In order to respect patient autonomy, Irish healthcare providers – organisations, hospitals, clinics, professionals – are increasingly committed to including patients in the decisions made about their medical treatment and care. One way of enhancing patients' roles in decision making is to ensure that they are reasonably informed about their medical condition. However, the obligations of health professionals, in relation to the information needs of patients who are terminally ill, are particularly challenging. Critically consider the following case, recounted by a nurse working in the west of Ireland. As you read, think about the ethical values that might be at risk in this situation.

Talking to the Doctors

And the whole culture lends itself to dealing with the family as opposed to dealing with the patient because if somebody’s relative comes and says they want the progress up to date and the patient is dying then the consultant will say 'let the family come and talk to me or when the family comes in I’ll talk with the family' and they may not have discussed the resuscitation status with the patient directly but it will be discussed with the families.

When you talk about prognosis with families, the one thing is they’re very protective of what you tell the patient or what you have discussed with the patient. Protecting them in the sense that ‘oh I hope you didn’t tell them that their disease has progressed or that they’re not able to swallow?’ It’s almost like keeping the person in the dark. I think it’s a real protective thing: ‘don’t be telling’. Where I work, the layout of the ward makes it difficult so that if you have families coming down the ward they’ll almost sort of nearly shield their faces after speaking to the doctor to make sure that their mother or father doesn’t see them going out because if they see them going out it is always an indication that they are after being told bad news.

Just the other day we had a gentleman, Patrick, who came in because the doctors wanted to speak to him because his wife, Mary, was quite ill and death was, you know, soon. So we rang the husband to come in and he wanted to know over the phone, ‘was she that ill?’, ‘Had she deteriorated that much?’. So we found it very hard to say ‘well actually your wife is dying, you need to come quickly’. So when he came in he didn’t want to go in to see Mary because he said, ‘I know she’ll know I’m going to talk to the doctors and I don’t want her to know that’. So he spoke to the doctors and when he went in to see his wife, she said, ‘I know you’ve been talking to the doctors’. Mary just knew by the reaction on his face and she goes ‘I know you’ve been talking to the doctors, tell me what they told you?’ And Patrick didn’t tell her at all, it was like they all denied what was going on and yet the tears were streaming down their faces. (adapted from Quinlan, C., & O’Neill, C. [2008] Practitioners’ narrative submissions. Dublin: Irish Hospice Foundation)
**Discussion**

The case, Talking to the Doctors, which represents some of the attitudes and practices in relation to breaking bad news that currently prevail in Irish hospitals, involves the collusion of health professionals and a relative in withholding vital information about her illness from a patient. One way to analyse this case from an ethical point of view is to think about reasons why it is important to tell the patient, Mary, the truth about her illness and to consider if, there are any reasons to justify deceiving her.

**Take a few minutes to jot down why breaking bad news might be the right thing to do here. Also write down reasons why it might be ethically acceptable to deceive Mary.**

**You might think about some of the following reasons for breaking bad news:**

**a)** Providing Mary with information respects her autonomy and will enable her to make choices about her treatment, care and life plans in general. Mary is a competent person and there seems to be no doubt about her ability to understand the reality of her situation.

**b)** Mary’s treatment and care is ongoing. In this case, Mary may benefit therapeutically if she knows what she is being treated for, what therapeutic options she could choose and why doctors or nurses might recommend certain treatments over others.

**c)** From an emotional point of view, Mary seems to want to talk openly about her illness. She is suffering because information directly related to her is being withheld from her. Moreover, she is denied emotional support and the opportunity to discuss her fears in relation to her deteriorating condition.

**d)** From a practical perspective, it is clear that Mary knows that Patrick has received bad news about her condition. Moreover, there seems to be no doubt that Mary is capable of understanding what is going on; the deception, rather than avoiding confusion and emotional upset, adds to it.

**You might think about some of the following reasons against breaking bad news:**

**a)** In some situations and circumstances, competent individuals choose not to be informed about their condition and they make this clear. It could be objected that, given Mary is so very ill, it is not clear exactly what she wants. She might be happy for Patrick to talk with the health professionals on her behalf. By involving Patrick, the professionals are respecting Mary’s autonomy because they are respecting her choice to involve him in her care.

**b)** One concern that could arise is that if Mary were informed about her diagnosis that she might refuse to adhere to treatment and care that would benefit her. In such instances it could be argued that health professionals should exercise **therapeutic privilege** which means that they are not required to divulge information that would be potentially, and seriously, harmful.

**c)** From an emotional point of view, the truth may, sometimes, harm a patient by causing serious distress and taking away hope: the worry is that information about the seriousness of her illness is likely to cause considerable distress, tears and fear to Mary.

