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ETHICAL ISSUES IN REHABILITATION MEDICINE

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It is only relatively recently that we have begun to examine ethical issues as they relate specifically to the speciality of Physical Medicine and Rehabilitation. Prior to this, most ethicists were more concerned with acute care medical issues involving life and death decisions. However, with the ageing population and the emphasis society now places on returning patients to the maximum possible level of function, greater consideration is being given to ethical dilemmas that are relevant to rehabilitation medicine. This paper examines the major ethical principles of autonomy, beneficence and justice. The issues of resource allocation and patient selection, the ethics of team care and ethical issues in goal setting, as they relate specifically to rehabilitation medicine, are examined in some detail.

Key words: ethics, rehabilitation medicine, ethical principles.

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INTRODUCTION

Within the past two decades there has been a vast increase in the awareness of ethical issues and dilemmas within the medical profession. Many of these issues have involved acute and emergent concerns, such as life and death decisions during an acute illness or trauma. Until more recently, the problems of chronic illness, and more specifically of rehabilitation-related issues, have received relatively little attention. Some articles began to deal with ethics in rehabilitation medicine or long-term care beginning in the 1970s (1–3). However, there was no real interdisciplinary relationship at that time between ethicists and rehabilitation specialists.

The first major examination of ethics in the setting of rehabilitation medicine, according to Haas & MacKenzie, probably occurred from 1985 through 1987, when the Hastings Center assembled a task force to examine ethical dimensions of rehabilitation. This was the first time that a body of professionals who were specifically concerned with ethical issues had studied problems associated with rehabilitation and chronic care (4).

Since that time there has been a tremendous increase in the amount of literature concerning various ethical dilemmas that occur specifically within the context of rehabilitation medicine. The goal of this paper is to provide a brief overview of the major ethical principles as well as some specific examples of ethical issues that might be encountered on a day-to-day basis by the rehabilitation practitioner.

ETHICAL PRINCIPLES

It can sometimes be quite difficult to determine whether a particular action is or is not morally acceptable. However, if we can agree that a certain act is wrong, it will likely have similarities to other wrong actions. When trying to determine what these shared features might be, we develop ethical principles that we then try and apply across a range of issues and cases. These principles should allow us to take a consistent position on specific and related issues. Three moral principles serve as a framework for medical ethics: respect for autonomy, beneficence and justice (5).

Respect for autonomy

In moral philosophy, autonomy refers to self-governance, or the personal rule of the self. A person must have adequate understanding and not be controlled by others or by personal limitations that prevent choice (5). When we respect people as autonomous, we recognize their right to hold views, make choices and take actions based on their own set of personal values and beliefs. They must be accorded the moral right to have their own opinions and act upon them.

Beneficence

The term "beneficence" means kindness, charity and the doing of good. It refers to a moral obligation to help other people, to avoid harming them, and to try and balance benefits with harms. In the health care setting it means an obligation to promote the health and well being of the patient and to prevent disease, injury, pain and suffering (6).

Justice

People are treated according to the principle of justice if they are treated according to what is fair, due or owed (5). The principle of justice concerns the question of what is due to whom, and how to distribute the costs and benefits of living in a society (6).

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ETHICAL DILEMMAS IN REHABILITATION MEDICINE

Ethical and moral decisions are made on a daily basis in the field of rehabilitation medicine. Many of these are minor, such as the decision to explain the risks and obtain consent for a joint injection or electrodiagnostic procedure. Others, however, are more complex and difficult, and may involve the participation of several different people. Some issues are fairly specific to the speciality. Keeping in mind the ethical principles just mentioned, ethical issues in three settings commonly encountered in rehabilitation medicine will be discussed: resource allocation and patient selection, the ethics of team care and ethical issues in goal setting. The aim is not necessarily to provide firm answers, but to consider the issues and the various possibilities that may be used to make decision-making a bit easier.

Patient selection and resource allocation

The selection of patients who are to be admitted to a rehabilitation medicine ward is generally made by the physiatrist. Because in many centres demand for admission exceeds the number of available beds, difficult decisions often have to be made. In some cases there may be a clearly defined set of guidelines available, but selection is often more subjective.

