

Do Not Attempt Resuscitation Decisions and Disability in Scotland

Scotland

Disability Rights Commission

The Disability Rights Commission (DRC) is an independent body, established by Act of Parliament to eliminate the discrimination faced by disabled people and promote equality of opportunity. When disabled people participate – as citizens, customers and employees – everyone benefits. We have set ourselves the goal of “a society where all disabled people can participate fully as equal citizens.”

We work with disabled people and their organisations, the business community, Government and public sector agencies to achieve practical solutions that are effective for employers, service providers and disabled people alike.

There are around 10 million disabled people in Britain. This covers people with epilepsy, cancer, schizophrenia, down's syndrome and many other types of impairment.

Under the Disability Discrimination Act 1995, many legal rights and obligations affecting disabled people's access to services and employment are already in force. Others become law in October 2004.

Many disabled people are still not aware that they have many new rights. Employers and service providers are often unsure how to implement “best practice” to make it easier for disabled people to use their services or gain employment.

The DRC has offices in England, Scotland and Wales. For further details of how we can help you, please contact our Helpline – contact details are featured on the back cover of this publication.

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A report to the Disability Rights Commission

Acknowledgements

We would like to thank the authors of this report, Sheila Riddell and Charlotte Pearson from the Strathclyde Centre for Disability Research, University of Glasgow and Nick Watson from the Department of Nursing Studies, University of Edinburgh. We would also like to express our appreciation to the Health Boards, Trusts, consultants and the voluntary organisations that gave up their time to participate in the research. Finally we would like to thank Caroline Johnston and Adam Gaines at the Disability Rights Commission, and Moira Dunworth (an independent consultant) for their input into the report. It should be noted that the report contains the views of the researchers and does not necessarily reflect the Disability Rights Commission's views.

Foreword

The rights of disabled people and equality of treatment are key issues for the Disability Rights Commission. We have an interest in the position of disabled patients and their rights in resuscitation cases arising from cardiopulmonary failure, and in end of life matters such as withdrawal of treatment. Given resuscitation policy is a complicated and sensitive issue, we decided to commission independent research into policy and practice in Scotland. This topic is of importance, because it deals with life and death issues, and can provoke strong emotions and opinions. The differing views amongst people with disabilities, as well as doctors, is an indication of the complexity of this issue.

We are keen to ensure that disabled people's rights are supported and clarified. The Commission has taken an active interest in such matters including our intervention in the recent case of Leslie Burke concerning artificial nutrition and hydration. The Disability Rights Commission believes in the importance of dignity, choice and communication, and they need to be central to any debate.

We hope this research will help elucidate the issue and dispel a few myths. We are very grateful to the Strathclyde Centre for Disability Research at Glasgow University, and the Department of Nursing Studies at Edinburgh University for their hard work in carrying out the research.

It is welcome that the research shows that Health Boards and the previous Trusts in Scotland have policies on Do Not Attempt Resuscitation decisions, and that they all believe in the need to consult with patients and their families on such matters. This shows there is a growing recognition and understanding of the issue. However, it would appear that more can be done to ensure policies and practice are disseminated across the health field and become best practice.

We see this research as making a key contribution to informing the discussion, providing information for all those concerned, as well as helping Health Boards and medical professionals access information about best practice. The research indicates that more could be done:

- to increase communication and advocacy support for patients
- in spreading greater information about the Adults with Incapacity (Scotland) Act 2000
- in updating Trust policy documents to include specific reference to Scottish law, in line with the British Medical Association, Resuscitation Council and Royal College of Nursing guidelines

This is not an issue with simple answers or where prescription politics can provide an answer. We hope that by providing more information about disability, doctors, health staff and people with disabilities and their families will be better informed, and disabled patients and their families will be further included in decisions affecting their futures.

Elaine Noad
Scottish Commissioner
Disability Rights Commission

Chapter 1: Background to the study

Introduction

Within the UK National Health Service, there is a concern to include patients in all important decisions about their care and to avoid discrimination against particular social groups in access to services. The Disability Discrimination Act 1995 (as amended) places a duty on providers of goods and services to avoid discriminating against disabled people. In addition, the Human Rights Act 1998 underpins a number of fundamental human rights. Provisions particularly relevant to Do Not Attempt Resuscitation (DNAR) decisions include the right to life (article 2) and the right to freedom from inhuman or degrading treatment (article 3). These may affect decisions that either deprive an individual of life sustaining treatment or subject them to treatment without benefit. Article 8, the right to respect for privacy and family life, may also be related to the extent to which patients should be involved in decisions, the amount of information provided to them and communication with the friends and relatives of both competent and incompetent adults. Furthermore, the right to be free from discriminatory practices is covered by article 14.

British Medical Association (BMA) guidelines on the use of DNAR notices, published in 2001 in collaboration with the Resuscitation Council (RC) and the Royal College of Nursing (RCN), establish new standards in terms of patient consultation. However, there is continued disquiet among some disabled people concerning equal access to health services and treatments. Prior to the publication of the BMA/RC/RCN guidelines, guidance did not indicate the necessity of consulting competent patients before writing DNAR notices. In this report, we focus on issues surrounding cardiopulmonary resuscitation (CPR). However, within a wider context, disabled people fear that they may be denied a range of life saving operations and treatments, such as rehydration, artificial - nutrition or specialised treatments such as dialysis. Some of these issues were recently considered in the English High Court case, *Leslie Burke v GMC* (case no Co/4038/2003), which was heard before Mr Justice Mumby.

The research reported here provides a brief review of UK policy with regard to DNAR notices within the wider context of human rights legislation. This is followed by a content analysis of DNAR policy guidelines produced by NHS Trusts and Health Boards throughout Scotland. In-depth interviews were conducted with consultants in a range of specialities to explore views on the implications of the guidelines in their particular areas of expertise. The views of a small number of voluntary organisations were also explored and contrasted with the views of consultants.

It should be noted that this was a small-scale study, and part of the aim was to identify areas where further research is needed. In particular, the scope of the study did not allow us to spend time exploring the views of disabled people themselves with regard to accessing health services and treatments. However, voluntary organisations provided some insights into the gap between policy guidelines and user experiences.

Policy guidance on resuscitation

In 2001, the BMA, the RC and the RCN published a document entitled **Decisions Relating to Cardiopulmonary Resuscitation**. This set out the legal and ethical standards for planning patient care in the area of resuscitation. One of the main reasons for the update was the implementation of the Human Rights Act 1998 in October 2000, which incorporated many of the provisions of the European Convention on Human Rights into UK law. In order to meet their obligations under the Act, health professionals must be able to show that their decisions are compatible with the Human Rights Act. The guidelines emphasised that whilst the same broad principles should apply in all cases, different decisions might be made in relation to superficially similar cases because of varying personal and social considerations:

‘These basic principles are the same for all patients, in all settings, but because a range of clinical and personal matters has to be taken into account in each case, the decision arrived at in the care of one patient may be inappropriate in a superficially similar case.’

(BMA/RC/RCN, 2001, p5)

In the following section, we note some key points contained in the guidelines and consider their implications.

A fundamental principle reflected in the guidelines is the need to inform patients and relatives about the likely benefits and burdens associated with the use of CPR. All DNAR orders, it is stated, should be discussed with competent patients, unless they indicate that they do not want to do this. This marks a significant change from earlier guidelines. Previously, if a doctor felt that a DNAR order was appropriate on the grounds that CPR was unlikely to succeed, this did not need to be discussed with the patient. There was no obligation to offer, or even discuss, useless interventions.

