
- Do not resuscitate orders in intensive care (Bedell, 1986; Brown, 1990; Marsden, 1993)
- Brain stem death (Pallis, 1983).

There is no doubt that these subjects have moral relevance, especially to doctors and nurses. Seedhouse (1988, p. 34) refers to such dilemmas as 'specific or dramatic ethics' and argues that such scenarios are usually characterized by a pressing need to make a clear decision about a definite course of action. To illuminate his position, he gives the following example:

For instance, the choice might be whether to switch off a life support machine in order to transplant a variety of organs to three waiting recipients, all of whom stand a good chance of further fulfilling life, or whether to keep the machine on because of the slim possibility that the body might regain consciousness (Seedhouse, 1988, p. 34).

Such dilemmas are usually categorized as 'medical ethics' because it is the doctor who has the clinical and legal autonomy to be prescriptive about the chosen outcome. To try and increase nursing's autonomy and continued professional emergence, nurses in some countries increasingly undertake work that was once performed only by doctors (Marshall, 1997). In effect, this has challenged and blurred traditional working boundaries and in the United Kingdom, this situation has been formalized by nursing's governing body in its document *The Scope of Professional Practice* (UKCC, 1992).

In essence, this document sought to broaden the parameters of professional autonomy by encouraging nurses to deliver safe, competent and accountable care. It gave nurses the freedom to perform activities that fully challenged their skills and expertise, while at the same time achieving a corresponding reduction in the working hours of junior doctors.

Some commentators have explored nursing's preoccupation with increased levels of technical care giving as Castledine (1993, p. 686) suggests:

I do not mean to imply that the nurse of tomorrow should take on all the tasks that doctors do not want to perform. Rather, I am suggesting that the present and future role of nurses covers a wide span, ranging from the most simple tasks to the expert, professional techniques that are necessary in acute life-threatening situations.

A key supporting theme is that professional autonomy increases through such avenues, as it may be argued that if the technical delivery of care is increasingly shared between doctors and nurses, they should, at the very least, have equal voice when decisions are ethically sensitive. To do less than this denies the moral agency of the nurse.

Such notions are, however, fallacious because they create an illusion that nursing's increased involvement with technical care somehow increases the worth and currency of the ethical decisions made by its practitioners. This form of argument is similar to the common misnomer that increased technical competence somehow increases the essence of nursing's value and professional creed. Instead, the worth of the nurse as a moral agent is intrinsic and advancing technical ability does not add to this. The nub of the issue is captured by Bergum (1994, p. 78):

The nurse and the doctor must move from the technological reasoning of the scientific laboratory to the bedside, where tact and thoughtfulness may bring forth new and necessary knowledge. The startling picture of real people being fragmented into abstract parts can be lessened through further development of abilities to enter relationships with patients that focus on understanding human experience.

Sharing ethical decision-making

Difficult ethical decisions should be explored on a shared footing that values each practitioner's right to voice his or her moral concerns and perspective, be they nurse, doctor or other member

of the team. Such themes are essentially Kantian and reflect the third formulation of the Categorical Imperative which states: 'in wishing to be moral, individuals must act as members of a community where everybody is seen as having intrinsic worth (ends in their own right)' (Korner, 1982, p. 63). Commenting on this formulation of the Categorical Imperative, Kendrick (1993, p. 924) applied its sentiment to nursing practice and states:

As nurses, we often meet colleagues or clients who hold differing views to our own. While it is legitimate to hold contradicting attitudes towards the same issue, the central principle is that both parties have equal licence to hold, express and defend their respective positions.

Doctors have no mandate to hold sway over moral decisions which should be based on a shared governance. If the current vogue for interdisciplinary working and learning is to be founded on more than rhetoric and empty semantics, it must grasp the ethos of 'teamwork' in its fullest sense and meaning. In this way, the central ethical issues that face nurses in critical care are no different from those faced by colleagues in other areas of care delivery. The context may be different, but the desire to be acknowledged and listened to remains the same. The common essence, focus and purpose of nursing surpasses contextual considerations and it is this that creates and defines its moral milieu. Taking this further, Melia (1996, p. 141) states:

At heart then, all these issues come back to the same principles that nursing in general relies on in order to focus on its moral basis. We do not need to create a special ethics for intensive care, what we work with already in nursing will suffice, it is only the cases and contexts that differ, the principles transcend the setting.

What is certain is that ethics is a vital, challenging and vibrant part of nurses' itinerary; as Tschudin (1993, p. 1) eloquently asserts: 'Ethics is not only at the heart of nursing, it is the heart of nursing.' With ethics firmly placed at the centre of the nursing endeavour, we will now consider specific research that explores how nurses deal with the moral dimensions of delivering critical care.

The Swedish experience

In a major Swedish study, Söderberg and Norberg (1993) conducted research into situations that caused ethical difficulty in delivering intensive care. This involved 20 doctors, 20 registered nurses and 20 enrolled nurses, each narrating their experiences about situations that had caused them moral concern. The main reason the researchers chose this approach was because 'narratives about ethically difficult care situations may disclose differences of perceptions, feelings, reasoning and actions' (p. 2008).

Each narrated story was recorded and later transcribed. Each transcript was then examined using phenomenological-hermeneutic analysis (Ricoeur, 1976, 1984). This involved initially dividing the plot of each story according to the dominant influence of one of two themes: action ethics or relational ethics. In this respect, Söderberg and Norberg adopted Lindseth's (1982) distinction that action ethics is concerned with focusing on the right choice of action within the limitations of a given context and situation, while relational ethics is concerned with how people relate to each other in various situations.

During the structural analysis the main context of each story was characterized according to whether an action element or a relational element dominated. In order to establish which perspective was dominant in respective stories, the researchers asked the following questions:

- What choice of action does the story represent? (action ethics)
- What does the story tell us about the relationships between the actors? (relational ethics)

Perhaps the most pertinent theme emerging from this research was the finding that physicians, registered nurses and enrolled nurses all 'saw themselves as equally lacking in influence in ethically difficult care situations' (p. 2008). This finding makes a fascinating basis for comparison as we explore research that reflects the experiences of nurses in a British intensive care unit.

The British experience

In a small-scale, published research study, Basset (1995) used a phenomenological framework to explore how intensive care nurses deal with ethical dilemmas. He describes the purpose and focus of the project in the following way:

The researcher in carrying out this research does not expect to gain an absolute 'factual truth', but hopes to gain 'insight' into this key area. From this he hopes to better manage his own approach to the ethical decision making process and by dissemination of the findings, aid others in considering their own positions (p. 168).