Haas (7) points out that patient selection requires consideration of both medical and non-medical factors. Medical factors include diagnosis, prognosis, secondary complications, functional performance and prognosis and ability to learn. Non-medical factors can be social, vocational, personal and financial (presumably financial factors would be less of a concern in the Canadian health care system, but source of payment can certainly be a large consideration in the American system). Other factors might also have to be taken into consideration. Fluctuations in bed availability might affect decision-making. Some patients with uncertain prognoses might be rejected if there is a long waiting list, while those same patients might be accepted if beds were open at that time. In some centres particular needs, such as the need for respiratory support, might influence decision-making.

It must be recognized that not all patients who are referred for physiatric assessment will benefit from therapy; this is why patients must be screened. Although the rehabilitation process involves a team approach, the ultimate selection is frequently made by the physician (8), often with little or no input from other team members.

The practice of selecting patients for rehabilitation can raise various ethical concerns. The rights, duties and responsibilities of both patients and practitioners must be considered. As mentioned, there is the potential that the process will be too subjective—thus the potential for injustice. The principles of beneficence and utilitarian justice must be considered, and may sometimes be in conflict.

Physicians often are forced to play the role of gatekeeper to the rehabilitation centre. If patient need exceeds available resources, then resource allocation decisions must be made. The principle of beneficence requires that the physician should help people and do them no harm. However, utilitarianism requires a certain yield from dollars spent, meaning that not all patients can be guaranteed care. Therefore, those who are felt to be less likely to progress will be rejected. The concern is that physicians may provide services based more on utility than beneficence (7). This means, in essence, that physicians may be forced by the system's expectations to deny treatment to needy patients. It could be argued that patients thus deprived have suffered an injustice.

As Haas points out, physicians can also suffer in this system (7). They have been taught and trained to do good, to help and care about others and to relieve suffering. Because relationships with patients are based on trust, one could argue that there should be a commitment to serve the patient first (9). When physicians must consider resources on a larger scale, without firm guidelines to help them with their decisions, there is a concern that they might be asked to put aside their basic commitment and compassion for individual patients. Physicians are therefore placed in an awkward situation: they must try and do their best for individual patients (be beneficent) while also controlling costs and assuring maximum productivity for every dollar spent (adhering to utilitarianism).

However, it is not practical to eliminate selection procedures entirely, and we cannot accept all patients for whom transfer is requested. Obviously, patients who are too sick to participate in therapies, or who lack the cognitive ability to do so, are excluded. But not all cases are so simple.

Haas (7) recommends some guidelines for the screening process that promote justice for all patients who are evaluated. First, patients and families should be made aware of the availability of rehabilitation and the process by which patients are selected. In addition, patients should have the right to appeal a decision if they are rejected. However, such a process has the potential of being too expensive and unwieldy to be completely effective. Haas also recommends that rejected patients be informed of the availability of follow-up evaluation to determine future candidacy. At our centre, the patient's family physician is often contacted and asked to notify the physiatrist if, at any point in the future, the patient's status changes to the point that he or she may become a candidate for rehabilitation, either as an inpatient or outpatient. The patient is then re-evaluated by the staff physiatrist with respect to his or her rehabilitation potential.

The problem of patient selection and resource allocation is a difficult one. The physiatrist must attempt to strike a balance between beneficence and justice. In the end, though, the choice is often subjective. In addition, it seems reasonable to make an attempt to follow those patients who are initially rejected to ensure that their situation does not at some point change.

Ethical issues in teamwork

Because of its emphasis on maximizing a patient's physical, emotional and psychosocial well being and independence, rehabilitation medicine places a premium on teamwork to help a patient achieve his or her goals. Each team member has his or

her own specialized training and responsibilities, although there is often some overlap. The emphasis within rehabilitation is to try and develop interdisciplinary or transdisciplinary rather then multidisciplinary teams, which means that each person functions within the context of the team, rather than as an isolated individual. The team generally consists of a physiatrist, nurses specialized in care of the rehabilitation patient, a social worker and multiple therapists, although team makeup may vary depending on the rehabilitation centre and the focus of the team. The patient should also be included as a member of the team, and whenever possible, should be involved in discussions and decision-making.

