

Ethical issues in nursing and midwifery from a local perspective

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Ethics is concerned with what is right or wrong, good or bad. This may appear to be misleadingly simple. Trying to determine what is good or bad in different situations, for different people, different cultures and different moral values can be confounding, especially as each of us brings something of their own history, experience, beliefs and values to any given situation (McHaffie 1995). This is why although there is such a vast amount of literature on health care ethics, it is sometimes impossible to find a clear cut solution to the different practical problems that one encounters in the clinical area.

I would like to explore how some local factors such as the size of our country, our culture and religion can have a bearing on the common ethical issues encountered in the clinical area.

Size

Malta's size as well as the fact that there is only one public general hospital, has implications for maintaining patients' right to choose, privacy and confidentiality.

Life style

The family in Malta is still very close knit. Although it is becoming increasingly difficult to physically look after elderly parents, with more married women now working, families are still very involved with each others' welfare.

Religion

The majority of Maltese are brought up in the Roman Catholic religion. So, whether still practising or lapsed, they have an awareness of the

implications of being Roman Catholic. But is there such an emphasis on the implications of other religions on the needs of patients? The Roman Catholic religion also influences our laws, such as in matters of divorce, abortion and euthanasia.

Having given this brief overview of local factors I will now explore how these can affect ethical issues locally. In order to determine the most common issues, I decided to prepare a questionnaire which I analysed following the introduction of the first Ethical and Legal Issues Course offered by the post registration section within the Institute of Health Care. I would like to stress that though this was not a scientific study but an analysis of answers given by the 33 managers, nursing officers and deputy nursing officers who attended for the first lecture, it does throw light on some of the pressing issues of nursing and midwifery ethics locally.

Common ethical concerns

One of the questions asked was:

‘Which are the common ethical concerns you encounter in your clinical area?’

The answers were analysed and grouped into four themes (Table 1). As can be seen from the table the most common theme mentioned was that of information giving, and this incorporated truth telling to patients who are diagnosed with a terminal illness or a chronic condition, gaining patients’ consent and questions relating to who would give consent when children have parents who were separated.

This was followed by issues of confidentiality especially when nurses come from the same locality as the patient, those who are HIV positive and are reluctant to reveal their diagnosis to their partners, and the involvement of relatives in confidentiality issues.

The problem of when to let patients die with dignity, or whether to continue with treatment even when patient's condition is very poor was another issue of concern.

These were followed by issues of ward management such as lack of resources or prioritisation and the issue of reporting colleagues who are not up to standard.

Table 1: Common Ethical concerns encountered in clinical area

Theme	Frequency
Information giving Truth telling Chronic conditions Separated parents	16
Confidentiality Same locality HIV Relatives	9
Letting die	6
Accountability Reporting Ward management issues Resources Priorities	5
Miscellaneous Attitudes Labelling Rights Social cases Others	11
No Comment	3

The three most common issues mentioned were information giving, confidentiality, and issues relating to letting a patient die. Despite the changes in health care and the increasing impact of technology, clinicians are still faced with these fundamental ethical problems. Therefore, I will be focusing on these aspects for this presentation and I will start by outlining the issues related to informed consent.

Information Giving and Informed Consent

Ethically, it is our collective responsibility as health carers to ensure that competent patients are given information that they can understand and which will help them make a decision. This information must be in a language that they can understand, without the use of jargon or complicated language. It is also important to give them enough time to ask questions and clarify points. The importance of this concept is acknowledged in the Patient Charter (Hospital Management Committee 2001) which dedicates a whole section to Informed Consent, and in the Maltese Code of Ethics which states that:

“nurses and midwives should: within their sphere of responsibilities, ensure that patients / clients are given adequate and correct information enabling them to make a free informed choice as to the provision of their own care” (Nursing & Midwifery Board 1997).

The development of the Maltese Code of Ethics was a milestone in the development of nursing and midwifery ethics, as it provides local guidelines to practitioners to carry out responsibilities consistent with ethical obligations of the profession and with high quality care.

However, this statement poses a problem for practising nurses. This statement specifies that nurses and midwives are bound to give information ‘within their sphere of responsibilities’, but what exactly are the boundaries of one’s responsibilities? Legally, I am sure Dr Gafa, the next speaker, will explain that it is the doctor who is responsible to give information about diagnoses. Nurses are bound to give information

about nursing care, but nurses and doctors do not work in isolation. If patients are really going to be informed about any procedure, investigation or treatment, then nurses, midwives, doctors, physiotherapist, radiographers and all the health care team have to work together.

