

Truth telling in palliative care nursing: the dilemmas of collusion

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Abstract

Most patients diagnosed with a life threatening illness want to know the truth regarding their situation to enable them to plan their remaining time their family's future (Fallowfield 2002). In palliative care practice dilemmas and conflicts about truth-telling may involve collusion between health care professionals and the patients' relatives to withhold the truth from the patient. This article discusses the ethical theory and legal considerations pertaining to truth-telling and collusion in the UK. It focuses on situations where the adult patient is deemed to be competent and extends arguments about collusion beyond ethical theoretical perspectives and legal considerations to include the emotional and practical consequences of withholding the truth. A case study serves to highlight the complex interplay between these aspects and the author argues that they must all be taken into account when making decisions about truth-telling. The potential role of the nurse within the context of truth-telling and the avoidance of the pitfalls of collusion are considered.

prognostic uncertainty (Costello 2000). Health care professionals often collude with the patient's relatives to withhold information from the patient, a breach of trust that subsequently impacts upon the relationships between the patient, the family, the nurse and other Health care professionals. Randall and Downie, (1999) suggest that though requests by the relatives to withhold information may appear selfish on their part these are more likely to be motivated by an act of love and the desire to protect. The distress experienced by relatives regarding their loved one's potential reaction to such bad news and concern that the patient may deteriorate faster with the knowledge that time is limited is a frequent occurrence within the author's practice as a Macmillan Clinical Nurse Specialist. Information is withheld to comply with the relatives' wishes but the relationship with the patient is consequently uncomfortable for the Health care professional.

Truthfulness is a fundamental moral value within society; harmonious community living is dependent on truth and openness between individuals. Extending this value to the health care context suggests that a person has an implicit right to information about their body and health in order to maintain emotional and psychological wellbeing (Randall and Downie, 1999). This article discusses the ethical theory and legal considerations pertaining to truth-telling and collusion in palliative care in the UK.

Most patients diagnosed with a life threatening illness want to know the truth to enable them to make plans for their remaining time and arrangements for the future of their families (Fallowfield, 2002). However, in practice dilemmas and conflicts arise regarding divulging to patients the seriousness of their condition. This is often because of the sensitive nature of the information, concerns about how the patient may react to such news and the

CASE HISTORY

Mr Smith, a 55 year old married man with an adult stepdaughter, presented with advanced bowel cancer and liver metastases. He was treated with palliative chemotherapy. The Macmillan Clinical Nurse Specialist's (CNS) first visit involved a frank discussion with Mr and Mrs Smith regarding his illness. Although distressed he expressed a wish for openness, to be fully informed of his condition and involved in decisions about his care. Chemotherapy had little impact on his disease, and during the course of his treatment he contracted gastroenteritis and was admitted to hospital. He was neutropenic, anaemic and very frail. In view of his deterioration Mrs Smith and her daughter were seen alone by the oncologist and informed of the inappropriateness of further treatment. They were adamant that Mr Smith

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should not be informed of this, to which the oncologist agreed.

Conversations with Mr Smith were uncomfortable for the nursing staff as he continued to discuss having treatment. The Macmillan CNS found it difficult to visit Mr Smith and avoided conversation about treatment. She felt she was deceiving him, denying him the right to make decisions about future care and to have precious time at home with his family. Discussion within the multidisciplinary palliative care team meetings highlighted some discontent with decisions made regarding withholding information. All the nursing staff felt he should be told but the medical staff defended their decisions that they were acting in his best interests at a point when he was too ill to embark on lengthy discussions and were being guided by his wife who knew him well.

Mr Smith recovered sufficiently to be discharged home but was too ill to attend outpatient appointments. He became increasingly anxious and agitated to the extent that he required medication for this. One afternoon he stated he was too ill to undergo more treatment and that death was inevitable, requesting confirmation of this statement. Although Mrs Smith was very distressed, she also acknowledged relief that she no longer carried a burden of secrecy. They were able to have meaningful discussions and he died 3 days later.

THE ETHICAL PERSPECTIVE

Promotion of physical and emotional wellbeing is a core value within nursing and inevitably requires judgements and decisions as to whether an action is right or wrong. Application of different ethical perspectives provides a structured approach to dilemmas enabling the nurse to make a reasoned judgement in the situation (Kendrick 1994a). Consideration is given to the two main ethical theories, utilitarianism and deontology with the additional application of the four principle biomedical framework of Beauchamp and Childress (2001), these four principles of biomedical ethics first having been proposed by the authors in 1977 and continuously revisited and revised since then.