**d)** Practically speaking, Mary is imminently dying and so is unlikely to have the chance to find out about her true situation or be in any position to make treatment decisions or life plans in relation to it. Moreover, it is possible that Mary is not capable of understanding the information that might be shared with her. On this view, it is kinder and gentler not to give any direct answers to her questions.
Weighing these arguments for and against breaking bad news in this case; we suggest the following professional responsibilities to address the ethical challenges that arise. Discuss your response to these suggestions and consider any others that you think should be added.

**Suggested Professional Responsibilities**

1. **Establish patient preference and act accordingly:** Efforts should be made to determine if a patient wants to know the truth about their situation. If it is clear that they do, they should be informed of their prognosis along the lines of the principle of truth-telling and best practice in relation to breaking bad news (See Irish Hospice Foundation 2009; Buckman 2005).

2. **Promote informed consent through collaboration:** The fact that a dying patient does not know about the seriousness of their situation has implications for their capacity to provide informed consent for treatment decisions and care. A collaborative approach would encourage patients to adhere to treatment and care procedures and to provide more information about the effects of these on them. It would also encourage them to communicate their needs and to provide a more complete picture of the whole of their concerns in relation to proposed treatments or care plans.

3. **Support patient’s family:** The fears and concerns of a patient’s loved ones need to be addressed in order to enable them to come to terms with the fact that the patient is dying.

4. **Maintain patient confidentiality:** The practice of disclosing information about a (competent) patient’s illness to family members without the patient’s permission breaches patient confidentiality. It is a mark of respect for patient autonomy that they control who, and who may not, have access to information about them. Professionals should be clear on who has the right to be involved in communications around a patient’s health and well-being.

5. **Communicate over time:** Information and bad news will need to be disclosed and re-visited over time. Patients require access to clinicians over time in order to discuss the implications of bad news and professional responsibility extends to more than a single episode of breaking bad news.

6. ??

**Key Terms**

**Principle of Truth-telling**
In general, the health professional should tell the patient:
- the truth about their illness,
- in a measured manner,
- in language the patient can understand,
- in the presence of those whom the patient has chosen,
- unless there are good reasons to believe that a degree of harm, more serious than a temporary emotional depression, would follow as a result of telling the truth.

**Therapeutic Privilege**
When health professionals believe that telling a patient the truth about their illness risks seriously harming them;
they may withhold that information. This action is described as the exercise of therapeutic privilege. Notice how this privilege was incorporated in the general principle of truth-telling outlined above. Appeal to therapeutic privilege is very controversial because it can be over-used in order to avoid difficult challenges in communication with patients. What is required is a sound medical judgment, based on knowledge of the patient, that to divulge the information would be potentially harmful to a depressed, emotionally drained or unstable person. The privilege does not justify the doctor remaining silent simply because disclosure might prompt the patient to forego therapy that he or she feels the patient really needs. This would cut across the patient’s need for understanding their condition in order to give informed consent.

Activities

1. Research in Ireland and abroad indicates that most patients who are terminally ill want to be told the truth about their condition but health professionals and families tend to withhold (or partially relate) bad news for a variety of reasons. Think about your place of work; does this research finding match your experience of breaking bad news? If it does, can you suggest reasons why this is so? Or not?

2. A patient’s persistent refusal to talk about their illness is an exercise of their autonomy and many argue that it ought to be respected as far as possible. In addition, practically speaking, some claim that it is difficult, if not futile, to impose the truth on someone who really does not want to hear it. Can you recall any cases from practice where a patient refused information about their condition? What was your response at the time?

3. Some argue that telling the truth is not always appropriate: the capacity and the circumstances of every patient are unique. There are some situations where it is more important to sensitively communicate with patients in a way that is meaningful to them. Drawing on your own practice; can you think of any circumstances where it might be justifiable to deceive a patient?

4. The medical doctor and ethicist, Jay Katz, proposes a new model of trust in the health care context, a model that endorses the fundamental importance of communication to achievement of good medical and nursing practice and respectful patient care. Take a few moments to read what he has to say and share your response to it with your colleagues.

‘Both parties need to relate to one another as equals and unequals. Their equalities and inequalities complement one another. [Health professionals] know more about the disease. Patients know more about their own needs. Neither knows at the outset what each can do for the other. This trust cannot be earned through deeds alone. It requires words as well. It relies not only on [health professionals’] technical competence but also on their willingness to share the burden of decision making with patients and on their verbal competence to do so. It is a trust that requires professionals to trust themselves in order to trust their patients, for to trust patients, [they] first must learn to trust themselves to face up to and acknowledge the tragic limitations of their own professional knowledge’ (Katz, J. [2002] The silent world of doctor and patient. Baltimore: John Hopkins University Press, p.102).

5. Think about ‘bad news’ scenarios from your practice – did you and the patient have a similar understanding of the impact of the news? Did communication happen in only one conversation or over time? Is it helpful or unhelpful to think of ‘breaking bad news’ as a single event? Are there different ethical decisions if conversations take place over time?
Key Readings


Study Session 2

The Ethics of Breaking Bad News