Withholding truth from patients

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Summary
The issue of whether patients should always be told the truth regarding their diagnosis and prognosis has afforded much debate in healthcare literature. This article examines telling the truth from an ethical perspective. It puts forward arguments for and against being honest with patients, using a clinical example to illustrate each point.

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HEALTHCARE PROFESSIONALS ARE, in general, respected for their honesty (Glass and Cluxton 2004). Many professions have codes of conduct that address the issue of honesty and trust in relation to patient encounters. In Ireland, An Bord Altranais (2000) developed The Code of Professional Conduct for Each Nurse and Midwife as a framework to assist nurses and midwives to make professional decisions.

The code states: ‘It is necessary for patients to have appropriate information for making an informed judgement. Every effort should be made to ensure that a patient understands the nature and purpose of their care and treatment. In certain circumstances there may be a doubt whether certain information should be given to a patient and special care should be taken in such cases’ (An Bord Altranais 2000).

An ethical dilemma is any decision that has to be made between two or more undesirable options. Differing perspectives in healthcare teams can lead to conflict and a lack of co-operation (Botes 2000a). Chaloner (2007) asserted that to make an ethically appropriate decision, it is important to engage in a process of ethical analysis, for example the application of the ethics of care and the ethics of justice (Botes 2000a). Following a literature review, Tuckett (2004) identified themes relating to the ethical argument for and against truth-telling. These themes were autonomy, physical and psychological harm, intrinsic good and the uncertainty principle.

This article describes an ethical dilemma and analyses the arguments for and against withholding the truth from a patient. The ethics of care and the ethics of justice are used as a framework for the discussion. The principles that underpin the ethics of care and the ethics of justice are outlined.

Ethics of care and ethics of justice
Kinsella (2001) defined ethics as a branch of philosophy that centres on consideration of morality, moral problems and moral judgements. Traditional ethics provides four tenets obliging healthcare professionals to be truthful with patients and families (Glass and Cluxton 2004). These are respect for autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2001) (Box 1).

The ethics of care is a relatively new approach to ethical thought. It exemplifies an ethical approach in terms of care, involvement, empathy and maintenance of harmonious relationships. It is a holistic and need-centred approach (Botes 2000b). With the ethics of justice, ethical decisions are made on the basis of universal principles and rules, impartially and objectively, therefore ensuring fairness and equality for all people (Edwards 1996, Mathes 2004).

These two alternative ‘orientations’ to ethical decision making have emerged from the work of Kohlberg (1981) and Gilligan (1982), respectively. Kohlberg studied three levels of moral development: pre-conventional,
conventional and post-conventional. The latter is the level at which one can apply self-chosen principles such as justice, equality and the sacredness of human life unequivocally. Kohlberg believed that only 10-15% of adults reach this stage and not before their mid-thirties. However, Kohlberg’s (1981) work has been criticised for overemphasising justice and its male bias (Gross 1992). Gilligan (1982) argued that women’s morality is not the same as that of men and explored moral decision making among women. Gilligan (1982) found that women’s decisions reflect concern for the welfare of those with whom they have relationships.

Glass and Cluxton (2004) believed that the ethics of care is difficult for some healthcare professionals to embrace, as it does not have well-defined rules or principles. They describe the ethics of care as dynamic because it is determined by the relationship with the individual patient. As each patient relationship is different, the ‘right thing to do’ will vary. Following a comparison of the ethics of justice and the ethics of care, Botes (2000a) advocated the application of a combination of both principles when making ethical decisions.

Of particular relevance to the topic of truth-telling is the principle of veracity. This is the practice of habitually speaking, or being predisposed to speak, the truth (Hayward and Sparkes 1994). In health care, veracity implies comprehensive, accurate and objective communication of information, including how the professional fosters the patient’s understanding (Beauchamp and Childress 2001). Adherence to the principle of veracity implies a contract between patients and healthcare professionals that includes the right to the truth and the upholding of trust (Beauchamp and Childress 2001).