If a competent, fully-informed patient requests a DNAR order then the request should be respected. Health professionals should ask for the patient's permission to tell those close to the patient. A competent patient may not wish information to be conveyed to those close to him or her, and this must be respected. Relatives or friends may dispute a patient's request for a DNAR order on the grounds that they are not competent. It is also possible that a patient may cross a threshold between competence and incompetence prior to CPR being required. If there is a discrepancy between the doctor's and the relatives'/friends' views of the action which should be taken, then the doctor is advised to document the decision, and if possible seek a second opinion from a senior colleague and seek legal advice. It is suggested that local guidelines should provide information on accessing legal advice. This is clearly only possible if decisions are made prior to an emergency occurring. If an emergency occurs and there is uncertainty over a patient's wishes, then a clinician is permitted to use his/her professional judgement in deciding on a course of action. It is advised that guidance should be available to all staff at local level, and junior doctors should be given clear instructions on how to act in an emergency situation.

The utility of 'living wills' is noted in the guidelines. These are documents in which people state their wishes in relation to medical treatment in the event of their becoming incompetent in the future as a result, for example, of a progressive condition or illness. However, research by Collins et al (2000) found that Scottish GPs questioned the status of these documents, and did not consider that they should guide subsequent clinical decisions. The BMA/RC/RCN guidelines note that wishes expressed verbally to a doctor have as much weight as those which are written down. Clearly, complications may arise when a patient appears to express conflicting views at different times.

The guidelines state that if a competent patient does not want a DNAR order then one cannot be written. This represents a change from earlier guidance, which did not give a patient the right to refuse to have a DNAR notice attached to their notes. However, refusing a DNAR notice does not mean that CPR would automatically be given, since the guidelines also recognise that doctors cannot be forced to provide treatment which they think is not clinically indicated. In the guidelines, it is stated that:

‘(i) Doctors cannot be required to give treatment contrary to their clinical judgement and (ii) ...it is unlikely to be considered reasonable to attempt to resuscitate a patient who is in the terminal phase of an illness or for whom the burdens of the treatment clearly outweigh the potential benefits.’ (BMA/RC/RCN, 2001, p 9 and 7)

There is tension between respecting doctors’ judgement about the likely success of a particular treatment, and the need to respect patients’ wishes for a particular treatment to be carried out, irrespective of the likely chances of a successful outcome. The guidance notes:

‘Doctors cannot be required to give treatment contrary to their clinical judgement, but should, whenever possible, respect patients’ wishes to receive treatment which carries only a very small chance of success or benefit.’ (BMA/RC/RCN, 2001, p9)

The guidelines make clear that the severity of a person's impairment will be a relevant factor to take into account in reaching a clinical judgement. They note:

'Where patients suffer with such profound disability that they have no or minimal awareness of their own existence and no hope of recovering awareness, or where they suffer severe unmanageable pain or other distress the question arises as to whether initiating treatment to prolong their life would provide a benefit to them. In assessing the benefits that would arise in prolonging life, it is not only legitimate but ethically appropriate to consider whether cardiopulmonary function is likely to fail repeatedly and whether there are any costs to the patient in terms of pain or distressing side effects.'
(BMA/RC/RCN, 2001, p12)

It is evident that many important philosophical and ethical issues arise here, and that it is impossible for one human being to know the extent to which another has an awareness of their own existence. These issues are discussed further below in relation to the concept of quality of life.

In earlier guidance, doctors were advised that treatment should not be given if considered to be 'futile'. However, the concept of 'futility' is questioned more overtly in the 2001 guidelines (BMA/RC/RCN, 2001, p. 11), and the section which examines when it is appropriate to consider using a DNAR order presents a more detailed focus on questions around the benefits and burdens of treatment. Therefore, it is implicitly acknowledged that the use of CPR is justified even if it is likely to result in only a small improvement in the patient's condition. It is clear that, in assessing the issue of benefits versus burdens, clinicians are being called upon to use professional discretion, recognising that others might reach a different conclusion in a given set of circumstances.

In relation to 'incompetent' patients, different arrangements apply in Scotland as opposed to England, Wales and Northern Ireland. In Scotland, under the terms of the Adults with Incapacity (Scotland) Act 2000, a proxy decision-maker may be appointed to make legal decisions relating to health matters on behalf of the person with incapacity. In England, Wales and Northern Ireland, the views of friends and relatives do not have any legal status, and decisions are made by a senior clinician with regard to the best interests of the incompetent patient. However, the guidelines urge doctors to consult with friends and relatives, and attempt to achieve a consensus decision on a course of action should CPR be required.

The guidelines also note that important issues arise in relation to the management of decisions concerning children and young people. The guidelines note:

'It is recognised widely that medical decisions relating to children and young people ideally should be taken within a supportive partnership involving parents, their families and the health care team. The views of children and young people must be taken into consideration in decisions about attempting CPR.' (BMA/RC/RCN, 2001, p10)

In Scotland, a competent young person is empowered to refuse treatment. It is likely that, in Scotland, neither parents nor the courts are entitled to override a competent young person's decision. In the rest of the UK, by way of contrast, when a competent young person refuses treatment, the harm caused by violating the young person's choice must be balanced against the harm caused by failing to treat.

In terms of the locus of decision-making, the consultant with responsibility for patient care must take responsibility for orchestrating discussions between relevant parties, recording the decision in writing and communicating this to the health team, the patient and relatives. Where care is shared between a hospital and a general practice, then discussion should take place between the doctors involved, but one person should be charged with responsibility for recording and communicating the decision. The guidelines note that patients have a legal right to see and copy their medical notes.

The guidelines emphasise that the health team should be made aware that DNAR notices only apply to CPR, and that all other forms of treatment and care should be considered and offered. It is interesting that a relevant factor to be borne in mind in decision-making is the impact on the morale and commitment of health teams of conducting unsuccessful CPR attempts. This is used as an argument for only using CPR in cases where there is a reasonable chance of a successful outcome.

Stewart, Spice and Rai (2003) suggest that the following points emerging from the BMA/RC/RCN guidelines are of particular relevance to geriatricians:

- There is a need for the involvement of senior experienced doctors, who have had training in communication skills, and other professionals, particularly well-trained senior nurses.
- The right of competent individuals to be involved in decisions and to refuse DNAR decisions must be recognised.

- Futility is no longer used as a rationale for a decision not to resuscitate. Rather, consideration must be given to the prospect for restoration of pulse and respiration and then to benefits to the patient.
- More sensitivity must be given to the place of relatives and friends, particularly if acting as the legal executor for an incompetent individual.

Despite new attempts to involve patients in clinical decisions, it is evident that the balance of power still lies with the professionals. Whereas a patient has the right to refuse treatment, clinicians are not obliged to comply with a request for treatment. The clinician maintains the right to refuse treatment irrespective of the patient's wishes. There is an emphasis throughout the guidelines on the need for legal protection for medical personnel. Doctors are advised to request in writing, training in communication skills in sensitive areas from NHS Trusts/Health Boards, if this is not routinely available. They are encouraged to seek legal advice immediately should any difficulty arise, and to ensure that their employer informs them of where such advice may be obtained. Clinicians are advised to audit the use of DNAR notices using National Institute for Clinical Excellence (NICE) guidelines, and to seek a second opinion from a senior colleague in case of disagreement. Compared with the back-up available to doctors, the guidelines do not concern themselves with support for patients or their families. There is no mention of advocacy, which may be the legal entitlement of a person with incapacity.

Key concepts in the application of the guidelines

Quality of life

Throughout the BMA/RC/RCN guidance, there is an implicit concern with the concept of 'quality of life' and it is emphasised that life should not be prolonged at any cost:

'Prolonging a patient's life usually provides a health benefit to that patient. Nevertheless, it is not an appropriate goal of medicine to prolong life at all costs with no regard to its quality or the burdens of treatment on the patient.' (BMA/RC/RCN 2001, p. 7)

The BMA noted that:

'In the most extreme cases of profound disability, treatment to prolong life artificially may not provide a net benefit to the patient' (BMA, 1999, para. 3.1).