This is particularly important in view of the fact that it is common for patients to accept whatever the doctor tells them, irrespective of whether they had fully understood the implications of the information given to them, and then ask other health carers about care, diagnosis and treatment. In such a situation, are nurses and midwives to give or re-enforce information, wait and ask the doctor to explain again if the patient had not understood the information given, or, refer the patient back to the doctor, knowing that the patient will most probably spend the rest of the time worrying about the problem, and having difficulty asking the 'busy doctor'?

Patients tend to shop around for information and may not ask the doctor, and may instead ask the junior nurse who in their eyes may seem to have more time than the doctor or senior nurses. It is therefore, imperative that the team members caring for a patient are aware of what the patient knows or does not know. Withholding information from patients for whatever reason can have far reaching consequences (Vetch 1981) as patients will never be sure whether they are being told all the truth. This can have negative effects even on patients who have minor disorders, who, on experiencing anything they had not anticipated, would assume the worse, however unfounded their fears might be.

Informed consent does not only refer to giving the patient his/her diagnosis. Patients should also be aware of the implications of this information on their lifestyles even if it merely refers to taking a diuretic and not being able to go out to places that do not have access to toilet facilities. Likewise the implications of submitting to investigations and knowing the results, whether this is checking a blood glucose level, a blood pressure, a HIT test, a removal of a lump, or an HIV test.

The advent of HIV and its implications brought into focus the issue of whether patients are aware of what investigations are being carried out, and made us think about preparing patients for a negative result. But do we ever stop to think how devastating it is for a person to be told that s/he is a diabetic and has now to change his/her life style, and take treatment for the rest of his/her life? Can we ever really prepare anyone for a free informed choice when it is so difficult to really appreciate what a person is going to feel, and how that person is going to react to changes in life? Whilst it is easy to explain to a patient that following this or that procedure they would need to rest for a period of time, or adopt a different diet, have we ever stopped to think what it means to a person to become a patient – to become dependent on outside forces? Perhaps the majority of you have not experienced the transformation from a ‘person’ to a ‘patient’ but this change is like a leap into the dark unknown. And it is a leap which we tend to take for granted.

To have to depend on others for the most basic needs for a limited period of time is difficult to describe; to prepare people to change their life style for the rest of their life is a mammoth task, especially as people react to changes in such different ways. Therefore, preparing patients for a totally free and informed choice is not easy to achieve.

The principle of autonomous decision-making is relative, and is not an absolute principle (Beauchamp & Childress 1989). Moreover, whilst we believe that patients are autonomous, health carers also have a duty to be beneficent and promote patient welfare, and prevent harm. But does this mean that we can be paternalistic and take decisions on behalf of patients? Beauchamp & Childress (1989) argue that paternalistic interventions are seldom justified, as patients’ right to act autonomously almost always outweigh health carers obligations of beneficence. But there is always a grey area, such as when patients want to know the truth, but their relatives indicate that the patients will not cope with bad news, or that they may commit suicide if they know the truth.

When promoting autonomous decision making, one is always aware of the importance of assessing the patient’s ability to understand and cope with the level and type of information being given. But assessing

this ability requires time and expertise. It requires the ability to be objective, as well as assessing and communication skills. However, would this assessment really be so objective, given that health carers are also influenced by their beliefs and culture? A health carer who believes that the principle of beneficence, that is the duty to protect and not harm patients, overrides the principle of autonomy, may find it difficult to give bad news to a patient for fear that the patient may not be able to cope with the information.

In the questionnaire I mentioned earlier, candidates were asked whether ‘Relatives have a right to request to withhold information from patients?’. The answers were interesting (Table 2). Seventeen participants (53%) stated that **patients** and not their relatives have the right to information and to make decisions about their care, making comments such as “patients have a right to all care’, and ‘I would want to know’. On the other hand 12 participants (38%) felt that relatives have the right to make such a request, with three not being sure. These participants felt that relatives know the patient and how information would affect him/her. Relatives can prepare the patient in the first instance, and then the patient would be given information. However, some stated that they feel that relatives know the patient best, and they would not be ready to lie to patients.

Table 2 – Do relatives have a right to request to withhold information from patients?

Response	Frequency	Comments
No	17	Patients have a right to information Patients have a right to ‘all care’ I would want to know’
Yes	12	Relatives know the patient best Relatives can prepare the patient first Relatives can support patient Patient may commit suicide
Unsure	3	Depending on the patient I would not be ready to lie to patient

Relatives know the patient better than health carers, and may be in a better position to determine whether a patient is capable of accepting a negative diagnosis. On the other hand, keeping in mind the family structure in Malta, is an unwillingness to disclose information always an objective assessment of patients' ability to cope with information or could it sometimes be the result of the paternalistic attitude arising from the characteristic dependency and protectiveness of Maltese families?