**Autonomy**

Autonomy is defined as having self-determination and self-governance over one’s actions (Tuckett 2004). Patients and healthcare professionals are equals (Tschudin 1992). The relationship between the two parties is based on reason and mutual confidence, underpinned by professional ethical standards such as the ethics of justice and the ethics of care. Thompson *et al* (2006) suggested that autonomy is not a principle, but a precondition to allow a person the liberty to claim his or her rights, legally and ethically.

Patients have the right to know and be kept informed about their condition so that they can make decisions regarding their care and treatment (Glass and Cluxton 2004). For example, informed consent is a practical application of autonomy. Ethically and legally, patients should be able to make educated, uncoerced decisions about their treatment (Van Dokkum 2005). Withholding the truth impairs patients’ ability to give informed consent. There is a legal requirement that consent is established for all aspects of medication and interventions, including examination, diagnosis and treatment (Daly 2009). Informed consent can only happen when the medical professional properly informs patients of the nature of the intervention, the proposed outcome and the consequences and risks of the intervention, in a way that is fully understood (Van Dokkum 2005). Van Dokkum (2005) also pointed out that it often falls on the nurse to ensure that patients have understood the information given. The nurse’s duty of care for patients demands that action should be taken if the nurse is in any doubt that they have understood the information provided.

According to Vivian (2006), in end-of-life care, autonomy and telling the truth are imperative, because patients need to be given the chance to say goodbye, put their financial affairs in order and prepare for their death. Affording patients these opportunities will help them to have a ‘good death’ (Steinhauser *et al* 2000). Tuckett’s (2004) review of truth-telling in clinical practice revealed that a patient’s ability to be autonomous diminishes without truthfulness. Glass and Cluxton’s (2004) research found that most patients and their families want truthful disclosure about illness, even when it is not good news, a point supported by Fallowfield *et al* (2002).

Conversely, respect for autonomy has been cited as a reason for withholding the truth (Tuckett 2006). Tschudin (1992) asserted that people’s needs, desires and concerns are different. As previously stated, a patient has the right to know. However, that does not mean that patients have to exercise that right (Thompson *et al* 2000). If a patient asks not to be given information regarding diagnosis or prognosis, withholding the truth is permissible (Tuckett 2004). Patients’ wishes should be checked regularly throughout the illness trajectory. To force information on a patient who specifically asks not to be informed could be
viewed as paternalistic (Tuckett 2006). Acting on the assumption that healthcare professionals know what is best for patients has been termed ‘hard paternalism’ (Beauchamp and Childress 2001).

Patients need to be assessed regarding the level of information they require (Glass and Cluxton 2004). A commonly cited reason for non-disclosure of the truth is that the information has not been requested (Hancock et al 2007). Diagnostic and prognostic information is sometimes withheld from patients at the family’s request (Begley and Blackwood 2000, Vivian 2006, Hancock et al 2007). Such requests from relatives can create dilemmas in terms of confidentiality (Thompson et al 2000). According to Van Dokkum (2005), this situation is fraught with legal and ethical problems. Ethically it suggests that patients are considered incapable of coping with the news of imminent death. Legally it means that confidentiality has been breached, as the relatives should not be given information regarding the condition of a patient without the patient’s consent. As the patient has not been informed, then he or she could not have consented to the disclosure being made to the family. Collusion with families is a breach of trust that will leave a negative effect on relationships between patients, families and the healthcare team (Thompson et al 2006).