Basset asked four nurses to take part in a guided discussion, which would be recorded, subsequently transcribed and analysed. Throughout the discussion, the researcher used open-ended questions to guide the dialogue. The recorded discussion took place in a small private room and lasted for an hour and 15 minutes. When analysing the transcript of the discussion, Basset divided the statements into categories and then into themes. In describing this process he states:

A knowledge of intensive care nursing proved to be useful in this process, understanding the language of intensive care nurses. Statements and phrases directly relating to ethical factors were highlighted and bracketed, this process helping to maintain reliability and validity by reducing possible bias (p. 168).

Three themes emerged from the analysis: senselessness, stress and impotence. To reflect the theme of senselessness, Basset quotes the feelings of one nurse involved in the care of a patient whose life was seemingly being prolonged beyond any chance of recovery:

I remember a patient who was quite literally 'rotting' and in a terrible state, but we (as nurses) had to keep this patient as comfortable as possible. This went on for several days, there was no chance of recovery (p. 166).

The theme of stress is illustrated by a nurse talking about the sometimes futile purpose of ventilation: 'sometimes you go off duty and the patient just goes with you, it is impossible

sometimes to forget them (the patient). You just keep thinking about the stupidity of keeping them ventilated at any cost' (p. 166).

The final theme, impotence, finds most focus in the nurses' feelings about relationships with doctors: 'I consider myself and my colleagues as being expert in what we do, we are at least as professionally well qualified as many doctors, but we are not considered as such by some' (p. 166).

Basset acknowledges that the transcribed material concentrates on the negative; however, he also argues that the key aim was to encourage nurses to talk about the ethical issues that cause distress within the unit. The final comment in his paper holds tremendous resonance for nurses working in intensive care units: 'It is important that we as nurses involved in critical care learn more about ethics, value conflicts and communication. The dilemmas we face will not disappear, there will be more and more in the future' (p. 169).

Comparisons and reasons

It is interesting that Söderberg and Norberg's Swedish research showed doctors and nurses to feel 'equally lacking in influence' with regards to moral decision-making; conversely, Basset's British research found that nurses often felt ethically impotent because they considered that doctors held a demeaning attitude towards them. Such themes are further supported by Johnstone (1989, p. 1) who states:

Some doctors apparently believe that nurses are incapable of sound rational thought, and are incapable of grasping the essence of sound moral thinking. These doctors are loath to accept that nurses have any independent moral responsibility when caring for patients. As these doctors are invariably in positions of power, they are more than able to ensure that a nursing perspective on patient care, and related moral issues, are effectively constrained.

Part of the reason Swedish nurses and doctors felt equally fettered with regards to moral decision-making may lie in the absence of status, class, gender and other social barriers. Such themes have traditionally enmeshed and supported restrictive

working practices and unequal opportunities in the British social system.

The British health care system is a microcosm of its broader social milieu and reflects its dominant norms, values and means of maintaining the status quo. Such themes are further supported by the experience of foreign nurses who come to work in the United Kingdom. Unshackled by the restrictive elements of power and status so inherent in British society, they do not acquiesce to the dominance of medical patriarchy. Instead as Mackay (1993, p. 122) asserts:

These overseas nurses may show none of the deference and acquiescence of the British trained nurse. They are not part of the class and status system. Because of that, these nurses are treated differently, enjoying more of an equal status with the medical profession; and they treat doctors differently, as equals. These nurses can be particularly scathing about home grown nurses' refusal to question doctor's decisions or to take responsibility.

However, despite this level of perceived authority by foreign nurses working in the United Kingdom, the reality is that, with regard to diagnosis and treatment, nurses are powerless and must await the legal prerequisite of 'doctors' orders' before implementing the care associated with such orders. Once again, the cure-orientated aspects of clinical medicine seem to hold more intrinsic worth than those of nursing's care-based elements. This is a theme which continues to influence the hidden agenda in nurse-doctor relationships. While this perception is allowed to continue there is little chance of an enacted sense of parity between doctors and nurses. Adshead and Dickenson (1993, p. 167) reflect these sentiments in the following way:

If nursing is defined as being about caring, and medicine about curing, medicine will continue to be seen as more important. If the role of the female paradigm profession of nursing is seen as caring, the old stereotype of the nurse as the doctor's 'helpmeet' will be revived. Caring is likely to be seen as less important than curing because we fear death and wrongly attribute to medicine the power to cure us of mortality.

This section has suggested and explored some possible reasons to explain the differences towards ethical decision-

making between doctors and nurses in Sweden and Britain. What has emerged is that British nurses are submerged in a power-based scenario that perpetuates and reifies the mythical theme of medicine's hold over death. Giving this further credence, interprofessional relationships take place in a working culture that fully mirrors the British class system in which issues of gender, educational background and status are important influences.

Given the combination of factors that maintain and reinforce nursing's subservient position to medicine, it is not surprising to find British nurses playing such a small role in ethical decision-making. This feature not only disempowers nurses but chisels away at a concept that is central to nursing's professional creed, that of patient advocacy. Logically, if research suggests that British critical care nurses have little say in clinical situations that are morally problematic, how can they play an effective role as patient advocates? That this role assumes such central importance for critical care nurses is evidenced by the fact that patients requiring critical care are frequently unable to speak for themselves due to the nature of their conditions. To explore this question demands further analysis of those themes that surround advocacy in the delivery of critical care.

Ethical advocacy

In recent decades, the mantle of advocacy, with its central purpose of representing, safeguarding and promoting the interests of patients, has been firmly grasped by the nursing profession. One result from this has been a host of papers arguing that nurses are ideally placed to play an advocacy role (Abrahams, 1978; Murphy and Hunter, 1984; Penn, 1994) as it represents a key element in the ethos of caring. Advocacy presents itself when practitioners become an 'active voice' when, for whatever reason, patients feel unable to articulate or represent their own best interests. Such notions seem to reflect the core moral principles of beneficence, non-maleficence and respect for persons. Indeed, the *Concise Oxford Dictionary* (1992, p. 18) reinforces such themes with its definition of an advocate as a person 'who pleads for another'.

Against this background, advocacy is portrayed as a virtuous endeavour that sits comfortably with the values that have traditionally underpinned contemporary Western health care. The essence of the nurse's role as patient advocate in critical care is given sharp focus by Drought and Liaschenko (1995, p. 297) who state, 'Nursing's role is to hold foremost the overall well-being of the patient, and to advocate for the patient, not for the technology'.