Utilitarianism

The utilitarian ethical principles stated in the writings of Jeremy Bentham (1748–1832), cited by Hare (1997), focus on the moral consequences of an action and are applicable, therefore, to truth-telling or

collusion. Often translated simplistically as 'the end justifies the means', this useful phrase implies that it is acceptable to tell the patient that they have a poor prognosis if as a consequence he or she dies peacefully, surrounded by a caring, united family having had an opportunity to make emotional and practical preparations. These factors were identified by Low and Payne (1996) as influential concepts of a 'good death' indicating the need for openness about prognosis.

However, Johnston and Abraham (2000) demonstrate a conflicting view in that an openness does not necessarily reduce the pain of parting for the family and that the burden of sharing caused emotional and physical withdrawal. Secondly, utilitarianism advocates the view of promoting happiness for the greatest number. This suggests that it was morally justifiable to withhold the truth and collude with Mr Smith's family on the grounds that as a family they represent the greatest number (Kendrick 1994a). However Mr Smith's family although initially happy to withhold the truth in time became uncomfortable and unhappy with this decision. This demonstrates a weakness of utilitarian theory in that in some contexts it is difficult to predict the consequences of the moral action taken, here withholding the truth.

Hare (1997) takes a more contemporary utilitarian view that values such as truthfulness have a utility; that is, generally believed to be of benefit to society and so quantified as good within this theory. This suggests that from a utilitarian approach being truthful is part of the equation in the decision making process as to whether Mr Smith should have been informed of his poor prognosis and questions whether withholding the truth and colluding with his family was morally justified within this theory.

Deontology

In contrast deontologists emphasise the moral worth of the act rather than that of its consequences. The act of being truthful is of extreme moral value, so withholding the truth would be viewed as unacceptable.

Immanuel Kant (1724–1804) devised a collection of moral principles known as the categorical imperative, of which three are relevant to Mr Smith's case. The first categorical imperative (cited by Kendrick, 1994a) states that an act is morally justified if applicable to everyone including one-

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self. This necessitates that the nurse treats the patient in a manner that he or she would wish to be treated and highlights the influence of the nurse's personal beliefs and values which may bias judgement but cannot be ignored (Stewart, 1983). This point offers some explanation as to why the nursing staff had such strong feelings regarding the withholding of information from Mr Smith.

Kant's second categorical imperative (cited by Kendrick, 1994a) states that individuals should not be treated as a means to an end but as an end in their own right implying that the truth should not be withheld solely for the family's benefit. This rule acknowledges respect for the person as an individual, something that is paramount in the nurse/patient relationship (Kendrick, 1994a).

Kant's third categorical imperative (cited by Kendrick, 1994a) states respect for the knowledge and freedom of others and so demands equality when opinions are expressed. This demonstrates that the nurse had a duty to respect the opinions of Mr Smith and his family, even if they differed from his/her own (Kendrick 1993).

These rules and duties are congruent with the beliefs and values underpinning nursing (Kendrick, 1993). The ethical principle is stated in the Nursing and Midwifery Council (NMC) Code of Conduct 2004; clause 1:4. Most nurses would advocate that it is wrong to lie to patients but this cannot be an absolute rule; there are exceptions for example when the patient is distressed by a concurrent life event or the doctor is unsure of the prognosis (Gillon, 1985). Basing one's decisions on purely deontological rules offers only a rigid answer to the dilemma because there are always exceptions to the rule. At the point decisions were made regarding discontinuing treatment Mr Smith may have been too ill to comprehend the information given to him.

Beauchamp and Childress

More applicable to ethical dilemmas in health care are the four principles of Beauchamp and Childress, (2001); autonomy, beneficence, non-maleficence and justice. Maximum autonomy requires full capacity to make decisions regarding treatment and end of life care and is information dependant (Kendrick, 1994b). Jeffrey (1993) states that respect for autonomy is paramount in palliative care as it allows the patient to make meaningful realistic

decisions about management of their care and preparations for their death. This argument extends the view that colluding with families and withholding the truth undermines autonomy (Harris 1985). The patient alone is the best judge of whether knowing the truth is in his or her best interests (Buckman, 1992), and indeed Mr Smith had expressed a desire for openness.