As noted above, it is ultimately the doctor rather than the disabled person or their medical proxy who decides whether treatment is in the patient's 'best interests'. There are clearly difficult philosophical issues to be dealt with here, since it is difficult for one human being to make a judgement about another's subjective experience of the world. In the context of limited resources within the NHS, health economists have developed systems to prioritise patients for particular procedures based on the number of quality of life years which are likely to result for a given individual. A DRC report from a seminar held in November 2002 (Disability Rights Commission, 2002) noted that such calculations were likely to be biased against disabled people, since some might have shorter life spans than non-disabled people and doctors might judge the lives of disabled people to be lower in quality.

Age Concern (England), the Down's Syndrome Association and Enable have publicised cases (see chapter 3 for more details) where decisions seem to have discriminated against older and disabled people, on the grounds that their quality of life was likely to be less than that of younger and non-disabled people.

Defining the patient's best interests

Before the publication of the BMA/RC/RCN guidelines, there was greater acceptance that the role of the doctor was to make decisions about the best interests of the patient (O'Keeffe, 2001). If a doctor felt that a DNAR order was appropriate on the grounds that CPR was unlikely to succeed, then discussion with the patient was often not felt to be necessary, as there was no obligation to offer or even discuss such interventions (Doyal and Wilsher, 1993). A review of the wider literature prior to the 2001 DNAR guidance highlighted inconsistency and confusion surrounding decision-making and dialogue between patients, relatives and the medical profession. Hill et al's (1994) survey of 80 hospital doctors, for example, found that only one of the 34 doctors returning the questionnaire thought that patients should be consulted routinely on the decision to resuscitate. The remaining 33 thought that patients should never or only rarely take part in the decision. Moreover, in practice Hill et al found that none of the doctors interviewed discussed resuscitation with their patients, although two spoke to relatives. In contrast, all patients interviewed in the study thought that resuscitation should be discussed with them.

Sayers and Perera (2002) compared non-treatment decision-making by GPs and geriatricians in response to vignettes, to see whether doctors' decisions were informed by ethical or legal reasoning. Using a random sample, GPs were asked whether patients described in various scenarios should be admitted to hospital for further care and to give supporting reasons. They were asked with whom they would consult, who they believed ought to make such decisions and whether relatives' preferences would influence their decision making. Only 10 per cent of the doctors participating in the study said that they would provide life-prolonging treatment to patients with severe brain damage, whereas most stated that they would admit a surgical patient regardless of age or disability. Findings also showed that little attempt was made to link decision making with ethical or legal concepts, and there may have been non-recognition or denial of the ethical consequences of the failure to admit.

Studies carried out prior to 2001 also highlighted researcher bias in relation to the value of a disabled person's life. For example, a questionnaire survey carried out by Morgan et al (1994) to determine the views of older patients and their relatives in relation to CPR included the following questions:

- Some people are physically disabled and depend on others to care for them continuously. Do you think that they should be resuscitated in the event of a cardiac arrest?
- Some people are mentally disabled (demented). Do you think that they should be resuscitated in the event of a cardiac arrest? (Morgan et al, 1994, p. 2)

Complex issues also arise in relation to determining whether to continue treatment, including emergency resuscitation, of babies and children. McHaffie (2001) notes that three factors are likely to be considered in relation to such decisions: the imminence of death, the futility of treatment and the quality of life. She argues that whilst clinical assessments may be made in relation to the first two factors, quality of life is a more 'polymorphous collage' (Dracup and Raffin, 1989). The notion of quality of life embraces:

'Ideas of the capacity to function in normal everyday life, intellectual capabilities, the ability to relate to others or communicate, the potential to appreciate with the senses, and satisfaction with life. All of these things are difficult to quantify, especially for a neonate (a child less than one month old). Furthermore, children who would objectively rate low on some of these factors can lead happy lives.' (McHaffie, 2001, p 2).

Despite the elusiveness of the concept of quality of life, families of babies and children are likely to have important views which need to be taken into account and which may differ from those of the medical team. McHaffie comments:

'...although it is generally accepted that the wider interests of society and of costs are secondary considerations which should never overrule the best interests of the individual baby (McHaffie and Fowlie, 1996; Fulbrook, 1992), the infant's interests cannot be altogether divorced from those of the family. These lives are intertwined, and what impinges on the one may affect the other. Children with severe impairments will place significant demands on their family. Parents' feelings towards a child may be affected if the baby is kept alive against their better judgement; their own lives may be irrevocably altered if the child either lives or dies. Objectively it could be argued that only they can determine the limits which should be set in the case of their own child.' (McHaffie, 2001, p 3)

However, this is not a view which is widely shared by health workers. McHaffie and Fowlie (1996) surveyed opinions of workers within Neonatal Intensive Care Units. They found that only 3% of doctors and 6% of nurses felt that patients should take responsibility for decisions about life-saving and sustaining treatment. Overall, McHaffie maintains that there is an overall lack of clarity about the balance of power in decision-making within the 'moral community', consisting of the baby's family and the medical team.

Defining competence

The law of Scotland presumes that adults (people over the age of 16) are legally capable of making personal decisions for themselves and managing their own affairs. That presumptions can be overturned on evidence of impaired capacity. The Adults with Incapacity (Scotland) Act 2000 allows people to anticipate their own incapacity by granting a power of attorney in relation to property, financial affairs or personal welfare (including health). Welfare attorneys have powers over a person's health and social welfare, which commence when the person becomes incapable of making key decisions for themselves. The Act recognises that a person may be capable of making some decisions and not others. For the purposes of the Act, 'incapable' means being incapable of:

- (a) acting;
- (b) making decisions;
- (c) communicating decisions;
- (d) understanding decisions;
- (e) retaining the memory of decisions.

The guidance accompanying the Act stipulates that a welfare attorney's action must benefit the individual in that 'such benefit cannot reasonably be achieved without the intervention' (para 2). In determining this, the Act emphasises the importance of both present and past wishes and feelings of the incapable person, and the need to take into account advance statements such as living wills.

In cases where a proxy has been nominated, the Act states that they must be consulted about treatment decisions 'so far that it is reasonable and practicable to do so' (para 4d). However, nominated proxies are unable to demand treatment which is judged to be against the patient's best wishes. As noted earlier, in England, Wales and Northern Ireland, whilst the views of relatives and friends must be noted, there are no legal provisions for the appointment of a medical proxy.

The issue of competence in relation to children is discussed by Hill and Tisdall (1997). Traditionally, parents have been accorded authority to make decisions on their child's behalf in relation to areas such as education and health. However, the 'Gillick' principle enunciated that, in common law, children under the age of 16 should be able to make a decision in relation to such matters as medical treatment or contraception, without parents needing to know, once they were judged to have 'sufficient understanding' (Children's Rights Office, 1996; Lansdown, 1996). This still left adults with the discretion to decide when a child's level of understanding was sufficient, but the presumption was that the child's choice should be respected wherever possible. However, subsequent cases modified the principle of self-determination. Whilst it was accepted that children could give consent to a given course of action, they could be prevented from opting out of a course of action by anyone with parental responsibility.

The Gillick principle was not incorporated into English statute, but the Age of Legal Capacity (Scotland) Act 1991 specified that:

‘...a person under the age of 16 shall have the legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment wherein the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment’
(Section 2(4)).

