Journal of Radiotherapy in Practice

Journal of Radiotherapy in Practice 1999
1, 97–100
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Essays in Ethics

Part 2: Patients' rights

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Abstract

The issue of patients' rights has become an important part of modern health care practice due to patients being much more aware of what they can expect from health care professionals when they enter the health care environment. This paper commences by explaining what rights are, followed by a discussion of two fundamental rights issues considered important in the relationship between patients and health care professionals in order to ensure good health care practice.

Keywords

Rights; confidentiality; truth-telling; radiotherapy practice

INTRODUCTION AND DEFINITIONS

In the previous article ('Part 1: an introduction to health care ethics' 1999; 1(1): 39–42) the reader was introduced to some of the moral theories concerning human behaviour in the health care setting. One such theory, that of Immanuel Kant, concerned duty – the duty health care professionals have towards those human beings that come into their care. The other side of this coin is that patients have a right to morally acceptable behaviour from the people who are to care for them. This begs the question,"What rights do patients have?". To answer this, it is first necessary to determine what a right is and where rights come from. This can then be applied to the health care situation in radiotherapy practice.

WHAT ARE RIGHTS?

Beauchamp & Childress[1] explain that rights should be defined in terms of claims that demand respect. In other words, just and fair claims that individuals and groups can make upon others or upon society. A dictionary definition gives rights to mean, that which one is entitled to.[2] A right can also be thought of as something over which a person has control, so that a person can choose to assert their right or not. This indicates that there are distinctions which can be made concerning rights. For instance, the notion that there are natural rights, to which each human being has automatic entitlement.

There are some disagreements as to whether natural rights truly exist, and that if they do, what they are. One such rights claim said to fall into this category is the claim to the right to life. This means that once an individual is alive, their life must be respected, nurtured and protected to ensure its continuance. However, problems arise even with this most fundamental of rights claims. The problems relate to at what point is life entitled to claim respect, nurture and protection, as occurs in the debates about abortion and euthanasia. The issue is not one concerned solely with rights as many other factors are involved, such as freedom of choice and deciding priorities. What this example shows is that the subject of rights is extremely complex. A further distinction that can be made about rights is that between legal rights and moral rights. Legal rights are claims that are justified by

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https://doi.org/10.1017/S1460396999000163 Published online by Cambridge University Press

legal principles and rules, whilst moral rights are claims that are justified by moral principles and rules.[1] Thus, the claim by individuals not to have their property taken from them without first having given their permission for it to be taken, i.e. theft, falls within the legal rights claim arena. On the other hand the claim by individuals to be told the truth concerning the state of their health, falls within the moral rights claim arena. Many of the problematic issues in the health care setting fall within this latter arena.

A distinction can also be made between what are termed positive rights and negative rights. The distinction is based on the difference between the right to be provided with something by others, i.e. a positive right and the right to be free from action taken by others – i.e. a negative right. The claim to a right to health care when an individual becomes ill is an example of a positive rights claim and is enshrined in NHS legislation. Whereas, the claim to having the right not to be operated on without first having given your permission for the operation, is what would be deemed a negative rights claim. It is generally easier to justify negative rights, especially those that call for non-interference, with recourse to the legal system if necessary. However, positive rights are usually more problematical, implying that there is a corresponding obligation on other people to supply what the right holder makes a claim for.[3] Many of the positive rights claims concern welfare issues which in modern societies has extended the range and power of such claims but not necessarily the extent. Thus a claim to the right to health care does not necessarily imply that society or its representatives, the government, has to provide every individual with every service. There is an expectation, however, that it will provide an acceptable minimum.[3] This has been laid out in guidelines such as the Patient's Charter[4] and The American Hospitals Bill of Rights.[5] One other distinction that can be said to exist in rights claims is that between general rights claims and special rights claims. General rights claims and the obligations associated with them bind all members of the community because they are members of that community.[1] Special rights claims, however, hold only because of the special relationship that exists between the parties involved. Such a relationship is that between a health care professional and a patient. An area where this special relationship between the health care practitioner and the patient is particularly relevant pertains to information i.e. information patients give to health care practitioners and information that health care practitioners give to patients. These are referred to in health care ethics as the concepts of confidentiality and truth-telling respectively. As rights claims that patients can demand respect for they bear greatly on the day to day work of health care practitioners in radiotherapy practice. The remainder of this article will focus on these two concepts.

CONFIDENTIALITY

There is no legal requirement to maintain confidentiality for patients but the value of confidentiality is accorded great weight in the health care field. Most codes of professional conduct make reference to it. For instance, the Hippocratic Oath dating from the 5th century BC required doctors to affirm, "whatever, in connection with my professional practice, not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret".[3] The College of Radiographers Code of Professional Conduct states that "radiographers must hold in confidence any information obtained through professional attendance on a patient".[6] Incidents of radiographers in breach of confidentiality can be brought before the disciplinary committee of the radiographers' board of the professions supplementary to medicine. So although no legal sanction exists to safeguard patients interests with respect to confidentiality, such is the seriousness with which such behaviour is deemed by the profession and its regulating body that it can enforce its own sanctions, to the point of dismissal of offenders should it be deemed necessary.