However true autonomy in these situations is greatly debated as serious illness may impair the patients ability to reason (Spriggs, 1998). Mr Smith's family felt he was too ill to participate in decisions and could see little point in giving more bad news. Some health care professionals argue that a patient may not possess sufficient understanding of his or her condition to make decisions and would therefore wish to be guided by the health care professional although this does not necessarily require that the truth is withheld (Randall and Downie, 1999).

Beneficence and non-maleficence are two clearly distinguished principles. Beneficence entails prevention of harm and promotion of good and is akin to utilitarian principles (Beauchamp and Childress, 2001). Telling Mr Smith the truth may have initially caused distress and therefore harm but the consequences were of ultimate benefit to his family as he was able to attend to his legal affairs and make meaningful plans for their future. Non-maleficence is defined as a duty not to deliberately cause harm (Beauchamp and Childress, 2001). Telling Mr Smith the truth may have been harmful because of the subsequent emotional pain and distress experienced by him and his family. Equally it could be argued that the harm lies in lack of respect for his autonomous right and need to be told the truth. These principles can in some contexts be viewed as performing an interchangeable role (Kendall, 1995). Initially Mr Smith was very distressed but he also had the opportunity to make choices and preparations for his family's future without him.

The principles of autonomy, beneficence and non-maleficence do however conflict in situations of truth disclosure resulting in the concept of paternalism and the belief that the doctor knows best (Beauchamp and Childress 2001). Traditionally within cancer care information is filtered according to what the doctor thinks the patient needs to know to protect them, this view is now questioned (Fallowfield et al, 2002). Mr Smith's case demonstrates that the

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oncologist acted paternalistically but the reasoning behind this also demonstrates the complexities of adhering to these principles.

Finally the principle of justice demands entitlement and equality of access to health care services in order to maximise the welfare of the patient (Gillon, 1985). In situations of collusion, patients may potentially be denied access to specialist palliative care services for management of pain and complex psychological and physical symptoms, as they are unaware of their need for them. Although one acknowledges that this should not be the sole reason for making decisions regarding truth telling it is relevant if attempts are being made unsuccessfully to manage complex problems.

Applying the theory

Application of utilitarian and deontological ethical theories alongside the four principles biomedical approach demonstrates again the views of Hare (Hare, 1997;1999) that deontological theory, i.e. rights and duties can be incorporated into utilitarian theory. Both theories have a formal base of practical principles (categorical imperative and utility) which reflect moral values and actions which are of benefit to society. The value of understanding these theoretical perspectives should not be underestimated but application of one theory alone does little to assist the nurse's ability to make decisions regarding truth-telling and in situations of collusion. It is appropriate to utilise this knowledge to adopt a response which incorporates several perspectives (Kendrick, 1994a).

THE LEGAL PERSPECTIVE

Legal principles established in previous case law regarding information disclosure are relevant in arguments surrounding truth-telling and collusion and focus on law relating to information disclosure, consent, capacity and confidentiality. Currently in English law the patient has no automatic legal right to all the information relating to their illness and is denied access to potentially distressing information by clauses in the Data Protection Act 1998 (DOH 2004), although this is an ever evolving situation as more recent developments in case law suggest.

Early case law indicates that the respect for clinical judgement of the Health care professional is important. However more recent cases indicate a shift to the doctor's duty to answer questions truthfully

to protect the patient's right to decide and reflects the ethical principle of autonomy (Grubb, 1998). The law in this way implies that patients should be given sufficient information to allow them to make informed choices, which may involve disclosure of prognosis. It is important to be aware of the potential for litigation should a patient feel they have not received adequate information. However, information can be withheld if thought to be detrimental to the patient's wellbeing, i.e. on the grounds of the therapeutic privilege. This concept is however no longer an automatic defence to withholding information and is open to judicial scrutiny. Although the doctor may believe he is acting in the patient's best interest it denies the patient the right to decide (Kennedy and Grubb, 2000)

The legal requirements concerning consent are paramount in health care and closely linked to autonomy providing protection of patients and allowing them to maintain their rights in decisions about care. Recent developments on Guidelines for Consent (DOH 2002) advise that good practice involves obtaining consent prior to administering treatment and provision of care. For example administration of potent drugs such as morphine should be given with the consent of the patient; this would involve some discussion regarding their condition and the rationale for using such drugs. However, the law does not dictate that consent involves fully informing the patient of their condition therefore administering opiates without answering questions in depth about prognosis could be judged to be acceptable practice.