Whether a child’s refusal can override consent by someone with parental responsibility has not been tested by any Scottish cases to date. In relation to resuscitation, a competent child could therefore request a DNAR notice, although, as with adults, if a child requests resuscitation, the ultimate decision rests with the clinician.

Advocacy

Given the complexity of the issues in relation to the use of CPR, this appears to be an area where advocacy for vulnerable people might be used extensively. The role of advocates is to offer independent support and advice to vulnerable people about rights care and services they are entitled to receive. The policy paper **Our National Health, A Plan for Action, A Plan for Change** (Scottish Executive, 2000) required all Health Boards to ensure that independent advocacy was available to all patients by December 2001. Health Boards were required to submit plans to the Scottish Executive explaining how they intended to fulfil this requirement.

In 2000, the Health and Community Care Minister Malcolm Chisholm announced funding to set up an Advocacy Safeguard Agency and a Scottish Independent Advocacy Alliance to develop independent advocacy services for people with health problems, particularly mental health problems and learning disabilities.

The role of the Advocacy Safeguard Agency was to ensure the availability of services and to work with Health Boards developing these services. The Scottish Independent Advocacy Alliance was to work with existing advocacy agencies to develop their services to meet the growing need. However, as noted above, the BMA/RC/RCN guidelines made no mention of the role of advocacy. Future work is clearly needed to assess the effectiveness of advocacy services in this area.

Conclusion

Overall, it is evident that decisions around the issue of resuscitation have become increasingly complex and contested. Whereas in the past doctors were relatively free to make clinical judgements on life and death issues, there is a growing emphasis on the right of patients to play a key role in such decision-making, perhaps having the final say in relation to whether a life-sustaining treatment is carried out or withdrawn. There are also growing concerns about issues of alleged doctors' abuse of power, which have been highlighted by a number of high profile cases. In the US, greater weight is given to patients' wishes and in the UK the pendulum is swinging in this direction. At the moment, in Scotland, whilst the patient or his/her legal executor can request a DNAR notice, a clinician has the discretion to override an expressed wish for resuscitation on the basis of his/her professional judgement of the best interests of the patient. Many grey areas persist, in particular the role to be played by parents and the extent to which the wishes of a child or young person are to be acted upon.

The recent guidelines (BMA/RC/RCN, 2001) emphasise the need for a more consultative approach, but it is clear that their provenance is from a medical perspective. Whilst this is a perfectly legitimate concern, there is a need to balance this with ensuring that the wishes of patients are fully addressed. Thus doctors are urged to ensure that they receive proper training in communication skills and have access to legal advice and support from senior colleagues, but the need for vulnerable patients to receive support from advocates is not mentioned. The guidelines are produced to cover the whole of the UK, but perhaps do not reflect the increasing emphasis on advocacy in Scotland. It is evident that this area of medicine could become increasingly litigious. Whilst legal challenge may play a part in challenging established practice and promoting the rights of patients, it also uses up resources which might be better spent on patient treatment.

Overall, there is a need for further research in this area on a range of topics including the following:

- The use of advocacy in decisions about CPR
- The role of legal attorneys
- The decision-making roles accorded to children and parents
- The attitudes of doctors and other health professionals to disabled people and quality of life issues
- The basis on which clinical decisions are made in relation to medical and quality of life factors
- The nature of the legal advice given to doctors in the light of the Human Rights Act 1998

Chapter 2: Local NHS Trust policy documents on DNAR

Introduction

This section provides an analysis of the main issues covered in the local policy documents on DNAR received from the Hospital Trusts for this study. The level of detail within each of the Trust documents varied considerably, although all had been updated in the last year in response to the revised BMA/RC/RCN guidelines and subsequent requirements from the Scottish Executive (Scottish Executive, 2000a).

A letter was sent to all NHS Health Trusts and Health Boards in Scotland requesting a copy of their DNAR policy for the study. Documents were received from 23 of the 27 hospital trusts and from seven of the 14 Health Boards (see appendix 1). It was clear from the responses received that DNAR policies were mainly devised at Hospital Trust level. Most documents were therefore received through this route.

The length and coverage of documents received from the Trusts varied considerably. The shortest accounts were two sides of A4 and only included a copy of the DNAR form and a brief overview of guidelines. In such cases, information was replicated from the BMA/RC/RCN (2001) joint statement. Other Trusts provided more comprehensive accounts, providing a detailed overview of policy, together with practical advice on training and the more practical aspects of carrying out resuscitation.

Analysis of the policy documents focused on a number of themes related to DNAR, picked up from the wider policy and literature review and interviews with the hospital consultants. These are explored in the following sections. For the purposes of this review, all Hospital Trusts have been anonymised.

Criteria set out in local policies for use of DNAR notices

As discussed in Chapter 1, the main policy guidance in relation to DNAR is drawn from the joint statement produced by the BMA/RC/RCN, 2001. This has also drawn on human rights set out in the Articles of the Human Rights Act 1998. Since the publication of the BMA/RC/RCN guidelines, local NHS Trusts and Boards in Scotland have been obliged to reformulate their own DNAR policies. In 16 of the Trust documents examined, (including one covering both acute primary care sectors) the BMA/RC/RCN guidance is referred to directly, and in all but 3 areas the DNAR criteria are laid out (this is returned to shortly). The local policies therefore provide a broad overview as to how these issues have been addressed. Whilst their focus tends to offer a more general discussion of resuscitation, some of the language used and the coverage of issues in the documents highlight areas of potential concern for disabled people. One of the most blatant examples of this arose in a covering letter from a Hospital Trust, in which it was explained why a DNAR policy specifically for disabled people had not been put in place:

‘The patient population at Hospital X is of relatively young fit adults with very little in the way of classic disabilities. As a consequence, **all** patients [author’s emphasis] unless there are exceptional circumstances, are regarded entitled to resuscitation.’

In contrast, another policy made clear that any decision relating to resuscitation should be unrelated to any preconceived judgements:

‘Decisions not to resuscitate should not be made only because a person is old, has a severe mental illness or has a profound learning disability.’

Two other Hospital Trusts focused more directly on the use of CPR in relation to the patient's age. Whilst more general comments were made which dismissed a link between quality of life and age, one Hospital Trust in particular drew attention to long-term outcomes:

'Age itself has less effect on outcome than the underlying disease process or the presenting rhythm. Nevertheless patients in their 70s and 80s do not have good survival rates compared to a younger age group, generally because of underlying disease, and earlier curtailment of CPR is indicated.'

Other documents were more ambiguous, stating that:

'...basic principles are the same for all patients in all settings...' but adding that 'because a range of clinical and personal matters have to be taken into account in each case, the decision arrived at in the case of one patient may be inappropriate in a superficially similar case.'

However, attempts were made in many of the documents to lay out criteria where a DNAR order might be considered. For example, several policies focused on the following scenarios – all of which were derived from the BMA/RC/RCN guidance:

- (i) Where the patient's condition indicates that effective CPR is unlikely to be successful.
- (ii) Where CPR is in accord with the recorded sustained wishes of a mentally competent patient.
- (iii) Where CPR is not in accord with a valid, applicable, advance directive (such as an anticipatory refusal or living will).
- (iv) Where successful CPR is likely to be followed by a length and quality of life which would not be in the best interests of the patient to sustain.

Quality of life

As the example above indicates, many of the criteria for local DNAR policies remain vague. Around half of the policy documents examined clearly referred to the notion of 'quality of life' as a key indicator of whether CPR should be administered or not and made some attempt at a definition. However, there remains a lack of clarity as to the areas covered by the term. One document, for example, stated that a DNAR notice should be considered:

'...where successful CPR is likely to be followed by a length and quality of life, which would not be in the best interests of the patient to sustain.'