Teamwork as an approach to the provision of health care is relatively new; only during and after World War II did the idea gain more widespread acceptance (10). However, having several people assisting in the care and recovery of a single patient can present ethical challenges and dilemmas that the team must address if it is to function best and do the most good for the patient.

There are two areas of possible conflict: within the team itself, and between the team and the patient. Conflicts between the team and the patient most often arise over the issue of goal setting, when the patient's goals and desires are not always consistent with those of the other members of the team. This issue will be discussed below; we will focus here on conflicts between team members.

Because each team member is likely to have his or her own set of moral codes and standards, it is unlikely that all members will agree on each ethical question that arises. Conflicts between two members should be dealt with and solved within the team context. It is important that the team provide consistent information to the patient and his or her family. If possible, patients should not be made aware of a disagreement within the team, as conflicting messages can be confusing and upsetting for a patient who is already trying to cope with a new disability.

A practical example of poor teamwork affecting patient care in the rehabilitation setting involves the process of "group think". This is a process through which the desire to achieve consensus in the group can lead to inappropriate compromise (11). Instead of objecting to decisions with which they may not agree, at the risk of compromising team solidarity, some members may remain quiet. In the rehabilitation of the patient with a spinal cord injury, some patients focus on the attainment of ambulation to the exclusion of other functional accomplishments such as self-care, even if ambulation is ultimately not likely to occur. If the team presents a united front to the patient and agrees that walking should be set aside for the time being, often the patient will agree (see "Goal setting" below). However, if a physical therapist with a dominant personality wishes to pursue ambulation to the detriment of other skills, the team may have to stand up to this therapist. If the other team members acquiesce in order to maintain team harmony, they may be doing a disservice to the patient, and "group think" may be compromising patient care. In this case clear and honest communication among all team members, at the possible risk of perfect team harmony, is essential to ensure optimal patient care.

Solving conflicts within the team can be challenging, especially if the issue being debated involves strongly held beliefs or is controversial. It may be useful to establish an ethical framework for the team in advance, in order to predetermine which course of action will be followed for the more commonly encountered ethical dilemmas. Professional standards and codes of conduct can be used to find common ground in setting up this framework around shared principles and beliefs common to all groups and speciality associations.

When such a framework fails to resolve the conflict, a reasonable approach might be to gather all team members, excluding the patient. The issues can then be defined and debated, with all team members expressing their views and the rationale behind them. If common ground is found, a team consensus can be reached in this way. Although dissenting members might not be in full agreement, they may be better able to understand and appreciate the different viewpoints of other team members and may agree to support the team decision. In this way a unified front can be presented to the patient, who will then not receive conflicting information.

Thomasma (12) suggests that in order "to bring about a concert of moral interests within a team", five steps must be followed:

1. The team must develop a common moral language for discussion of moral issues.
2. Team members must have cognitive and practical training in articulating their feelings about issues rationally.
3. Value clarification exercises are needed.
4. The team must have common experiences upon which to base workable moral policies.
5. The team must develop a moral decision-making method for all to use.

However, there may still be times when all efforts fail and team members cannot reach an agreement on an important ethical issue, which could have serious repercussions for patient care. In such cases, it seems reasonable to consult the hospital's Ethics Committee for a decision to be reached at this level.

Goal setting in rehabilitation

When examining teamwork in rehabilitation medicine and the role of the patient within the team, one must also consider the importance of goal setting. Goals are the functional outcomes that the patient and team strive to achieve, and as such help to define and focus the team's entire rehabilitative treatment plan. Thus, goals can be used as outcome criteria for evaluating the efficacy of care (13). In fact, systems of goal setting have become so widely accepted in the rehabilitation industry that quality assurance examiners (13) sometimes use them as indicators.

It is important to consider who should set goals and who should determine which goals are most important. At least four parties have some influence on goal setting. First, of course, are

the patients themselves. Patients want to make their own decisions in societies that respect self-determination and individual rights (14). They know which goals and outcomes would be most meaningful to them and how much energy and time they wish to expend on therapy and retraining.