Developing the notion of advocacy in critical care even further, Rushton (1995, p. 388) states:

The goal of advocacy is to enable the patient, family and significant others to adjust to the changes in their own unique way. Nursing actions are directed toward maximising the control exerted by the patient and family, and assisting them to find unique meaning or purpose in their living or their dying and to realise goals that promote a meaningful life or death.

It is interesting to note that much of the interplay concerning advocacy involves the nurse playing an intercessory role between the patient and the doctor. A transactional analysis of the relationships between doctors, nurses and patients would certainly suggest an imbalance of power between these key players, as Chadwick and Tadd (1992, p. 65) state: 'characteristically the doctor has been portrayed as "all knowing" and powerful; the nurse as caring, unselfish, obedient and submissive; and the patient as helpless and utterly trusting'.

This triad of professional relationships discussed by Chadwick and Tadd is often placed under the umbrella term of 'parentalism' and results in the patient being treated in a way that is directly analogous to that of a child; reflecting the essence of this concept, Kendrick (1995, p. 241) states:

The characteristics of parentalism are heavily imprinted upon the traditional picture of the relationship between doctors, nurses and their patients. Resulting from this image of the 'pseudo-family' is a completely disempowered patient who passively conforms to the dominant wishes of 'mother' and 'father'.

Given what has been said about the lack of power that nurses hold in ethical decision-making, the language of advocacy pales into rhetoric, especially when viewed against the realities of

nurses' experience as documented in research (Mackay, 1993; Basset, 1995; Kendrick and Cubbin, 1996). Well-meaning, but quite empty, semantics abound in nursing literature and a further example is given by Brown (1985, p. 26) who states that advocacy is a 'means of transferring power back to the patient'. Given the lack of power nurses have in their relationships with doctors, how can such idealistic terms become reality? Put another way, how can the disempowered nurse empower the disempowered patient? In the light of such themes it is questionable whether nurses have a sufficient base to act as patient advocates and this finds particular focus when examining the notion of 'best interests' and who defines them.

Defining best interests – who decides?

At the core of advocacy lies the notion of 'best interests'. Murphy and Hunter (1984, p. 24) translate this to the delivery of patient care:

The professional, while obligated to act in the patient's best interests, is not permitted to define that interest in any way contrary to the patient's definition; it is not the professional but the patient that shall define what 'best interests' shall mean.

Relating these themes to clinical reality reveals a split between well-placed rhetoric and power-based reality. We have already noted that nurses share an unequal power base with doctors and these damaging but influential themes reflect negatively on the value of nursing and nurses. This is further supported and reinforced by media representations. Taking this further, Mackay (1989, p. 46) points out that:

Stereotypes in the mass media appear to enhance the status of doctors at the expense of nurses. Nurses are presented in the media as less helpful and less empathetic to the needs of patients and doctors. Yet when the reality of nurses' work is considered the stereotype is revealed for what it is: a put down of nurses and of women.

Thus, a structural analysis of advocacy reveals a scenario that is supposed to empower a disempowered patient; however, the previous reference strongly indicates that nurses are also

victims in a health care equation based upon power. To a large extent, nurses have been authors of their own oppression and traditionally have done little to confront the level of disparity between themselves and doctors at an operational level. Exploring reasons for this, Kendrick (1994b, p. 78) argues:

Nursing's failure to divorce itself successfully and universally from the medical model as a *modus operandi* for the delivery of care must be seen as a major contributing factor to the subordinate position nursing holds in relation to medicine.

Against this backdrop, the notion of the nurse as the patient's advocate seems fairly ineffectual. It is also unlikely that patients will be able to define their own 'best interests' when they hold least power in a power-based system. With analytical verve, Allmark and Klarzynski (1992, p. 34) comment upon the dubious nature of patient advocacy:

An advocate should plead someone's cause as the person, and not the advocate, sees it. If a liberal lawyer pleads the cause of a neo-Nazi group to have freedom of speech then this is true advocacy. A nurse is unable to provide the alcoholic with a drink, plead for the overdose not to be treated, and for the sectioned patient to be allowed to leave.

Relating the thrust of Allmark and Klarzynski's argument to critical care, how many nurses have the autonomy and power to stop treatment when clinical indicators point towards the futility of continuance, for example in the case where a patient has total organ failure? This is clearly mirrored by revisiting the words of one nurse in Basset's research: 'I remember a patient who was quite literally 'rotting' and in a terrible state, but we (as nurses) had to keep this patient as comfortable as possible. This went on for several days, there was no chance of recovery' (1995, p. 166).

How does the notion of the nurse as patient advocate stand in the light of such a damning remark? Clearly, advocacy is a power-laden concept that instrumentally supports a hierarchical structure which threatens patient autonomy, choice and, ultimately, dignity. Reflecting these themes further, Allmark and Klarzynski (1992, p. 35) make the following comment: 'To suggest that a patient has an advocate when it is that very person

who may be involved in the treatment that the patient is trying to resist is analogous to suggesting that the police can act as advocates for people in custody.'

Conclusion

This chapter has explored some of the key themes that influence and direct critical care nurses in relation to the moral dimensions of their practice. In comparing findings between two European countries where research has been conducted, Swedish nurses were found to be on an equal footing with doctors in relation to moral decision-making, in that both groups felt 'equally lacking in influence'. This compared favourably with British findings where the key themes of senselessness, stress and impotence framed the disempowered position that critical care nurses experience in moral decision-making alongside doctors. While this impoverished state is maintained, key elements at the heart of nursing's professional creed will be challenged and neutralized. This chapter has explored this notion in relation to patient advocacy.

What has emerged from this exercise is an understanding that ethics is fundamental to the work of practitioners, be they doctors, nurses or any other member of the 'hands-on' team. In Sweden, the very fact that nurses and doctors felt 'equally lacking' strongly supports the need for an educational programme that equips practitioners with the ethical 'tools' to confront the moral dimensions of their work. Scandinavia has a strong background in shared professional learning and ethics would fit comfortably into this policy (Regional Health University, 1981).