In around half of the other documents, only a limited focus was given to the term. In these cases, policies tended to refer more broadly to the articles of the Human Rights Act 1998. However, examples were also found where specific medical terms were identified as indicating that CPR should not be used. Thus it was noted in some cases that:

'Those least likely to survive are patients with severe chronic and irreversible illnesses such as organ failure, wide spread malignancy and other severely debilitating conditions.'

Other local guidance focused on a broader interpretation of quality of life, although emphasising the need to examine each individual case separately:

'The decision not to attempt resuscitation should be made in light of knowledge of the patient's quality of life, psychosocial and physical co-morbidity and prognosis and where resuscitation attempts are considered to be most likely to be unsuccessful, or result in unacceptable distress to the patient.'

Overall, quality of life was referred to as of great importance in DNAR decision-making within Trusts' policy documents, but the complexity of the concept was not fully acknowledged.

DNAR notices in relation to children and young people

Coverage of DNAR issues for children and young people was varied, and only directly covered in seven of the Trust policy documents. Only one of the hospitals (a children's hospital) referred directly to the guidance on emergency resuscitation produced by the Royal College of Paediatrics and Child Health (1997). In this case, the guidance laid out the five conditions where a DNAR decision might be considered. This included the contentious 'No purpose' situation, where the decision to administer a DNAR notice is directly linked with the level of 'physical or mental impairment'. Others made more specific statements regarding consultation with children and young people. However, the emphasis on consultation seemed to vary from one Trust to another. For example, one document stated that:

'The views of children and young people must be taken into account in decisions relating to CPR. If a competent young person refuses treatment or requests a DNAR order, it is likely that neither parents nor the courts are entitled to override this decision.'

Another Trust stated:

'Where the child, parents or legal guardians do not consent, or are in dispute with each other, then the DNAR decision cannot be taken and further advice must be sought with the Trust's Medical Director.'

These views are in line with the current legal position in Scotland which, as discussed in Chapter 1, differs from the situation in England. It is interesting that all Trust documents did not reflect these views.

Consultation

In all of the policy documents, there was a clear focus on the need to discuss DNAR related issues with patients and/or family, close friends and medical staff. One document stated unambiguously:

‘The policy which follows attempts to strike a reasonable balance between patient empowerment (patients deciding what they want done) and medical beneficence (doctors deciding what is good for patients).’

Others were keen to emphasise that DNAR applied only to one area of treatment:

‘When a ‘Not for CPR’ decision is made, it should be made absolutely clear to the patient that this applies solely to CPR; that the decision will be regularly reviewed and that all other appropriate treatment for the patient’s benefit will continue.’

The level of detail provided in relation to consultation on DNAR notices varied considerably across the Trust areas. In around a third of Trust documents, comprehensive information relating to patient consultation, input from family and/or friends and the role of the consultant was given. This type of information laid out the boundaries of responsibility in this area. For example, one Trust clearly set out scenarios where the views of family and/or close friends might be considered:

'If the patient cannot express a view, the views of the family or others close to the patient may be sought regarding what would be in the patient's best interests. Their role is to reflect what they believe to be the patient's views and not to take decisions on behalf of the patient.'

Hence although these views of family were generally highlighted as being important in the overall consultation, all documents were careful to state that they carried no legal status in the actual decision making process. In the light of the Adults with Incapacity (Scotland) Act 2000, it is possible for a legal attorney to be appointed who may act as a legal proxy for the patient (see below). This new legal development was not fully acknowledged.

Adults with Incapacity (Scotland) Act 2000

The level of detail also differed considerably across Hospital Trusts in relation to impact of the Adults with Incapacity legislation. Indeed, in only 11 of the documents examined (under half) was any reference made to the legislation. Some of the more detailed documents laid out scenarios where the intervention of a third party would and would not be considered, stating that:

'Any intervention under the Act must benefit the adult and must be the least restrictive option in relation to the adult's freedom.'

The duty to take into account the past and present wishes of the patient and, where possible, to seek their views was emphasised in some Trust documents. For example, one document stated clearly that:

‘It must never be assumed that the adult lacks capacity to make decisions and that he [sic] should be assisted at all times in participating fully in the decision-making process.’

Few documents discussed how views might be obtained from people who might, for example, have little or no speech. In addition, the possibility of a family member or friend acting as legal proxy was not routinely considered.

Recording and reviewing DNAR decisions

In all the Trust documents examined, the process of recording and reviewing DNAR decisions was considered. However, the main difference in this area was the frequency of review specified. Just under half of the documents did not specify the time intervals at which this should take place. Some stated that the decision should be reviewed every 24 hours, whilst others considered that it should be reviewed ‘as and when required’. All Trusts had also produced specific forms to record DNAR decisions. These forms all took a similar format and required a clear reason for stating why CPR would be unlikely to be successful. Details of consultation with the patient and next of kin were also required, together with two doctors’ signatures (including the consultant). In addition, review procedures were also included, stating whether the DNAR notice was cancelled or should remain in place. It was also stated clearly that the form should be displayed on the inside cover of the patient’s medical notes. It appeared that the patient’s or his/her legal proxy’s signature was not required.

Conclusion

It was evident that the BMA/RC/RCN guidelines formed the basis of the policy guidelines produced by the majority of NHS Trusts in Scotland. However, the changes reflected in UK guidelines were not clearly underlined. For example, the need for consultation was emphasised, but the possibility of using advocates to help patients express their views was not considered. The different legal position in Scotland vis a vis children and young people and incapable adults was not fully reflected. As noted in Chapter 1, in Scotland there is a duty to act upon the expressed wishes of competent young people and the legal proxies of incapable adults. However, this is not fully reflected in the local Trust guidance. Whilst quality of life was a key concept in most policy documents, the difficult issue of defining the concept and making judgements about the quality of life of others was not fully addressed. Finally, the fact that futility of further treatment is no longer an acceptable reason for employing a DNAR notice was skirted round. The power of the physician to make final life and death decisions was underlined rather than questioned.

Chapter 3: Interviews with hospital consultants and voluntary organisations

Introduction

This chapter focuses on the issues raised in the series of interviews carried out with hospital consultants and representatives of voluntary organisations. Five hospital consultants from Glasgow and Edinburgh hospitals were interviewed and their perspectives were contrasted with the views of representatives of two major voluntary organisations. In selecting the consultants, an attempt was made to include a range of specialities. These included:

- Anaesthesia
- Cardiology
- Neo-natology
- Neurology
- Paediatric medicine

The interviews covered a range of questions in relation to DNAR practice and many of the wider issues surrounding patient consultation and consent. Where appropriate, these were specifically linked in with a focus on disability.

Criteria for use of a DNAR notice

All of the consultants were keen to emphasise the importance of dialogue, consultation and consensus with patients and/or their families when discussing the use of DNAR notices. When asked about the circumstances in which a DNAR notice might be considered, all consultants stated that this would be when the chances of survival were minimal or when resuscitation would not be compassionate, because it would involve unacceptable suffering for little or no gain.

The cardiologist commented that CPR decisions were likely to reflect the extent to which the patient was likely to experience long-term major incapacity. At the end of a long-term degenerative illness, there might be agreement that CPR was not in the patient's interests. This would always be discussed with the patient and/or his or her family. If a patient entered hospital in a coma, then every effort would be made to save their life, with longer term decisions about their treatment being made at a later point. In the longer term, the implications of long-term 'dependence' would have to be explored with the patient:

'You have to look at degrees of independence beforehand. This assumes a physicality and there are certain people who have been physically incapable for a long time, but are intellectually active and find that rewarding, so that would have to be explored too.'