Patients provide a great deal of information about themselves, often quite personal information, which if it were not for the fact of them coming into the health care environment they would not divulge. Because much health care is carried out as a team approach, especially in radiotherapy practice, it does mean that many health care workers have access to the information that patients provide. This is acceptable on a "need to know" basis and does not constitute a breach of confidentiality. So what does constitute confidential information and how do we determine what is a breach and what is not a breach? Principally, confidential information is

https://doi.org/10.1017/S1460396999000163 Published online by Cambridge University Press

information that is secret and not in the public domain. Confidentiality therefore, is respecting peoples' secrets. As regards what constitutes a breach, most professional codes give little guidance. An article in 1987 by Simon Lee suggested that the UKCC advisory paper produced to help nurses with this issue did not go far enough in explaining what constituted confidential information. He therefore, proposed a series of questions to help nurses decide their responsibilities. The questions were:

- Has the information really been received "in confidence"?
- Why not ask the patient whether he or she will waive the confidentiality?
- If it is not possible or desirable, what do you think the patient would say if asked?
- Is there any other way of dealing with the problem without breaching confidentiality?
- Is there any overriding reason to disclose information, for example, serious danger to others?
- How will disclosure affect your relationship with this patient, his or her relationship with other medical staff, and other patients' trust in the profession?
- On balance, should the patient's prima facie right to confidentiality be defeated by another right, for example, the right of somebody else not to be infected by this patient?[7]

These questions are just as suitable for radiographers or any other health care worker in radiotherapy practice, as they are for nurses in the nursing environment and therefore may be used to guide your practice.

Much more information concerning patients is held on computer these days than ever used to be, and this in itself can give rise to a breach of confidentiality. Such records are subject to the Data Protection Act 1984,[8] which gives legal protection to individuals against the misuse of personal information held on computer. Further, patients have a right to have access to their medical records, be they written or held on computer. Therefore, everything that is held must be accurate. With the increasing use of transfer of data about patients between computer users, it should be borne in mind that only necessary information should be shared by users, and that unnecessary sightings of patient information should be prevented. Thus, in the radiotherapy department computers should be sited so that other patients, visitors and sundry staffs are not able to view patients or information concerning patients undergoing treatment. Computers should also be password protected, thus protecting confidentiality from unauthorised individuals.

There are situations where the right to confidentiality may be overridden, for instance, if a patient consents for their information to be disclosed to others. Other exceptions to the usual standard of maintaining confidentiality include:

- If required by law, for example, notifiable disease or DVLA requirements.
- To safeguard national security, for example, terrorist activity.
- To prevent serious risk to public health, for example, health risk in a workplace.
- Where an overriding duty to society exists, for example, murder or assault cases.
- For medical research purposes approved by local research ethics committees.[3]

TRUTH-TELLING

The second focus of concern of this article is about truth-telling. It has been linked for the purposes of this article with confidentiality, because if we expect patients to divulge as much information about themselves as they can to aid our decisions about the best management of their disease, then surely patients can expect the same from health care practitioners concerning their disease, and how it will be managed.

The relationship between health care practitioners and patients is one of trust, with honesty between the partners being a key element of this relationship. However, it is often thought that particularly for patients with a life threatening condition, such as cancer, that it is better not to tell patients the truth about the extent of their disease. This accords with the principles of beneficence, i.e. to do what is beneficial for patients and non-maleficence – i.e. not inflicting harm on patients.[1] In other words to tell patients fully the truth about their disease may actually cause them harm and therefore, it might be better to withhold the truth or even deceive patients regarding the extent of their disease. For some patients their disease may already be causing a severe burden for them, and to add to this burden by being totally truthful about their disease and treatment outcomes might detrimentally affect their morale and coping abil-

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ity. On the other hand, other patients may need this information in order to muster their fighting instincts, and to carry out any tasks or plans they feel are important to them, whilst they are still able. Usually the health care practitioners in radiotherapy practice who have the task of discussing the patient's disease with them are the medical practitioners. The British Medical Association recommends that the primary objective in this situation must be frankness throughout the doctor-patient relationship, although individual circumstances may sometimes modify this ideal.[3] It would seem appropriate to suggest that this recommendation of frankness is applicable to all health care workers in radiotherapy practice, regarding their dealings with patients. This is not to suggest that we should all be telling patients about their disease, its extent, or how it will be managed; but in the areas of our work for which we have responsibility, that we are frank and honest with our patients. The College of Radiographers Code of Professional Conduct states that, "the highest standards of personal integrity are expected".[6] Thus, health care practitioners' professional bodies advocate truthfulness and honesty. It is a right that patients can expect to be respected. An aspect of truth-telling that complicates the issue is the fact of what is the truth? There can be a reasonable degree of certainty regarding the pathology of a patient's disease, but not such certainty regarding how the disease might progress for individual patients, or for that matter how effective treatments might be. The only thing that health care practitioners can be certain about is how uncertain the situation is for patients. The truth of this should be conveyed to patients so that they do not feel that they are being deceived or fobbed off. There are, of course, aspects of a patient's disease management that can be truthfully conveyed. These usually concern the mechanics of the management of their condition, for example, what treatment will be used, how it will be administered, how often and so on. These issues fall into the category of information enabling patients to give an informed consent to undergo treatment, and will be discussed in more detail in the next article, in conjunction with the concept of patient autonomy.

CONCLUSION

This article has looked at the issue of patients' rights, what they are, and in what areas of health care, they can make rights claims. Particular focus has been placed on patients' rights in radiotherapy practice with regard to information, and has looked at the concepts of confidentiality and truth-telling in this respect. The concepts are complex so this article can only highlight the issues involved in an attempt to raise awareness amongst radiotherapy practitioners. The various professional bodies involved in radiotherapy practice issue guidelines on how their practitioners should behave with patients, concerning confidentiality and truth-telling. It is for individual health care practitioners to make themselves familiar with these guidelines, and to act according to them, to ensure that patients' rights are acknowledged and given the respect they deserve.

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