A vital legal component of consent is capacity. Relatives may argue that the patient lacks capacity to decide because of their illness. However, consent by others is not recognised in law and professionals should not be unduly influenced by relatives (Kennedy and Grubb, 2000). Illness, severe pain and fatigue do not remove the patient's capacity to decide as they are viewed in law as temporary states. The patient's capacity at the specific point the decision is made is paramount.

Of current relevance is the patients ability to comprehend, retain and balance information (Kennedy, 1997). The legal requirements regarding capacity are addressed in the Mental Capacity Act 2005 (DOH 2005) and due to be fully implemented in 2007. This Act aims to protect patients who are vulnerable and also ena-

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bles them to plan for situations when they may lose capacity and appoint a representative to make decisions on their behalf (DOH, 2005). This is particularly relevant in the context of palliative care where serious illness may potentially impair capacity.

Finally consideration must be given to the legal principles of confidentiality when disclosing information to relatives. Professional responsibility to respect confidence and right to privacy is identified in Codes of Conduct (NMC 2004) and in the Human Rights Act 1998 (cited in McHale et al, 2001). Information obtained during the course of investigation and diagnosis is not freely available to the family without the patient's consent (Kennedy and Grubb, 2000).

The General Medical Council, (GMC) offer extensive guidelines on confidentiality and when it can be breached. The GMC recognizes situations where the patient is unable to give consent because of serious illness and that in such circumstances the doctor may inform a significant person if it is viewed as being in the patient's best interests (GMC, 2000). The NMC advises the nurse to seek advice from colleagues, in this context the oncologist concerned. This gives legal justification for the practice of informing relatives when a patient is seriously ill.

The legal arguments for colluding with Mr Smith's family focused on the therapeutic privilege and that it was acceptable to breach confidentiality when he was first admitted to hospital because he was in a critical condition. However, he regained his capacity to make decisions in the following days and therefore questioned the need to continue to collude with his family.

EMOTIONAL RAMIFICATIONS

Colluding with relatives impacts upon the relationships of the nurse with the patient and family. Further relevant considerations are trust, destruction of hope and demonstration of powerful emotions.

Trust is a core component of the nurse-patient relationship and is closely linked to ethical arguments in favour of truth-telling (Kendall, 1995). The nurse may feel they are in breach of their code of conduct, (NMC, 2004), by failing to provide information. A situation of collusion destroys this valuable relationship and nurses often experience discomfort and are frightened of engaging in conversations for fear of difficult questions, which may lead to

avoidance behaviour (Costello, 2000). The emotional discomfort felt by the nurse may lead to powerlessness, inferiority, frustration and anger with both family and medical colleagues for making such decisions and lead them into an uncomfortable relationship with the patient (Georges and Grypdonck, 2002).

However nurses also have a moral duty of care to the family, this trusting relationship may be based on the fact that the nurse will not cause additional distress by telling the patient that life expectation is limited (Brewin, 1996).

Arguments in favour of withholding the truth relate to the concept that such bad news causes harm and destroys hope (Kendall, 1995). Without hope the patient may give up and die quickly (Johnston and Abraham, 2000). Randall and Downie, (1999) suggest that though requests by relatives to withhold information may appear selfish on their part these are more likely to be motivated by an act of love and the desire to protect. Fostering hope is debated in palliative care literature and indicates that patients can be optimistic and hopeful even when living with a poor prognosis. Open relationships with the family and staff were identified as a core component of living with hope (Benzein et al, 2001), and contradicts the need to collude with relatives solely for this reason.

Demonstration of powerful emotions is normal following receipt of bad news and is part of the journey towards psychological preparation for death (Kubler-Ross, 1970). Most patients want to know the truth, (Fallowfield et al, 2002), therefore one could argue that the patient is also aware that he or she may experience these emotions. As Gilhooley (1988) states, the benefit of knowing and being able to vent emotions is greater than coping with uncertainty. The family, however may be fearful of such reactions (Johnston and Abraham, 2000) and some nurses may feel that such distress is inappropriate, supporting the family's view (May, 1993).