The paediatrician drew attention to the five criteria outlined in the guidance on resuscitation issued by the Royal College of Paediatrics and Child Health document, **Withholding or Withdrawing Life Saving Treatment for Children (1997)**. This document is currently being revised, but in its original formulation it supports the idea that resuscitation should not be used if there is no long-term hope of survival and good quality of life. The clinician may decide to employ a DNAR notice if:

'...the patient (child) may be able to survive with treatment, [but] the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it...'

The paediatric consultant emphasised the combination of factors which had to be taken into account:

‘If you have no ability yourself to decide whether you live or die...then your appreciation of life is fairly basic. And if this is out together with severe medical problems and a complete dependency on others then that is how I view it – a sort of spectrum – none of these singularly but out together....’

The paediatrician and the neo-natologist felt that if a child was likely to have a high level of impairment, including incontinence, lack of ability to move independently and little awareness of self, then there was no point in prolonging life through heroic interventions. The paediatrician believed that supporting a child with a high level of impairment was likely to lead to ‘disorganisation in family relationships’, with the disabled child having no awareness of their impact on the rest of the family. Both the paediatrician and the neo-natologist believed that the 1997 guidance was correct to maintain that futility of intervention was an adequate reason for the use of a DNAR notice. The BMA/RC/RCN guidelines refer to both adults and children, but these clinicians did not appear to be aware that recommendations with regard to the futility criterion had already changed.

According to the paediatrician, it was a problem that ambulance staff were obliged to carry out CPR in cases where clinical staff had already decided not to resuscitate. As a result, in such cases parents were advised to either call a GP or delay calling an ambulance. The neo-natologist was aware that this was a contentious area, and that some disabled people were concerned that doctors might make unjustified judgements about disabled children’s quality of life. He commented that the key issue to bear in mind was the degree of intellectual impairment. As long as the child was able to have a sense of themselves as a sentient being, then effort should be made to preserve life.

Quality of life

Given the concern with 'quality of life' issues and the circumstances in which efforts should be made to prolong life in the BMA/RC/RCN (2001) guidance, and in the local Trusts' policy documents, the consultants were asked to define what they understood by this term. All of the consultants interviewed recognised the difficulties in using this term, and acknowledged that responses could be highly subjective and open to different interpretation by different doctors. The anaesthetist suggested that doctors' views varied from 'someone who believes in euthanasia to those who absolutely believe in the sanctity of life'. Given these diverse ethical positions, it was not surprising that views of quality of life varied.

Consultation with the patient, family and other medical practitioners was emphasised to enable the medical team to gauge an understanding of the person's life before the hospital admission.

The neurologist, in particular, suggested that patients rather than health professionals should be responsible for making decisions about quality of life. He was aware that judgements might be highly subjective, for example, a clinician might believe that incontinence or loss of movement inevitably produced an unacceptably poor quality of life. However, a disabled person might have a perfectly acceptable quality of life, and might resent a health professional making such a judgement on their behalf:

'I get very frightened by people who make pronouncements to me and say 'for me, being in a wheelchair would be intolerable, when none of us know how we would feel and I have other patients with profound disabilities who will say, 'I have quality of life, will you all piss off and stop telling me that my life is not worth living.'

The neo-natologist and the paediatrician were aware of the complexity of the concept of quality of life, but were aware that it was very difficult to project forward and predict what a child's future quality of life might be like:

'One of the main problems in this field is that you're basing decisions on probabilities. If you see a baby with a bleed in its brain, a guess can be made as to what it would be like aged 5. But nobody really knows, so you're basing it on probabilities.'

Children and young people: consulting parents

The paediatrician considered that the likelihood of long-term 'dependency on others' was sufficient grounds for a decision not to use CPR. However, it was acknowledged that parents and clinicians might have different views on the desirability of prolonging treatment. Where such a discrepancy of views emerged, the parents' wishes would be respected:

'Consultants can put forward a recommendation to parents but their wishes are paramount. For example, if the consultant thought the baby's future was hopeless and thought that they would deteriorate, but the parents wanted them to carry on, there is no question but the treatment would continue.'

It was also noted that a decision on treatment would not be made after a single meeting, but would be part of an ongoing consultation process. The neo-natologist commented:

'If the Unit is presented with a very sick child, then there is immediate consultant involvement with the family, so it is hoped that if a decision is going towards compassionate care, then this would not be at the first meeting.'

The paediatrician commented that whilst parents' agreement is always sought, this is usually done verbally rather than in writing. However, if parents are asked to agree that resuscitation should not be attempted, it is important that other members of the medical team witness this agreement in case of a later legal challenge. The paediatrician noted that there were moves to get parents to formally sign consent forms, for example, before a Guthrie test was performed involving a pin prick to the baby's heel for a blood test. It took time to educate parents about these procedures, and eroded the physician's freedom.

Consulting adult patients and families

Whilst those working with babies and children relied heavily on discussion, those working with adults preferred to have things written down:

'The easiest thing for staff is when patients and families have made their views clear and written them down – this is relatively straightforward and everything is done to respect these wishes. The next level down is where they have made their views clear to more than one person but not written them down. Then you start getting into a grey area and it is very difficult.'

The three consultants interviewed who were working in adult medicine were familiar with the Adults with Incapacity (Scotland) Act 2000. Each of them found the definition of competency highly problematic. It did not appear that advocates were being used to access the views of people who might have difficulty expressing their wishes, such as those with learning difficulties and mental health problems. Two consultants complained of the increased paperwork which they believed had arisen as a result of the new legislation.

Two of the consultants working in adult medicine welcomed the use of living wills. The neurologist expressed concern that in future scenarios might arise where living wills were written at significantly earlier stages of the life course, and views may have changed but without these being recorded. The legal status of these documents was therefore open to challenge.

With regard to communication with parents, patients and relatives/friends, the BMA/RC/RCN guidelines advise that training in sensitive communication may be required, which it is the legal responsibility of the employer to provide. If a clinician felt that they needed to develop their communication skills further, then they should request appropriate training from their employer in writing. However, none of the consultants mentioned that such training was available, and nor was it referred to in the local Trust documents (see previous chapter).

Recording a DNAR decision

As noted earlier, there were differences in approach between the neo-natologist and the consultants working with adults. The neo-natologist explained that the words 'Do not resuscitate' were not written down in the case notes. In cases where a child was likely to die, the consultant usually wrote a page of A4 describing the situation and why the medical team thought the future was bleak. Discussions with relatives would be noted and a last sentence might conclude, 'We have decided to reorient care to compassionate measures only'.

Dealing with disputes

The BMA/RC/RCN guidelines emphasise that differences of opinion between clinicians, patients and their friends/relatives, should not be dealt with simply by asserting the right of the physician to use his/her professional judgement as the grounds for a decision. Rather, after discussion disputed cases should be referred on to a colleague for a second opinion, and if doubt still remained then it is suggested that some form of legal review may be necessary (BMA/RC/RCN, 2001, p. 14).

Voluntary organisations' views

In the following paragraphs, we compare the perspectives of two major Scottish voluntary organisations with those of the consultants. Both organisations expressed particular concern about access to information in relation to the use of DNAR notices. They were also concerned that the implications of the Adults with Incapacity Act (Scotland) 2000 had not been fully appreciated by the consultants. In addition, ENABLE had been directly involved in a Fatal Accident Inquiry in relation to a 24 year old woman with profound learning difficulties and physical impairments who had died in a Glasgow hospital. This case offered more direct insight into some of the wider issues relating to DNAR and disabled people.