However, until an objective assessment has been carried out, one has to determine whether to rely on the relatives' plea to withhold information and risk upsetting the patient; or go against relatives wishes, disclose information and risk causing a set-back in the patient's condition. This dilemma is a common problem that most health carers face. In most countries, it is assumed that the patient should be the first to get information, however, in Malta, where families are so involved, and where young and old are still so protected, it seems that this dilemma is intensified. This is obvious from the fact that the Patient Charter (HMC 2001) even states that 'Patients have the rightfor their condition not to be divulged to next of kin, if patients so request in writing.'

The fact that patients need to express their wish to withhold information from relatives in writing seems to go against the common interpretation of confidentiality where the patient expects the health carer to refrain from sharing personal information obtained in the course of their work (Rumbold 1993). I will now discuss this notion of confidentiality in more detail.

Confidentiality

The importance of maintaining confidentiality has been widely discussed in health care ethics since the Hippocratic Oath (Beauchamp & Childress 1989). Patient care is built on trust. Patients have to entrust health carers with intimate information, to allow them to arrive at an accurate diagnosis. Health carers have to trust patients to give them all

relevant details to ensure that they can carry out their duties. Therefore, patients have a right to have personal information kept private and a responsibility to give health carers all the information necessary irrespective of how intimate and embarrassing this information may be. This dual right and responsibility is acknowledged locally by both the Patient Charter and the Maltese Code of Ethics for nurses and midwives.

But is confidentiality a reality or a myth? Patients' cases are discussed between practitioners, students, in academic journals, and sometimes even in social occasions when professionals meet socially and discuss cases forgetting that partners not involved in care may be present. Moreover, storage of files can lead to breaches of confidentiality, especially with the modern trend to store information electronically, and the ease with which hackers seem to be able to breach even the most secure national systems.

Confidentiality is also a problem in research or in education. It is common for students to discuss interesting case studies they have encountered, and due to the size of the island, identify patients even though they do not mention patients' names. The same situation can arise in research studies. If I carry out a study on nurses and midwives in, say, the special care baby unit, I have already identified the exact location. When describing the respondents – age groups, sex, and years of experience, I run the risk of identifying people. Therefore, sometimes one has to avoid giving certain data to protect respondents' confidentiality.

Another problem is that it is hardly possible to go to hospital whether for an outpatient appointment or as an in-patient and not meet people one knows. Whilst most times this is a bonus – as when one knows a member of staff and so can avoid waiting for a long period of time, it can be a problem if one wants to keep the visit a secret. Whilst health carers are bound by professional secrecy as stated in the code of ethics, other patients and visitors are not, and therefore, it is more difficult to

have a secret hospital appointment than a secret affair in Malta. However, a bigger problem for most patients will be maintaining their privacy when using hospital facilities. We repeatedly hear of how embarrassed patients feel when having to undergo intimate examinations by a doctor. How much more embarrassing is it to have the doctor interrupted by a nurse, a nursing aide, or sometimes even by security guards or porters coming in to talk to the doctor or get something from the cubicle?

In-patients have to talk to their doctors, nurses or midwives and discuss intimate details about problems relating to digestion, excretion, sexuality etc. in front of other doctors or students they might not have met before. They are usually separated from other patients by means of inadequate curtains which are ineffective in maintaining not only auditory privacy but even visual privacy, as attested by the common sight of nurses carrying pegs around with them to clip curtains to maintain privacy. Can we begin to imagine how horrendous it would be to be the patient nursed in the middle of a corridor? This problem is compounded by the fact that like most Mediterranean people we tend to have loud voices.

How would we like to come up here on the podium and discuss whether we have opened our bowels this morning, whether we have seen any discharge, experienced pain on sexual intercourse, or whether we have had unprotected sex and are afraid of having contacted a sexually transmitted disease? But these and sometimes even more personal questions are being asked everyday in our wards and we expect patients to answer truthfully, and moreover, to ask questions themselves if they had not been given the required information.

Boundaries to confidentiality

As we have discussed, confidentiality is essential to protect patients. However, there are exceptions to this rule, such as when information is required by law, or when information is necessary to safeguard the

well being of society. It is an undisputed fact that health carers have to report criminal offences such as a suspected attempted murder or a case of child abuse. Problems also occur in situations such as patients who find out that they are HIV positive and do not want to inform their partners. The infectious nature of this condition coupled with the life-threatening factor, has lead to ethical debates about confidentiality.