Finally, awareness of death allows the patient to search for meaning and purpose to their life and their relationships with those they love (May, 1995). (Jones, 1999) identified this as an opportunity for hidden pain to be verbalised. This catharsis may be invaluable in helping patients and families to endure emotional suffering.

The emotional consequences of collusion may have a detrimental effect on relationships between all those involved and

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supports arguments in favour of truth telling. In Mr Smith's case his family were concerned about his potential to be very distressed and that he would lose hope if told bad news. The nurses commented on their difficulties and feelings regarding maintaining this collusion and there were heated discussions in the multidisciplinary team meeting about this, which indicated fragmentation within the team. Once aware, Mr Smith was able to give value and meaning to his life, which his wife found invaluable during bereavement.

PRACTICAL RAMIFICATIONS

Within the literature surrounding truth-telling and collusion, reference is made to who should tell the patient and the effect of this on the relationships between the nurse, patient, relatives and within the multidisciplinary team is discussed.

Tradition dictates that the medical practitioner is responsible for divulging prognostic information and that this has evolved as an informally recognised agreement between doctors and nurses. In situations where the truth is withheld the professional retains ownership of the information which appears to contradict the rights of the patient (Costello, 2000). Although the literature on breaking bad news focuses on the doctor's role (Buckman, 1992), nurses are often asked difficult questions. However Morton (1996) argues that the nurse may have a greater understanding of the patient and their family and so be in a position to explore these issues.

Low and Payne (1996) identify that the patient's ability to maintain control was viewed by staff as an important factor in a 'good death'. In contrast, a bad death is characterised by a discordant family and a lack of capacity to address the patient's fears. This suggests nurses favour an environment of open awareness as being more appropriate to the provision of the holistic care particularly relevant within the palliative care ethos.

States of awareness are substantiated by Glaser and Strauss's Theory of Awareness Contexts (1965), cited by Copp, (1998). This theory identifies behaviour patterns within the variable levels of information disclosure and although dated remains applicable (Costello, 2000). Nurses tend to adopt avoidance strategies in suspicion awareness, mutual pretence and closed awareness. This is fundamentally unkind and leaves a lonely frightened patient

whose suspicion that something serious is wrong is confirmed by this behaviour (Morrissey, 1997).

Consideration should be given to the advocacy role of the nurse, which is stated in the code of conduct (NMC 2004) and linked to ethical discussions on autonomy and defending patient's rights. Hyland (2002) questions the nurse's supreme claim as patient advocate within the multidisciplinary team because reference to advocacy is implicit within codes of conduct of all health care professionals. However, the requirement to influence and lead patient care, the ability to analyse complex situations and the sharing of this knowledge and insight within the multidisciplinary team are implicit within the role of the nurse specialist (RCN, 2002). Hyland (2002) suggests that this is more compatible with open awareness situations as to advocate for the patient's right to autonomy is dependent on the patient being fully informed of their situation.

Discussion regarding the nurse's role can be expanded to address the practical effects of truth telling dilemmas on the multidisciplinary team. Within the team there will be different and conflicting views about truth-telling, influenced by each member's moral analysis of the situation (Georges and Grypdonck, 2002). Frequently the needs of the patient and the relative differ and consequently the health care professional struggles to meet these conflicting demands (Faulkner, 1998). Kristjanson et al, (2001) state that colluding with relatives leads to conflict and fragmentation of the team and as a consequence interaction with patient and family is reduced.

In addition lack of acknowledgement of roles, boundaries and philosophies compounds the distress to all concerned (Georges and Grypdonck, 2002). Reference is made in the NICE guidelines (NICE 2004) for the need to develop multidisciplinary working and greater collaboration as a means of ensuring patients receive the care they require.

Nurses are frequently concerned that collusion places unnecessary strain on family relationships (Johnston and Abraham, 2000). The burdens of deception or sharing may be great, leading to emotional and physical withdrawal as an act of self-preservation. However, these authors also found that open awareness did not automatically reduce the pain of parting. Furthermore, collusion denies the patient the right to make practical arrangements

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but maybe advantageous to relatives who wish to avoid painful issues and maintain normality (Stedeford, 1994).