Down's Syndrome Scotland

The issues raised by Down's Syndrome Scotland centred on more general concerns over access to information, by people with Down's Syndrome and their parents/guardians in the context of decision-making processes over the life course. The organisation is keen to involve the person with Down's Syndrome and/or their parent/guardians in decision-making across a range of issues, including resuscitation, at an early point in their lives. However, despite the considerable publicity associated with implementation of the Adults with Incapacity (Scotland) Act 2000, it was felt that many people remain unaware of their options. Decisions were still being made at a much later stage, when chances of a significant input from the person with Down's syndrome might be reduced. The responsibility of clinicians to work with disabled people in making such decisions is clearly of major importance.

We were informed that cases of medical discrimination against persons with Down's Syndrome in Scotland had not been as numerous as in England, and on the whole parents/guardians in contact with the organisation had largely been very happy with the treatment received.

ENABLE

Discussions in relation to DNAR also took place with the principal solicitor at ENABLE. ENABLE have been involved in a Fatal Accident Inquiry brought by the parents of a 24 year old woman with Rett syndrome who died in a Glasgow hospital in 1998. One of the main issues in this case was the existence, unbeknown to her parents, of a DNAR notice which was attached to her medical notes. The tag remained on her notes after being placed there during a hospital admission in 1993.

It was strongly felt by the parents that the presence of the notice, signified by a red tag, impacted on the level of care received by their daughter during her last hospital admission. The parents were unhappy at the Sheriff's determination in relation to the case; in particular his judgement that the DNAR tag bore only 'historical relevance' to the case, and did not impact on clinical decisions made at the time of their daughter's death. At the time of writing (April 2003), the General Medical Council had agreed to take on the case and pursue a public enquiry against a named consultant involved in the care of the woman. In addition, civil action is being pursued by the parents against the hospital involved.

Additional issues in relation to DNAR raised by ENABLE also centred on poor access to information and understanding of medical issues in relation to persons with learning difficulties and mental health problems by medical practitioners. Concern was expressed that issues were not routinely incorporated into undergraduate medical training. Furthermore, it was felt that changes brought in under the Adults with Incapacity (Scotland) Act 2000 have not been fully understood by clinicians, despite widespread training events and publicity organised by ENABLE and Alzheimer Scotland prior to policy implementation. At these events, only a few doctors came along, and participation from medical personnel was limited to more junior personnel.

The DRC in England have also reported findings from a range of cases highlighted by voluntary organisations linked to broader issues of disabled people's experience of discrimination in health services, alongside more specific incidences relating to the use of DNAR notices. Two days after Age Concern (England) publicised their campaign work on DNAR, they received calls detailing over 100 new cases of DNAR decisions being made without the involvement of older patients or their relatives.

Conclusion

There was a contrast between the views of the consultants and representatives of voluntary organisations in their views of the use of DNAR notices and communication with patients or their legal proxies. Consultants felt that the clinician had a duty to decide about the use of a DNAR notice, having considered a number of criteria. The criteria includes the extent to which the intervention was likely to be successful, would result in a person surviving with an acceptable quality of life and would not expose the person to unacceptable levels of pain. Whilst the BMA/RC/RCN guidelines emphasise that 'futility' is no longer an acceptable reason for failing to use CPR, it seemed that consultants were still relying heavily on their individual views of whether a disabled person would be likely to enjoy a sufficiently high quality of life. They were aware of the problematic nature of making judgements on someone else's quality of life, but nonetheless believed it was their duty to do this. Consultants working with babies and children took into account the quality of life of the entire family when making decisions on the use of resuscitation.

Consultants were aware of the need for sensitive communication with patients, relatives and friends. However, none of them spoke about using advocates to help disabled people or young people express their views. There have been some important changes in the legal definition of competence over the past ten years, both in relation to children and young people and adults with incapacity. Consultants did not appear to have a good awareness of these changes, and one of the voluntary organisations confirmed that attendance at training events had been poor. This raises important questions about how clinicians learn about and reflect on key ethical and legal issues which affect their professional practice.

In addition, there is a much stronger recognition that consultation can only be meaningful if those experiencing communication barriers are assisted to overcome these difficulties, perhaps with the use of advocates. Advocacy should be available to all those requiring it in the context of healthcare, but it did not appear to feature at all in the consultants' accounts of their communication strategies.

The discussions with ENABLE indicate the need for great care to be taken in the use of DNAR notices. All members of the medical team need to be aware of the status and currency of decisions which have been made in relation to CPR. It is very important, for the protection of both patient and clinician, that second opinions and legal advice are obtained where these may be necessary. In addition, decisions should always be made with the close involvement of the patient and, where appropriate, his or her family and friends. The consultants did not always convey the impression that they were working as a member of a 'moral community' such as this.

Access to CPR, as well as other forms of life-saving and sustaining treatment, is likely to become an increasingly important topic within the health service as clinical techniques and pressure on resources increases. It is widely acknowledged that quality of life cannot be reduced to a simple element in a cost-benefit analysis, and that philosophically there are major problems with any human being making judgements about another's experience. However, the complexity of the area does not mean that difficult problems will evaporate. For the sake of disabled people as well as medical practitioners, there is a need for ongoing discussion and greater clarity, particularly in relation to the nature of judgements about quality of life.

Chapter 4: Conclusion

Overall, it is evident that decisions around the issue of resuscitation have become increasingly complex and contested. Whereas in the past doctors were relatively free to make clinical judgements on life and death issues, there is a growing emphasis on the right of patients to play a key role in such decision-making, perhaps having the final say in relation to whether a life-sustaining treatment is carried out or withdrawn. There are also growing concerns about doctors' abuse of power, which have been highlighted by a number of high profile cases. In the US, greater weight is given to patients' wishes and in the UK the pendulum is swinging in this direction. At the moment, in Scotland whilst the patient or his/her legal executor can request a DNAR notice, a clinician has the discretion to over-ride an expressed wish for resuscitation on the basis of his/her professional judgement of the best interests of the patient. Many grey areas persist, in particular the role to be played by parents and the extent to which the wishes of a child or young person are to be acted upon.

The recent guidelines (BMA/RC/RCN, 2001) emphasise the need for a more consultative approach, but it is clear that their prime purpose is to safeguard the position of the medical practitioner. Thus doctors are urged to ensure that they receive proper training in communication skills and have access to legal advice and support from senior colleagues, but the need for vulnerable patients to receive support from advocates is not mentioned. It is evident that this area of medicine could become increasingly litigious. Whilst legal challenge may play a part in challenging established practice and promoting the rights of patients, it also uses up resources which might be better spent on patient treatment.

Overall, there is a need for further research in this area on a range of topics including the following:

- The use of advocacy in decisions about CPR
- The role of legal attorneys
- The decision-making roles accorded to children and parents
- The attitudes of doctors and other health professionals to disabled people and quality of life issues
- The basis on which clinical decisions are made in relation to medical and quality of life factors
- The nature of the legal advice given to doctors in the light of the Human Rights Act 1998

Local NHS Trusts have developed new policy documents to reflect the key changes in the BMA/RC/RCN guidelines. In Chapter 2, we presented an analysis of a sample of local Trust guidance. The changes at national policy level were not always fully reflected in the local documents. For example, the need for consultation was emphasised, but it is noted that advocacy was not mentioned in the guidelines, and using advocates to help vulnerable patients, including disabled people, to express their views was not included in the Trusts' policy documents either.

The different legal position in Scotland compared with England in relation to the legal status of children and young people and incapable adults was not fully reflected. As noted in Chapter 1, in Scotland there is a duty to act upon the expressed wishes of competent young people and the legal proxies of incapable adults. However, this is not fully reflected in the local Trust guidance.