In the UK, doctors must stop seeing situations that are ethically relevant as something to be subsumed under the broad notion of a 'clinical decision'. In essence, this should mean shared governance with other practitioners, as ethics belongs to us all and is not solely the domain of medicine. Educational programmes that are clinically relevant and delivered in or near to the clinical setting are ideal avenues for bringing team members together to explore the ethical issues pertinent to critical care. Cogently reflecting these themes, Melia (1996, p. 138) provides the perfect focus for such an endeavour:

Intensive care, with its emphasis on team work, is an ideal setting in which to promote health care ethics as a multi-disciplinary enterprise rather than as a major arena in which to battle out medical versus nursing ethics.

The gauntlet has been thrown down, who among us will pick it up?

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12

Nursing Ethics at the End of Life

Verena Tschudin

Introduction

'Human beings should revere life and accept death' (Thiroux, 1995, p. 180). With this simple statement Thiroux sums up what he describes as the Principle of the Value of Life. Because death has taken the place of an enemy to be fought with every means possible it can be said that we do not show the reverence due to life either. Today's world demands more and more from life (meaning here all life, plants and animals included) and when these demands cannot be met, we feel angry and try still harder not to accept the limits imposed by something which we cannot control. Because it is difficult to accept death, we try to defeat it with an emphasis on health and well-being which can border on excess. The claim has been made that because we do not accept death, countries are being ruined economically. Or, as Callahan (1990, p. 254) puts it, our 'single-minded ambition to overcome mortality will generate misery and social distortion [and] will create a house, our society, in which we would not want to live'. The ideals of the marketplace favour the individual, but these trends concern society. It is in this dichotomy between individual needs and societal possibilities that our greatest problems and our greatest challenges may well lie.

This chapter will address some of the issues raised by the ethical concerns at the end of life. In European countries the issues are fairly similar, except for the Netherlands. This is

one of the countries which will be compared with the United Kingdom (UK), the other being Switzerland, but references will also be made to other European countries.

End of life

In the literature the expression 'end of life' is used in preference to 'dying' as it can cover more specific issues. It is also perhaps a less emotive term, although it may be questionable whether or not this is helpful.

Under the heading of end of life several different issues can be addressed:

- Neonatal critical care
- Brain stem death
- Persistent vegetative state
- Care of the dying
- Care in different settings: such as intensive care, hospital, community
- Organ transplantation
- Care of the sick elderly
- Euthanasia
- Advance directives and living wills
- Resuscitation.

The most pressing problems faced by nurses in end of life situations are generally:

- When patients and clients request no further treatment and this is not respected
- When doctors order treatments and nurses do not agree with the orders
- When patients and clients are not informed of their conditions and request information
- When adequate care is difficult because of the patient's condition (fungating wounds, multiple disease problems, mental as well as physical illness) or the nurses' inexperience.

Perhaps the most pressing problem, as is so often the case, is that of communication: between nurses and doctors; nurses

and patients; doctors and patients; nurses and families; or patients and their families. Ethical problems are problems of fundamental right and wrong, but what is right and wrong needs to be understood, heard, expressed and respected, not simply prescribed or dismissed.

End of life issues in the UK

The debate about end of life issues in the UK has been dominated by several well-publicized cases in recent years:

- Tony Bland: a young man who was injured at the Hillsborough Stadium in 1989 and was in a persistent vegetative state (PVS) before he was allowed to die (Ellis, 1992)
- Laura Davies: a six-year-old child, who had a bowel and liver transplant in the UK, and then a six-organ transplant in the USA (Turner, 1993)
- Dr Nigel Cox: a hospital doctor who gave one of his patients an injection of potassium chloride to end her life after she had repeatedly asked that she should be helped to die (Castledine, 1994).

These three major events, and others amounting to the actual care given or not on the basis of 'value for money', have shaped the discussion in the UK in the last few years. The debate has been polarized into issues of euthanasia and who should receive treatment which is of debatable value given the limited resources. Perhaps the most striking outcome of all these problems and discussions is that no-one has been prosecuted for murder or killing and no professional has been removed from a register.

Neonatal care

The amendment of 1991 to the Abortion Act 1967 put the upper gestation limit for abortion for most reasons as the end of the 24th week (Paintin, 1991). Alongside this, 'neonatal intensive

care is an area where “hi-tech” medicine has been remarkably successful. Advances in perinatal care have been accompanied by improved survival among infants born in the middle to late second trimester who were previously considered non-viable’ (Gill, 1994, p. 448).

Therefore, ‘treatment withheld on a 24-week gestation baby in the neonatal intensive care unit might constitute a felony, whereas therapeutic termination of pregnancy of a similar gestation fetus is now legal’ (Gill, 1994, p. 450). The dilemma is whether or not to provide resuscitation. According to Gill (1994, p. 450) ‘the decision to resuscitate depends upon the personal philosophy of the primary care physicians and other health professionals, with variable input from parents’. Grimley (1995) describes a baby born at 29 weeks, weighing 930 grams who needed maximum ventilatory support. His outlook was poor: he had

a 95% chance of severe physical disability (spastic quadriplegia), learning disabilities and visual impairment. ...With modern technology at our disposal, we are better able to prolong and save the lives of babies who previously would have died. It follows, that we are also in a position to decide whether or not to continue treatment and, if not, how death will occur (Grimley, 1995, p. 42).

Whereas in the past such premature infants would have died, we now have to make decisions regarding their lives and their deaths. Too often in the past, the parents’ wishes have been disregarded. Grimley (1995, p. 43) sees it as the responsibility of nurses ‘to facilitate more understanding and to enable more than just token participation by parents in the decision-making process’. This demands a high level of communication, of counselling skills, of empathy, as well as knowledge of laws and policies.

Care of the dying

In the UK, care of the dying has been pioneered as a special category of care by Dame Cicely Saunders. As a qualified nurse, social worker and medical doctor she was in a unique position to understand the plight of patients who were dying. It is legit-

imate to claim that the care of the dying in the UK has been developed and led by nurses. According to Bycroft and Brown:

our confidence (as nurses) to stand alongside dying patients, no matter what happens to them, depends on us having knowledge, skills and support in our effort to understand the patients' needs, and to respond to them. Broadly, these needs will be:

1. to receive support based on understanding of their task of adjusting to dying;
2. to be relieved of distressing physical symptoms;
3. to know that their family and friends are supported, and will continue to be after their death (1996, p. 420).

Bycroft and Brown describe in detail the psychological support which patients and families should receive. The physical symptoms experienced by dying patients consist mainly of pain and the fear of pain, but anorexia, dry mouth, constipation, nausea, vomiting, insomnia, dyspnoea, cough or oedema (Bycroft and Brown, 1996, p. 428), are all well known.