A final practical consideration relates to the venue of care. The family may argue that they are decision-makers regarding this, as it is they who are physically responsible (Randall and Downie, 1999). This potentially contradicts the code of conduct (NMC 2004, clause 2), the requirement to acknowledge and support the interests of the patient in their care by assisting them to obtain the services relevant to their needs. In extreme situations, collusion may lead to uninformed patients being denied access to specialist palliative care. It is important to be aware that although trends have moved towards disclosure of prognostic information in Western society the UK is a multicultural society. This approach may therefore not be universally acceptable. In many Eastern cultures the family is central to the receipt of health related information and decision making. In order to protect the dying patient from the truth families may find the idea of collusion more acceptable (Dein and Thomas, 2002).

Nursing staff within the multidisciplinary palliative care team all raised their concerns regarding the practical ramifications of colluding with Mr Smith's family. As a Macmillan clinical nurse specialist it was important to highlight the fact that Mr Smith had requested open communication throughout his illness. The strain on the couple's relationship was obvious as his wife attempted to conceal the reality. Her relief at sharing the information about his prognosis was immense and he had an opportunity to discuss her future without him. This demonstrates the importance of considering all aspects involved in collusion and how they interrelate.

CONCLUSION

The preceding analysis of the ethical, legal, emotional, and practical and issues that arise in a situation where health care professionals collude with relatives to withhold information from a dying patient highlights the complexity of the dilemma and the interplay between these aspects. This interplay is illustrated by Mr Smith's case. Mr Smith expressed a desire for openness and in this way to maintain his autonomy. Withholding the truth undermined that autonomy and had a negative impact on his relationships with his family and the health care professionals. There

was also conflict amongst the multidisciplinary team.

Application of one ethical theory alone failed to address the practical dilemmas, (Kendrick, 1994a) and conflicting interests amongst family and professionals served to compound the problem

Several themes emerge that are relevant to palliative care practice. In situations where truth is withheld or professionals collude with the family relationship difficulties occur. The nurse patient relationship is compromised and directly affects the care the patient receives (Costello, 2000). The nurse's negative behaviour confirms the patient's suspicion that something serious is wrong (Morrissey, 1997). Health care professionals have concerns regarding the strain on the patient-relative relationship but it should also be noted that open awareness does not reduce the pain of parting (Johnston and Abraham, 2000). Collusion and closed awareness leads to conflict and fragmentation within the team (Kristjanson et al, 2001) because of confusion regarding roles and boundaries (Georges and Grydonck, 2002).

Tradition dictates medical power and dominance of information control. Breaking of bad news literature focuses on the doctors' role and ownership of such information. The relatives appear to exert control over the information divulged (Costello, 2000). The patient however has a right to the information to make meaningful plans for their limited future.

Nurses build close relationships with patients and are often in a position of translating medically orientated information. However there is little recognition of the potential role of the nurse in this context by the medical profession (Morrissey, 1997). Nurses should be in a position to challenge doctors' decisions regarding colluding with relatives (Kendall, 1995). In addition the advocacy role of the nurse is stated in the code of conduct (NMC, 2004) and linked to ethical discussions on autonomy and defending patients' rights.

Greater communication between doctors and nurses is required to ensure patients obtain the information to which they have a moral and legal right, ensuring that collusion and its ensuing difficulties do not arise. It is unwise, though not impossible, to be dogmatic and state that all dying patients should be told the truth because each individual case is different and may be complex.


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The nurse's role in decisions regarding truth-telling is an important element which may be significant in avoiding collusion. The nurse's knowledge of the patient and their family is important and should be recognised by doctors. Increased collaboration between doctors and nurses is needed to ensure patients obtain the information they require and to which they have a right.

Finally the law indicates the importance of giving patients sufficient information to make informed choices which may involve divulging prognosis. Health care professionals are reminded that consent by others is not legally recognised and of the importance of not being unduly influenced by relatives (Kennedy and Grubb, 2000). Professional codes of conduct reflect the legal stance on confidentiality and circumstances when it maybe breached. The advent of the Mental Capacity Act 2005 (DOH 2005) will enable patients to plan for situations when they may lose the capacity to decide, protect their wishes and avoid some of the pitfalls of colluding with relatives to withhold the truth.

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