Whilst quality of life was a key concept in most policy documents, the difficult issue of defining the concept and making judgements about the quality of life of others was not fully addressed. Finally, the fact that futility of further treatment is no longer an acceptable reason for employing a DNAR notice was skirted round.

In Chapter 3, the views of consultants and voluntary organisations were considered in relation to the decision-making processes surrounding the use of DNAR notices. There was a contrast between the views of the consultants and representatives of voluntary organisations, in their views of the use of DNAR notices and communication with patients or legal proxies. Consultants felt that the clinician had a duty to decide about the use of a DNAR notice, having considered a number of criteria. The criteria includes the extent to which the intervention was likely to be successful, would result in a person surviving with an acceptable quality of life and would not expose the person to unacceptable levels of pain. Whilst the BMA/RC/RCN guidelines emphasise that 'futility' is no longer an acceptable reason for failing to use CPR, it seemed that consultants were still relying heavily on their individual views of whether a disabled person would be likely to enjoy a sufficiently high quality of life. They were aware of the problematic nature of making judgements on someone else's quality of life, but nonetheless believed it was their duty to do this. Consultants working with babies and children took into account the quality of life of the entire family when making decisions on the use of resuscitation. The danger here is that the interests of the baby/child, independent of those of the family, may be obscured. Compared with consultants working with adults, those working with babies, children and young people appeared to regard it as acceptable for them to make judgements on the person's future quality of life.

Consultants were aware of the need for sensitive communication with patients, relatives and friends. However, none of them spoke about using advocates to help disabled people or young people express their views. There have been some important changes in the legal definition of competence over the past ten years, both in relation to children and young people and adults with incapacity. Consultants did not appear to have a good awareness of these changes, and one of the voluntary organisations confirmed that attendance at training events had been poor. This raises important questions about how clinicians learn about and reflect on key ethical and legal issues which affect their professional practice.

In addition, there is a much stronger recognition that consultation can only be meaningful if those experiencing communication barriers are assisted to overcome these difficulties, perhaps with the use of advocates. Advocacy should be available to all those requiring it in the context of healthcare, but it did not appear to feature at all in the consultants' accounts of their communication strategies.

The discussions with ENABLE indicate the need for great care to be taken in the use of DNAR notices. All members of the medical team need to be aware of the status and currency of decisions which have been made in relation to CPR. It is very important, for the protection of both patient and clinician, that second opinions and legal advice are obtained where necessary. In addition, decisions should always be made with the close involvement of the patient and, where appropriate, his or her family and friends. The consultants did not always convey the impression that they were working as a member of a 'moral community' such as this.

Access to CPR, as well as other forms of life-saving and sustaining treatment, is likely to become an increasingly important topic within the health service as clinical techniques and pressure on resources increases. The cases referred to the DRC indicate that there is widespread concern amongst disabled people and their relatives that the lives of those with impairments are regarded by clinicians as intrinsically less valuable and, in some cases, as a social burden. There is a need for a reappraisal of the concept of quality of life, as it may be assessed differently from different standpoints. It is widely acknowledged that quality of life cannot be reduced to a simple element in a cost-benefit analysis, and that philosophically there are major problems with any human being making judgements about another's experience. However, the complexity of the area does not mean that difficult problems will evaporate. For the sake of disabled people as well as medical practitioners, there is a need for ongoing discussion and greater clarity, particularly in relation to the nature of judgements about quality of life.

Implications for NHS Trusts

- There is a need to review the recently published local guidelines and consider the extent to which they accurately reflect the principles in the BMA/RC/RCN guidance.
- The use and impact of the guidance should be monitored.
- Training should be made available to ensure that key staff are aware of key pieces of legislation (e.g. the Adults with Incapacity (Scotland) Act 2000).
- There is a need to ensure that standard operating procedures in relation to decisions on CPR are drawn up and all staff are aware of these. These should emphasise communication issues, ascertaining patients' wishes, recording and reviewing decisions, seeking second opinions and accessing legal advice.

- There is a need for greater use of advocates to enable vulnerable people to express their views. Trusts should review their policies to ensure that all staff are aware of a patient's right to advocacy. In addition, there is a need to ensure that advocates are available when required.
- There should be ongoing discussion of ethical issues relating to medical practice, such as the concept of quality of life, the extent of professional discretion and the rights of people to request treatment. There is need to ensure that Trust policy and advice is up to date in these areas where thinking is developing rapidly.
- There should be regular clinical audits of the use of DNAR notices, and the results of these audits should be circulated as widely as possible.

Implications for consultants

- There is a need for consultants to ensure that their knowledge and awareness of key legislation (e.g. Children (Scotland) Act 1995, Adults with Incapacity (Scotland) Act 2000, Disability Discrimination Act 1995 (as amended) and the Human Rights Act 1998) is up to date.
- Consultants should always question the criteria they employ when making judgements on the likely success of treatment and the patient's future quality of life.
- Consultants should ensure that they have been trained in sensitive communication with vulnerable patients and their families.
- There is a need for consultants to make decisions as part of a team which includes the patient and his/her family.
- Consultants should ensure that the NHS Trust has appropriate legal advice to hand.

Implications for disabled people and parents of disabled babies, children and young people

- There is a need for disabled people to acquaint themselves as fully as possible with their legal rights. Sources of information and advice, such as the DRC, Law Centres and voluntary organisations, should be utilised.
- Those acting as legal proxies for disabled people (parents of a disabled child or legal attorney of an incapable adult) should also seek as much information, advice and support as possible in making decisions about CPR.
- NHS Trusts have duties to provide accessible advocacy services. Disabled people and their legal proxies should seek out and use these services, and complain if they are unavailable or inadequate.
- Disabled people and their legal proxies should seek to be included as full members of the decision-making team in the usage of DNAR notices.
- If dissatisfied with the quality of services or consultation, disabled people or their legal proxies should complain to the appropriate body, seeking support from the DRC if necessary.

Implications for the Disability Rights Commission

- The DRC should continue to monitor and review the use of DNAR notices, since this is of such concern to disabled people.
- Part of DRC's remit is to review the operation of the DDA and other relevant Acts (e.g. the Human Rights Act 1998). Therefore the DRC should ascertain the extent to which the principles of existing and new legislation is being reflected in healthcare policy and practice.

- The DRC should monitor the availability and use of advocacy services in hospitals.
- The DRC should work as closely as possible with professional bodies, such as the BMA, as they review their guidance.
- The DRC should work with voluntary organisations and groups of disabled people in monitoring and reviewing the extent to which the health service is delivering equal opportunities, treatment and outcomes to disabled people.

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Appendix 1: Letter to NHS Trusts and Health Boards requesting a copy of their DNAR policy

DATE
NAME
ADDRESS

Dear ADD DOCTOR'S NAME,

University of Glasgow research study: 'Do not resuscitate' policies for disabled people

I am involved in a piece of research with colleagues here at the Strathclyde Centre for Disability Research at the University of Glasgow and the Department of Nursing Studies at the University of Edinburgh. The study is funded by the Disability Rights Commission and examines policy used in Scottish hospitals for 'Do not Resuscitate' (DNR) notices in relation to disabled people and guidelines on the withdrawal or withholding of treatment.

As a part of the study I am looking to interview a number of representatives from across the medical specialities. As a specialist in ADD SPECIALITY, I am particularly interested in hearing your views surrounding DNR notices in relation to disabled people. The interview will only deal with general policy issues and will **not** involve discussion of individual patients. If you are willing to take part, perhaps we can arrange a brief meeting for the end of January/beginning of February or at another time at your convenience.

If you require any further information, please do not hesitate to contact me on *** and I look forward to hearing from you soon.

Yours sincerely,

Dr Charlotte Pearson

Disability Rights Commission
Marketing Department
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