The care of the dying has often been seen as a quest for giving quality of life to patients in preference to quantity, or the quest for a cure (Hunt, 1993). The transition from a search for cure to maintaining a quality which is acceptable is the area of greatest ethical problems. According to a Working Party Report (Gormally, 1994, p. 91) 'the first requirement of good terminal care is that the dying patient should be treated as a person'. This implies that much talking, listening and discussing should take place. 'At some point you have to talk about the purpose of life. Futile treatment, which cannot restore the patient's health, is not worth doing' (Shamash, 1995, p. 15).

The difference here between care of the dying and care for patients who are unconscious, mentally ill, or in persistent vegetative state (PVS), is essentially who is mainly or primarily involved in decision-making: the patient or close family, legal guardians or significant others. Dying is not a private affair, and other people are always involved, even if this may be a nurse caring for a person who has no relatives. Because nurses invest more and more care when someone is dying, while doctors invest less and less, it is imperative that nurses should be consulted in any decisions regarding the care that is to be given.

Care of the dying cannot be considered without mentioning hospices. The *Directory of Hospice Services in the UK and Republic of Ireland* (Hospice Information Services, 1997) lists 223 units with 3253 beds, about 400 home care teams and 234 day care centres available for the care of the dying, for a total population of about 60 million people. Hospices have changed their role considerably since their inception. Today they not only provide both physical and psychological care for the patients, but they also provide support for families during the patients' illness and in bereavement. Additionally, hospices are

taking on the role of educational and resource centres, accessed for education and training purposes and for advice and support on issues relating to palliative care, by medical and nursing colleagues who are caring for patients with advanced disease in hospitals, the community and in residential and nursing homes (Bycroft and Brown, 1996, p. 434).

Euthanasia

The subject of euthanasia used to be divided into different categories: active and passive, voluntary and involuntary. Today what is considered as euthanasia is 'the intentional taking of life by a person other than the one requesting it' (Visser, 1995). When a person asks to have his or her life ended, this tends to be referred to as assisted suicide. By creating this second category, the problem has not become easier, but the distinctions are clearer.

In a survey of its readers conducted by the *Nursing Times*, 69 per cent of respondents said that patients in their area of work had requested euthanasia. When asked whether such requests were made to nursing or medical staff or to both groups, 59 per cent said to nursing staff, 5 per cent to medical staff, and 33 per cent to both medical and nursing staff. Some comments made by respondents 'expressed their feelings on the subject, often out of deeply felt and painful personal experiences which illustrated how the terminal illness and death of a loved one can change a person's detached professional view of [the subject]' (Pyne, 1995, p. 36).

This point was also emphasized by Finlay (1995), who maintained that at different times in their illness, patients have different and changing needs: 'the views of the medically well alter when they are medically ill'. For this reason, Finlay believes, 'professionals need a clear ethical framework around which to base their communication with patients over treatment options and approaches to care'. The ethical framework should be 'based on evaluation of risks and burdens against benefits' and 'can be used in all clinical practice to ensure that patients are respected as individuals'.

The debate in the UK centres round the question of whether euthanasia should be legalized. This debate was brought sharply into focus after the previously mentioned Tony Bland case. The House of Lords Select Committee on Medical Ethics (1994) made various recommendations following its permission for fluids and food to be withdrawn. Among them was that the interests of the individual cannot be separated from the interests of society as a whole and that individual cases are not sufficient reason to weaken the prohibition on intentional killing which protects us all.

Castledine (1994, p. 360) highlights more of the conclusions drawn by the House of Lords report which have implications for nursing:

- Palliative care services should be developed more widely, in particular in the community
- Decision-making should be a collective act, and nurses should be more actively taking part in this process
- Definitions such as persistent vegetative state should be more clearly defined and a code of practice should be available for the treatments of patients in this condition
- Decisions concerning the limiting of treatment should not be determined by considerations of resource availability. 'This factor will be warmly, if not a little cynically, accepted by nurses in management and practice areas' adds Castledine somewhat wryly
- Research into pain relief and symptom control should be encouraged

- Nurses who take on ethical responsibilities and who make ethical decisions should receive adequate education and training
- In order to maintain the dignity and self-respect of patients in long-term care, nurses should develop core standards for their care.

Good palliative care is essential for patients of any age and in any setting. Even though large numbers of nurses have enough training and skills for this care, their medical counterparts are often not similarly trained and skilled and this can lead to misunderstandings and friction (Anon, 1992). Only a very small proportion of dying patients have access to, or want to die in, hospices. It is therefore not surprising that many patients fear a lingering or painful death and ask to be allowed to die before they become too dependent or too distraught. Some would argue that this is a plea for help or for attention. Finlay (1995), says that 'the duty to care is the duty to listen'. 'No-one is obliged to request euthanasia; on the other hand, no-one should be denied the freedom to do so' (Pyne, 1995, p. 36). But are nurses well enough trained to hear the distinction between a plea for help and a genuine request to end life? Perhaps this is the real challenge for nurses.

The care of patients in PVS can be particularly distressing especially as it is not entirely clear what PVS is. Although distinctions have been drawn between PVS and a 'locked-in' state, the urgency of the recommendation made by the House of Lords, for a clear definition of the condition, is readily apparent.

While the case of Tony Bland progressed through the various legal stages, much was written about his situation. His parents had requested that he be allowed to die and his father had apparently asked, 'they say that where there's life there's hope – but where there's no hope, should there be life?' (Ellis, 1992, p. 42). Ellis suggested that in cases such as Tony Bland's, three questions should be asked and answered. 'What are the consequences of allowing this person to die, for himself or herself, for the immediate family, and for society?' 'Is allowing this person to die an acceptable (good) action?' 'What are the duties of the health care professionals to this person, the family, the professions, and to society?'

The concept of 'best interest' is often used to come to a decision, but on closer inspection Rose (1995, p. 149) suggests that this notion is far from clear. Establishing who are the 'experts' in any particular situation, as well as defining the 'incompetence' of the patient, are difficult tasks. Rose (1995, p. 149) also points out that the term 'best interest' is not used in relation 'to actual outcomes but rather in relation to the intended outcome of long-term good'. In this sense, Ellis' (1992, p. 41) questions are more complex than they appear at first sight. Issues such as a 'right to die', 'what is the meaning of life', and 'who can make decisions in controversial situations', need much more attention and debate. The contribution by nurses and nursing to the debates are crucial at every level, particularly as nurses are taking their role of advocates more seriously (Love, 1995).