Impaired comprehension or competence has been suggested as another reason for withholding the truth from a patient. Tuckett (2004) revealed that people’s autonomy can be relinquished in the case of mental incapacity. Some people do not have the ability to make decisions for themselves because they lack understanding and awareness of their actions and the consequences (Van Dokkum 2005). Such people are said to have ‘legal incapacity’. This can affect people with learning disabilities or other impairments such as head injury or mental illness. Van Dokkum (2005) identified that these situations present two immediate problems in law. First, how is one to decide whether a patient is incapacitated mentally? Second, if mental incapacity is established then who is authorised to act on a patient’s behalf? In Ireland, the Mental Health Act 2001 provides guidance in terms of assessing whether a patient is capable of consent to medical treatment (Daly 2009). The Mental Capacity and Guardianship Bill 2007 is designed to reform the law concerning mental capacity and provides for the establishment of a guardianship board, which may appoint guardians in such cases. Similarly, in the UK, the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000 provide guidance for the assessment of a person who may be deemed incapable of making decisions regarding medical treatment. Hancock et al (2007) identified that a doctor’s perception of a patient’s understanding influences prognostic disclosure. Intervening and acting in a person’s best interest, for example making a decision regarding treatment options, when there is a cognitive impairment, is termed ‘soft paternalism’ (Beauchamp and Childress 2001).

Sharing truth, and particularly painful truth, requires sensitivity and skill on the part of the healthcare professional in terms of interpreting how, when and where truth-telling is appropriate (Thompson et al 2000). Reasons why some healthcare professionals avoid honest disclosure include failure to acknowledge their own mortality, having an unrealistic perception of their ability to halt the dying process (Glass and Cluxton 2004) and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment (Hancock et al 2007).

A study carried out by Oberle and Hughes (2001) identified a power struggle affecting nurses and doctors, with nurses feeling constrained by their perceived lower position in the hierarchical structure when confronted with ethical problems. Medical staff felt constrained by the healthcare system or the wishes of families. Nurses felt that their views regarding pain and suffering in end-of-life care fell on deaf ears when reported to doctors. They subsequently had to observe patients living with the decisions made by others. One doctor described exercising his own value system, by emphasising the facts that most closely favoured his own opinion. He did concede that this was misrepresentation of information to patients. This is reflective of a paternalistic, hierarchical healthcare system (Oberle and Hughes 2001). Other reasons offered by healthcare professionals for withholding the truth are a lack of training and time to initiate ‘courageous’ conversations (Glass and Cluxton 2004, Hancock et al 2007).

Hayward and Sparks (1994) defined hope as an expectant desire, a ground for expectation, trust or confidence. Ruddick (1999) stated that patients’ hopes often rely on beliefs about possible rather than probable outcomes. To remove hope by disclosing the truth may cause distress and despair. However, the truth allows patients to make decisions and put their affairs in order (Glass and Cluxton 2004, Vivian 2006). Tuckett (2004) identified that patients who are truthfully informed find it easier to trust and accept treatment from those responsible for their care. Peplau (1988) described nursing as a therapeutic, interpersonal process. According to Basford and Slevin (2003), making an emotional connection with patients will result in them being able to share their emotional pain. When considering an ethical decision, healthcare professionals who embrace the therapeutic relationship, subscribe to an ethic of care. Dooley and McCarthy (2005) defined this.
method of ethical decision making as placing relationships, interdependence and emotions at the centre of moral life.

**Physical and psychological harm**

Nurses have a legal and professional duty of care to patients (An Bord Altranais 2000, Nursing and Midwifery Council 2008). Care is characterised in the literature using terms such as empathy, compassion, kindness and commitment (Tschudin 1992, Tuckett 2005). Caring crosses the boundaries of rules or actions guided by ethical principles (Tuckett 2005). Dilemmas in truth-telling are borne out of this duty of care (Thompson et al 2000). Open and honest communication informs patients that the care provider is genuinely concerned about their wellbeing. This is linked to the principle of beneficence (Tuckett 2005) (Box 1). If honest disclosure assists a patient to concord with treatment then it is in the patient’s best interests to be told the truth.

Glass and Cluxton (2004) stated that it is unfair to provide incomplete or untruthful information to patients, as this may result in patients making treatment decisions that exhaust their physical and financial resources. They may not have made the same choices if they had known the truth. Turkoski (2001) asserted that truthful disclosure results in reduced pain and better health outcomes. Moreover, in situations of collusion, patients may be denied access to specialist services such as palliative care because they are not aware that they need them (Vivian 2006).