In health care it is accepted that confidentiality should not be broken unless it is in the interest of society. The arguments put forward are that whilst the patients or clients have a right to confidentiality, their partners should be told about the risks involved. Perhaps this issue is particularly relevant when the client has a long-standing partner, as it is assumed that in casual relationships it is the responsibility of whoever participates in high-risk activities to ensure that protective measures are taken. However, in long-standing relationships, refusing to tell the partner violates the trust upon which the relationship should be built. Health-carers also feel that they have a duty to protect people from harm.

Should health-carers share this information with partners for their safety, or withhold that information to maintain patients' trust and thus be in a better position to try to persuade the patient to reveal information him/herself, as well as encourage other patients to come forward when they suspect that they have problems? Ethicists are divided on this problem. One school of thought is that a strict rule of confidentiality is essential, as absence of strict confidentiality will prevent certain patients from seeking and making use of health care, thus creating even more problems to society. On the other hand, what about the problems to those harmed by maintaining confidentiality? Health-carers are also obliged to protect society from harm, as well as offering care in a family-centred care approach, which implies that care should be directed at the whole family and not just the person who has an illness. This dilemma poses a fundamental question relating to which rule of confidentiality would save most lives in the long run.

Letting die

The debate about 'sanctity of life' and 'quality of life' incorporates a number of ethical concerns in health care such as abortion, euthanasia, and prolonging life. Although abortion and euthanasia are illegal in Malta, local nurses may still come across situations where patients ask to be helped to die. This situation can cause conflict for those who, although aware of the legal position, may believe that these procedures are acceptable in certain situations. However, there is not enough time to discuss this complex issue today.

The issue that was commonly raised in the questionnaires, and in discussions during sessions, was whether nurses are expected to initiate resuscitation measures to patients who do not have a 'do not resuscitate' note documented in their files, even though they are terminally ill.

Nurses have traditionally left decisions related to prolonging life and assisting death to medical doctors. Ideally it should be patients who decide whether to continue receiving treatment or not (Bandman & Bandman 1990), however, as discussed previously, patients are not always aware of the implications of their condition. Even when patients have been given all the information, it is not always easy to assess what they want.

When patients refuse to continue receiving treatment, health-carers are also faced with the conflict of whether to accept the patients' request not to continue treatment, or abide by their responsibility of saving lives. This was another question that was explored in the questionnaire.

Candidates were asked whether patients have a right to refuse life-saving treatment (Table 3). Twenty-four respondents (73%) stated that competent patients have a right to make such a decision as it is their responsibility. They also stated that it is the quality of life which is important, and if this was to relieve suffering and the patient had a terminal condition then they had a right to refuse treatment. However,

6 candidates (18%) did not agree, as they felt that it is our responsibility to save life and moreover, patients may change their ideas later, and they can be irrational during a time of crisis. Two candidates were unsure, stating that they felt that it is a very difficult decision to make.

Table 3: Do you think that a patient has the right to refuse life saving treatment?

Answer	Frequency	Comment
Yes	24	Patients have the right / responsibility to make decisions Relieve suffering Quality of life
No	6	Patients may change their minds Irrational at time of stress Sustain life
Unsure	3	Difficult to decide

These decisions are difficult when there is time to discuss the situation with patients, but the difficulty is greater when patients are admitted in an emergency. When faced with a patient who has collapsed, health carers would do their utmost to prevent the patient from dying. But it is essential that we avoid subjecting elderly or terminally ill patients to the undignified rigours of enthusiastic but futile resuscitation measures. (McHaffie 1995).

The problems arise because it is difficult to have clear guidelines of when to resuscitate or not for all possible occurring situations. It is therefore, essential that when elective decisions about whether to resuscitate have taken place, these should be clearly documented in patients' files to avoid any confusion (Aarons and Beeching 1991). It is also essential that more multidisciplinary discussions about patients' suitability for resuscitation take place.

Conclusion

From this brief exposition it is clear that health care ethics is a very complex subject. I have attempted to look at the most common problems that are encountered in local practice, and looked at some specific factors which make our problems unique. I am aware that I have raised more questions than given solutions, but I hope that these questions will provoke more discussion during the workshops this afternoon, which I have no doubt will be very stimulating. Ethical issues are by their very nature complex, and when associated with health-care they become even more complicated because health carers deal with different people who have only one thing in common, that is their vulnerability. Nurses and midwives do not work in isolation but as part of a multidisciplinary team which incorporates patients, relatives, society and all professionals making up the health care team. The only way that some of the issues effecting the provision of high quality care to patients can be tackled is by multidisciplinary discussion and co-operation. I am sure that we need more common fora where we can get together to discuss these issues.

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