One way of minimizing the dilemmas at the end of life is by having and using advance directives, or living wills. Such documents are not law in the UK, although in the USA, Canada, Australia and the Netherlands 'laws have been passed concerning the use of advance directives and health-care proxies' (Schlyter, 1992). The House of Lords Select Committee (1994) has also recommended that living wills should be taken into account when caring for people who have written such documents but who are no longer in a position to speak for themselves.

A living will gives a person increased self-control during a time when they may experience loss of control (Watt, 1995) and when 'quality of life is of more central concern, particularly if it is viewed in terms of its relationship to health and... life satisfaction, happiness and wellbeing' (Fox, 1994, p. 203). Bassett (1993) argues that over the last 200 years too much responsibility has been taken away from patients concerning the living and dying, and living wills are one way of returning this responsibility to them.

Resuscitation

Stories abound in the nursing and medical literature of patients who, either implicitly or explicitly, had stated that they would

like to die but when they arrested, were resuscitated (Schultz, 1997). The question usually posed then is, 'why'?

According to Schultz (1997), a survey conducted in Sweden in 1990 in all 92 acute care hospitals, found 191 different symbols and 31 written code words to indicate the not for resuscitation (NFR) status of patients.

Cardiopulmonary resuscitation (CPR) has become possible because of technology, but for many people, CPR is not an appropriate intervention. When faced with 'the problem of determining under what conditions, according to what criteria and by whom' (Schultz, 1997, p. 231) such decisions are made, the outcome is one of confusion rather than clarity.

A statement issued jointly by the Royal College of Nursing (RCN) and the British Medical Association (BMA) in 1993 (RCN, 1993a), the following guidelines are advocated:

It is appropriate to consider a do-not-resuscitate (DNR) decision in the following circumstances:

- a) where the patient's condition indicates that effective cardiopulmonary resuscitation (CPR) is unlikely to be successful
- b) where CPR is not in accord with the recorded, sustained wishes of the patient who is mentally competent
- c) where successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient.

Schutz (1994) believes that the practice of not involving patients in resuscitation decisions has usually been defended on the grounds that 'such involvement may be harmful for patients as it may spoil their enjoyment of their last few weeks of life' (p. 1075). She goes on to quote Loewy (1991), who states that 'involving patients in resuscitation decisions may be more painful for health care professionals than for patients' (Schutz, 1994, p. 1078).

The problem of CPR is a typical end of life problem which technology and science, rather than medicine, have created. The procedure is not in question in emergency situations: it is applied anyway. But in the long-term and chronically ill (Kent, 1996), the sick elderly and the severely ill, a decision of NFR is much more difficult to make and is more controversial.

The RCN/BMA (RCN, 1993a) statement says that 'DNR orders may be a potent source of misunderstanding and dissent

among doctors, nurses and others involved in the care of patients'. Schutz (1994, p. 1078) says that this is 'usually the result of a failure to address the issue at the right time'. Tackling this problem needs all the tact and communication skills available but, above all, a team approach is vital if patients, their families and those close to them are to feel confident and trust is to be maintained by all involved.

Organ transplantation

In the league of scarce resources, organ transplants are classed as the paradigmatic case (Dickenson, 1994, p. 207). For lay people it is easy to see that organ transplant decisions have to be made entirely on medical grounds, but as Dickenson (1994, p. 208) shows, this is far from the case: in 1986 in the USA, 'Baby Jesse' was refused a heart transplant on the grounds that 'his parents were unmarried teenagers with a criminal history and drug abuse problem. They were judged incapable of providing the necessary follow-up procedures, such as punctual administration of immuno-suppressive medications.' The case of Laura Davies mentioned above brought the debate about organ donation to the fore in the UK.

Organ transplantation can be offered to patients for the wrong reasons, for instance 'as a way of keeping hope alive and denying mortality' (Iliffe and Swan, 1993, p. 60). Iliffe and Swan (1993) list this as one of the special considerations which apply to organ donation. Others include the following requirements: that patients should be allowed to refuse assessment for transplant without recrimination; that they know what is in their best interest so as to give informed consent; that helping patients to maintain a positive attitude in the waiting period can conflict with the ethical requirement to discuss the risks of rejection and death with them; and that patients often seem to need to make an impression of being good and worthy of the transplant.

In their very thoughtful chapter, Iliffe and Swan (1993) discuss several of the more intangible aspects of organ transplantation. Among other things, they say that, 'the considerable financial resources put into the transplant programme finally benefit a relatively small number of people, and no

human audit is taken of those who were not eligible for assessment, those who failed to meet the assessment criteria, those who died while waiting and those for whom transplant was unsuccessful' (p. 69). The ethical questions revolve around these issues. The high cost of transplants compared to other, simpler measures of enhancing the quality of life for many more people, is a point which always needs to be kept in mind.

Turner (1993) reinforces the claim which Iliffe and Swan (1993, p. 61) also make, that patients and relatives need more information about the possible complications following the transplant. It may be that patients and families have been given as much information as possible, but that under the circumstances, they simply could not absorb this information for various practical and psychological reasons.

In the case of Laura Davies, Turner (1993) quotes Baroness Warnock as saying 'that it would be dishonest to pretend that such a multiple transplant [the second, six-organ transplant carried out in the USA] could have been considered anything other than experimental' (p. 18). Questions about the purpose of treatment and of the quality of life and respect for the person, need to be addressed again and again. Turner (1993, p. 18) asks, 'could nurses help to safeguard the rights of the children within this very sensitive area of organ transplantation?' Nurses at Great Ormond Street Children's Hospital in London have learned that 'it is both wise and possible to bring children, even as young as three, into the decision-making process' (p. 18). What is possible with children must be possible with adults. It may be argued that the language may need to be as simple with adults as it is with children, because when faced with such decisions, we are all 'children'.

For transplants to be possible, the less glamorous aspect of 'organ retrieval' is necessary and this topic attracts periodic discussion among nurses. The criteria for brain death are laid down in law (RCN, 1993b), but ethical issues arise because of the speed with which it is necessary to act. Durman and Hudson (1993) describe the guidelines developed at the Royal Devon and Exeter Hospital. These give clear instructions for every part of the organ retrieval process when a potential donor is admitted to the hospital.