Conversely, if the truth about a diagnosis or prognosis is revealed, the patient may refuse treatment because of the loss of hope and may deteriorate more quickly (Vivian 2006). Ruddick (1999) cited the maintenance of hope as physically beneficial. Hopeful patients are thought to do better in treatment. Hope may achieve effects in the same way as a placebo and aid concordance with exhausting regimens (Ruddick 1999). This is encompassed in the principle of non-maleficence (Box 1). Fostering hope, in the interest of psychological benefit, is a common reason for healthcare professionals and families to withhold the truth from patients (Glass and Cluxton 2004). Begley and Blackwood (2000) asserted that withholding the truth from patients helps them to continue with family and life events. Ruddick (1999) stated that, in such circumstances, withholding the truth allows people to carry on with normal day-to-day life and to focus on the things that give their life meaning. However, patients can also do this when they know the truth and one of the main aims of palliative care is to help them carry on with the things that give their life meaning.

When considering the psychological benefits of telling the truth to patients, the principles of non-maleficence and beneficence are commonly cited (Glass and Cluxton 2004, Tuckett 2004, Hancock et al 2007). Tuckett (2005) asserted that if a deception is discovered, mistrust will place strain on the therapeutic relationship. Family members can also benefit when the truth is disclosed. Glass and Cluxton (2004) stated that adaptation to their illness helps patients to focus on preparing themselves and their family for death. Vivian (2006) stated that, in end-of-life care, disclosing a poor prognosis is acceptable if, as a result, the person dies peacefully.

Ruddick (1999) advised that it should not be assumed that the loss of hope is harmful. Discovering the truth may be liberating, freeing all concerned from the burden of treatment and deception. Nurses can assist patients through this process towards acceptance. Advocacy is an integral part of the nurse’s role (Vaartio et al 2008). It includes promoting and safeguarding the wellbeing and interests of patients. MacDonald (2007) described advocacy as a moral obligation in nursing, asserting that it is a form of caring and compassion. However, MacDonald (2007) suggested that collaboration skills (negotiation, mediation and conflict resolution) are vital when nurses attempt to advocate for a patient in an environment of competing values (Hancock et al 2007). MacDonald (2007) stated that nurses’ relationships with other healthcare professionals can influence significantly their ability to advocate for patients. Therefore, collaborative relationships and examination of their own values and the values of colleagues can create an environment that supports advocacy in nursing.

**Intrinsic good and uncertainty**

Tuckett (2004) identified the theme of ‘intrinsic good’ – the culmination of the healthcare professional’s obligation to patients – as a rationale for honest disclosure. Vivian (2006) stated that truthfulness is a central moral value in society. Rooted firmly in the ethics of justice, there is a general belief that truth-telling in health care is a universal rule (Turkoski 2001, Glass and Cluxton 2004). Tuckett (2004) identified the uncertainty principle as a reason for withholding the truth. This principle supposes that there is no certainty in health care and subsequently no absolute truth to reveal (Tuckett 2004). With regard to life-limiting illness, Hancock et al (2007) revealed that the majority of doctors would not reveal the truth if there was a life expectancy of more than a year.
Case study

With specific regard to the ethical dilemma described in the case of Lisa (Box 2), the author would suggest that the truth should have been disclosed to the patient and her children. Lisa tried to remain independent and autonomous. Imparting the truth would have empowered her and enabled her to make subjective decisions regarding her care and ultimately her death. Respecting Lisa’s autonomy by telling the truth about her prognosis would have given her and her family the opportunity to say ‘goodbye’ and ‘I love you’ (Glass and Cluxton 2004). Steinhauser et al’s (2000) study confirmed the importance of completion in terms of faith issues, life review, resolving conflicts, spending time with family and friends, and saying goodbye. As Lisa was a competent adult, there is no doubt that collusion with her parents was legally and ethically wrong. Van Dokkum (2005) stated that unless the patient has appointed a relative to act as his or her agent then disclosure of information is not justified.