In Britain, there is a 'chronic and worsening shortfall of donor kidneys' (Evans, 1993, p. 34). Quite why this is happening is not clear. The editor of the *Bulletin of Medical Ethics* (1994a, p. 1) stated that 'organ donation in Germany dropped 20% this spring when Protestant bishops suggested that brain death was an invention of doctors for their own purposes and did not really represent death'. He suggested that organ donation is not in keeping with the respect we owe the dead. In an ethics course for qualified undergraduate nurses studying for various nursing degrees, the question as to whether or not they would be prepared to be donors if the circumstances were there, was asked. Two-thirds of the class said no. Asked if they would accept organ transplants if they needed them, they also said no. In the discussion which followed, the reasons they gave were that they preferred to maintain their bodily integrity. Perhaps this is an indication of the direction in which people who either think about the issues or are aware of the consequences of transplants may be heading.

End of life issues in the Netherlands

It is feasible to assume that for most nurses in the Netherlands many of the problems discussed so far are very familiar, with the one exception of euthanasia. The Netherlands are always quoted as an example of how euthanasia is either helpful, 'euthanasia as practised in the Netherlands is caring at its very best' (Pyne, 1995, p. 38), or that 'there is disturbing evidence not only of a high incidence of euthanasia in Holland but also of widespread breach of the guidelines' (Gormally, 1994, p. 161). The practice of euthanasia in the Netherlands, therefore, colours the discussion of all the end of life issues.

The guidelines which govern physicians in the practice of euthanasia in the Netherlands were published in 1984 by the Royal Dutch Medical Association (KNMG). The five points considered to be conditions in which euthanasia (meaning 'voluntary euthanasia') accorded with medical ethics are:

1. The request must be made of the patient's free will, and not result from pressure by others.

2. The request must be 'well-considered', and not be based on a misunderstanding of diagnosis or prognosis.
3. The request must be 'durable', and not arise from impulse or temporary depression.
4. The patient must be experiencing 'unacceptable suffering'; he must feel the suffering to be 'persistent, unbearable and hopeless'.
5. The doctor must consult with a colleague before performing euthanasia, and report it to the legal authorities afterwards as a non-natural death (Keown, 1992, pp. 160–1).

In 1991 the government commissioned a survey of the practice of euthanasia, chaired by Attorney-General Remmelink, which published its report in 1992. The results of that survey are widely used as the basis for discussion of the practice of euthanasia in the Netherlands.

The Survey shows that for the calendar year 1990, there were 2,300 cases of (voluntary) euthanasia and 400 cases of assisted suicide. There were... over 8,000 cases in which doctors administered morphine, and almost 8,000 cases in which they withheld or withdrew treatment 'explicitly' or 'partly' with the intent to shorten life. ...The Survey revealed over 1,000 cases in which doctors stated that they had terminated life without the explicit request of the patient (van der Maas *et al.*, 1992, p. 1).

These figures should be seen in perspective. The Netherlands have a population of approximately 14 million people. In 1990, 42 per cent of deaths took place at home, 41 per cent in hospital and the remainder in nursing homes (*Bulletin of Medical Ethics*, 1994b). Nursing homes are often seen to be the place for palliative care and care of the dying. Statistics from the Ministry of Public Health, Welfare and Sports (Rijswijk, 1996) show that between 1988 and 1996 the number of beds in nursing homes has barely changed, but the number of personnel employed in them has increased from 79,000 to 96,000.

According to Sheldon (1995), a member of the largest nursing organization in the Netherlands, Nieuwe Unie '91 (Nu91), is quoted as saying that 'euthanasia is often misunderstood in foreign countries. Euthanasia is not easy in the Netherlands – it is very complicated' (p. 16). Nurses are frequently confronted

with requests for euthanasia (Sheldon, 1993) and they have to respond. In order to help nurses, Nu91 (1993) has published guidelines for nurses (in conjunction with the KNMG). This document mentions that nurses' 'continuing involvement' and 'special knowledge' are 'highly desirable' when they have to consider a request for euthanasia. 'If a nurse disagrees with a doctor's refusal to perform euthanasia, it advises the nurse to seek a second opinion from another doctor, ward sister or hospital director to avoid a psychological conflict of duties from which there is no exit' (Sheldon, 1993, p. 15).

The guidelines 'make it clear that while both the decision to proceed with euthanasia and its implementation lies with the doctor, the nurse who gives continuing care for the patient should preferably be involved' (Sheldon, 1993, p. 15). Indeed, in the test case against Dr Henk Prins (Sheldon, 1994), he made it clear that the nurses who cared for the baby he killed played an important role in his decision.

Several cases of euthanasia in the Netherlands have become well known because they have been widely disseminated. Dr Prins had followed the guidelines strictly, consulting with several colleagues on the chances of survival of a four-day-old baby who had several disabilities including spina bifida, hydrocephalus and brain damage. Dr Prins could have prescribed increasing doses of morphine, but he argued that this would only have prolonged her pain and suffering and created increasing uncertainty about the moment of death. Giving her one injection meant that she died in the arms of her mother. In this way Dr Prins made himself culpable before the law (Sheldon, 1994).

In March 1995 BBC television showed the documentary *Death on Request*, which was a record of the last months of Cees van Wendel de Joode, showing his death by injection, given by his GP Dr Wilfred van Oijen (Sheldon, 1995).

While these cases clearly argue for euthanasia, some people in the Netherlands are not convinced in the same way. At the conference, 'Euthanasia: Towards a European Consensus?' in November 1995 in Brussels, some Dutch speakers commented that the Dutch experience is not easily transferable to other countries not in sympathy with the guidelines in the Netherlands; that good palliative care can never be a substitute for euthanasia;

that once euthanasia has been officially sanctioned, it develops an impetus of its own; that conflicts of duties are becoming clear: the duty to preserve life versus the duty to kill – obeying the law versus respecting the patient; that in cases which were not reported, colleagues were consulted less; and that the incidence of palliative care in the Netherlands has dramatically increased in recent years. The large increase in personnel in nursing homes in recent years must bear on this topic.

A recurring question at the conference concerned the knowledge base for end of life decisions. Perhaps the practice of euthanasia in the Netherlands is pushing in the direction of better practice generally, showing, as is so often the case, that ethics follows practice and does not lead it.

End of life issues in Switzerland

The Swiss Nurses Association (SBK – ASI) published its code of practice in 1990. Apart from the actual code, the document also contains short explanations of ethical principles, recommended reading, the ICN *Code for Nurses* and the UN Declaration of Human Rights, 1948.

Switzerland has a population of just over 7 million people and belongs neither to the European Union nor the United Nations; the latter is for reasons of housing the headquarters of the UN, the former because a majority voted against entry in recent referenda.

The Swiss health care system is organized at cantonal level, with 26 cantons, each featuring different systems. Although a new federal health insurance law implemented in 1996 demanded, for the first time, compulsory health insurance for all, its interpretation by the different cantons varies considerably.

As yet, in the majority of cantons nurses are either not mentioned at all as health care professionals or they figure as assistants to physicians. In the realm of nursing education there are plans to offer university level programmes within the next five years and the first of these to be offered at Basle university received approval in 1997. It is therefore not surprising that nurses have had little impact on public or medical decision-making in health care issues.

Care of the dying

The health care system in Switzerland relies on obligatory health insurance for everyone.

Although palliative care has long existed in Switzerland, it was not until 1988 that the Schweizerische Gesellschaft für Palliative Medizin (Swiss Association for Palliative Medicine) came into being (Serena, 1989). The aims of the association are to: develop palliative care without making it a speciality; train and educate medical and nursing personnel; exchange information; develop the methods of care; and inform health care personnel as well as the general public. In 1993 the first home care centre for the care of the dying was started in Sion (canton Valais) (Kocher, 1994). This centre employs 15 people and domiciliary care is offered by a team of specialists. It acts as a centre for information and documentation, offers psychological and social help and serves as a research and training resource (Kocher, 1994).

As a subject, care of the dying is frequently discussed in nursing journals, the literature and in seminars (Jost, 1995).

Euthanasia

The word used to describe euthanasia is *Sterbehilfe*, meaning 'helping to die'.

The Schweizerische Akademie der Medizinischen Wissenschaften (SAMW: Swiss Academy of Medical Sciences) has guidelines for the care of dying and cerebrally damaged patients (SAZ, 1995). These guidelines were first published in 1976 and revised in 1981, 1988 and 1993. The 1995 text is significant in several areas. Compared with the earlier guidelines, the 1995 text asks physicians not to prolong life for those who are dying, whereas before, this was only considered a possibility. Living wills (*Patiententestament*) must now be respected, whereas before they need not have been. Assisted suicide is definitely excluded and physicians should consult with relatives and the caring team regarding any decisions which may be irreversible. Thus the duties of physicians have been more clearly defined and according to Ernst (1996), their freedom has been curbed, but

the responsibility for making the final decisions is now shared and no longer rests on the physician alone.

A Member of Parliament, Victor Ruffy, tabled a motion in September 1994 which would regulate assisted suicide. The government may have to debate and rule further on the question of euthanasia.

A question which disturbs nurses is what to do when a dying patient refuses their care, such as being turned (Spichiger, 1995). Spichiger suggests in her study that nurses tended to show an unthinking and paternalistic attitude. More discussion on the subject of the care of the dying and sharing of experiences through, for example, reflective practice, would be one way of helping to make the patients' dying easier. Remmers (1996) also suggests that an ethic of care needs to be established in nursing so that 'helping to die' is not a major problem for nurses.

Organ transplants

Switzerland has six centres where organ transplants are carried out. In 1996 a total of 357 organs were transplanted and more than half of them were kidneys. But in January 1997, 464 people were on waiting lists. Schlumpf (1997) believes that transplants suffer because people do not want to face illness and death. Swisstransplant, the organization responsible for co-ordinating the transplant programme, believes that an advertising campaign will help. The SAMW published two documents in 1996 concerning transplants and a new law should be introduced in the future which should help to remedy the situation. In the documents the role of nurses is not mentioned (personal communication), but it is clearly a part of patient care about which they are concerned (Haupt, 1994; Gonseth, 1996).

Conclusion

End of life problems have always existed, but modern medicine has made them much more difficult. Death has become the Big Problem. We no longer believe in a better life here-

after to look forward to, therefore all our efforts are concentrated on this life.

At present, our efforts to make the last stages of life dignified still have a cloak of morality about them, but in all of the problematic cases which reach the media, a financial aspect is always involved. In a market-led society people do inevitably have a price tag and establishing how much someone is worth is really what we are saying in relation to the various techniques described in this chapter. The individual is seen and treated as an isolated entity to the detriment of society at large.

Perhaps the real moral and ethical challenges for nurses, and health care workers generally, is how to maintain the dignity of, and respect for, the individual person, who is also a member of, and has responsibilities to, a family, a community and a society, each of whom rightly claim the person as their own.

Although political and economic issues play some part, many of the problems involving end of life issues arise because of poor communication. Essentially, this means that we are no longer competent to talk with and listen to each other. By fostering these aspects, nurses will make a much bigger impact on end of life decisions than may yet be envisaged. This takes empathy, compassion and courage.

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Appendix

Extract from *The Midwives Code of Practice* (UKCC, 1994, pp. 4–6) incorporating the Activities etc.

The activities of a midwife are defined in the European Midwives Directive 80/155/EEC Article 4:

Member states shall ensure that midwives are at least entitled to take up and pursue the following activities:

- 5.1 to provide sound family planning information and advice;
- 5.2 to diagnose pregnancies and monitor normal pregnancies; to carry out examinations necessary for the monitoring of the development of normal pregnancies;
- 5.3 to prescribe or advise on the examinations necessary for the earliest possible diagnosis of pregnancies at risk;
- 5.4 to provide a programme of parenthood preparation and a complete preparation for childbirth including advice on hygiene and nutrition;
- 5.5 to care for and assist the mother during labour and to monitor the condition of the fetus in utero by the appropriate clinical and technical means;
- 5.6 to conduct spontaneous deliveries including where required an episiotomy and in urgent cases a breech delivery;
- 5.7 to recognise the warning signs of abnormality in the mother or infant which necessitate referral to a doctor and to assist the latter where appropriate; to take the necessary emergency measures in the doctor's absence, in particular the manual removal of the placenta, possibly followed by manual examination of the uterus;
- 5.8 to examine and care for the new-born infant; to take all initiatives which are necessary in case of need and to carry out where necessary immediate resuscitation;
- 5.9 to care for and monitor the progress of the mother in the postnatal period and to give all necessary advice to the mother on infant care to enable her to ensure the optimum progress of the new-born infant;
- 5.10 to carry out the treatment prescribed by a doctor;
- 5.11 to maintain all necessary records.

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