Many authors believe that families make requests to withhold the truth regarding terminal diagnoses from patients because of their own failure to accept the reality of the situation (Fallowfield et al 2002, Van Dokkum 2005, Vivian 2006). However, it is widely acknowledged that acceptance by all parties, including the patient, family and healthcare professionals, will benefit everyone throughout the trajectory of illness, death and grief (Kübler-Ross 1970, Steinhauser et al 2000, Vivian 2006). The collusion in the case of Lisa was a breach of trust that had a negative effect on the care she received and relationships involved. When trust is upheld patients are more likely to concord with treatment. If the truth was disclosed, Lisa may have accepted the care offered more readily, enhancing her comfort and quality of life and removing unnecessary physical discomfort. There is little doubt that disclosure of a terminal diagnosis to a patient will cause psychological pain. That said, by assisting and supporting Lisa through a process of acceptance the healthcare team could have assisted her preparation for death (Craig and Jones 2005). The therapeutic relationship was affected. The healthcare professionals involved would not have been able to make a true emotional connection with Lisa and therefore were unable to share the emotional burden.

The theme of intrinsic good applies to this case. It was the professional obligation of the healthcare team to disclose the truth to Lisa and to uphold her right to confidentiality. If she had been asked if she wanted to know the truth, she may have indicated that she did not want to know or that she was happy for her family to receive information regarding her condition. However, this was not established. Understanding her views would have required skill in communication on the part of the healthcare professional and a team approach to assessing and evaluating the ethical opinions of all involved. It would be difficult to apply the uncertainty principle to this case, as there was no doubt that Lisa’s prognosis was terminal. It could not be used to justify non-disclosure.

Discussion

In answer to the question, ‘Is it ever right to withhold the truth from a patient?’, the author cannot answer ‘no’ unequivocally. However, withholding the truth is not desirable or advocated. There are many strategies to aid nurses in successful moral decision making. Turkoski (2001) recommended that when the principle of veracity is the source of conflict, nurses should try to resolve the dilemma with the use of effective and open communication. Discussion that takes into account the ethical views of all involved, that is, patients, families and healthcare professionals, will help in the resolution process.

Glass and Cluxton (2004) offered several approaches to disclosing painful truths. They recommended the full involvement of all parties, and giving information over time, therefore providing all involved with the opportunity to adjust and formulate questions. In this way the truth can be delivered sensitively and concisely. The use of ethical and professional codes and discussion of experiences of similar cases are also recommended as tools to aid ethical decision making (Kinsella 2001).
ethics issues

The author concedes that arguments for withholding the truth are generally weak, for example the placebo effect of fostering hope. Ruddick (1999) suggested that such effects are superficial in comparison to the arguments for truthful disclosure, including professional obligation, empowering, liberating and respecting the patient's autonomy. Nevertheless, the author finds it hard to remove herself from the fact that each individual situation is just that – individual. Many authors believe that the principles of veracity and respect for persons, autonomy, beneficence and non-maleficence are correct. However, in attempting to avoid paternalism, there may be a risk that adhering to moral absolutes in all situations can do more harm than good (Begley and Blackwood 2000). Some suggest that an absolutist outlook towards truth-telling may not always be helpful in health care because of the individuality of each person and circumstance (Begley and Blackwood 2000, Thompson et al 2000). Hayes (2004) acknowledged the challenge of making ethical decisions in complex sociological, technological and legal contexts. Decisions are based on probabilities as there are few absolutes in health care. Therefore, every situation is unique and should be decided on in context.

Conclusion

Ethical theory identifies the general principles that form the ethical basis of professional practice. However, it is through human relationships that the individual becomes known (Woodward 1998). Bearing in mind all the arguments for and against honest disclosure, the author believes that each individual ethical dilemma regarding truth-telling should be made holistically, fairly and subjectively, subscribing to elements of ethics of care and ethics of justice.

References