The members of the rehabilitation team generally set patient goals and then review them with the patient. Because most members of the team want to provide the patient with the highest possible level of functioning, they may assume and expect that patients will seek and generally follow their advice (13). If they disagree with a patient's wishes, or feel that the patient's goals are unachievable, they may be tempted to override the patient's decision-making power. This can place team members in a position of conflict with the patient.

Family members often wish to be involved in the design of the treatment program. This expectation is quite reasonable, as family members often assume the burden of providing ongoing care for patients and should be involved in decision-making that affects their own futures. In some cases, they may be more objective than the patient in assessing needs. In addition, some caregivers have specific needs of their own which need to be met before the patient can return to their care. For example, a wife who weighs 50 kilograms will need her 100 kilogram husband to be nearly independent in his transfers if she is to meet his other daily needs. Therefore, independence in transfers would be an important goal so that this patient could return home.

The fourth party with an influence on goal setting is society itself. We value independence and self-sufficiency, and often place a high premium on physical mobility and cosmesis (13). Patients sometimes take this into account in determining their goals.

When conflicts arise between the patient and other team members in trying to determine which goals are realistic and desirable and which are not, the concepts of autonomy and beneficence are often at the forefront. Patients may not pursue goals that the treatment team believes to be practical and achievable—they want to be autonomous and establish their right to choose for themselves. However, team members want to do what they feel is best for the patient, within the context of their professional training—they want to practice beneficence. Accommodating the wishes of patients, families and other team members during the establishment of goals is one of the most demanding tasks which rehabilitation practitioners must confront.

There are three primary models of relationships between patients and providers: Hippocratic, contractual and fiduciary (15). In the Hippocratic model, professionals are urged to serve patients in the way they believe to be most suitable. Physicians are felt to possess specialized knowledge and skills, and therefore to be in the best position to make medical decisions for patients (14). This is the traditional model of medical paternalism, and provides little or no consideration of patient autonomy, with patients not contributing towards goal setting.

In the contractual model, patients are provided with the right to make choices about the type and extent of care they receive. Caregivers must provide the best level of care possible, but they are required to limit their treatments to those that are desired by patients. This is the model most commonly employed at present.

Caplan (15) has argued that neither of these two models is sufficient for rehabilitation medicine because the speciality differs so much from traditional acute care medicine. It involves many professionals, takes place in a number of settings over a longer period of time and involves family members in active roles. Because of these factors, Caplan has proposed a fiduciary model of relationship, which respects the need for time to allow patients to adjust to the reality of a severe disability. In this model, the physician initially takes a more paternalistic approach than is emphasized in the contractual model. He or she attempts to help the patient adapt to his or her disability and educates the patient and his or her family about the disability and potential problems. The model assumes that the patient will ultimately become free to make voluntary choices, after an initial period of adjustment. Professionals who employ this method must be very careful to avoid practising persistent beneficence, which will be to the patient's detriment over the long run.

Whichever model is used, there are general guidelines, suggested by Haas (13), that the physician can follow when setting goals. The physician should seek patient input early during the rehabilitation process to help guide the setting and revising of goals. Patient preferences should be respected as treatment progresses as long as there are no serious safety concerns. Patients and their relatives know best that what the patient *can* do is not always what they will *choose* to do after leaving hospital. It is useless to prescribe and train a patient in the use of a prosthetic device that will be discarded following the patient's discharge from the facility.

Patients should be informed about possible anticipated needs, and clinicians should willingly negotiate with patients and restructure their goals as necessary. The decisions patients make at one point in time may change at a later date, and they may discard prior goals or return to goals they had previously abandoned. Treatment should be envisioned as a series of steps that will ultimately fit with the patient's needs.

The best way to resolve conflict in goal setting between patients and other team members is usually through clear and open communication. If the patient is competent, his or her wishes must prevail. However, it may be reasonable to encourage the patient to consider the values of his or her social framework and the impact of his or her decision on family members (13).

CONCLUSION

The study of ethical issues in rehabilitation medicine is a relatively new area, one in which clear and easy answers are not often available. The principles of autonomy, beneficence and justice must all be considered, and an attempt to strike a balance must be made. In this paper, the issues of resource allocation, teamwork and goal setting within the context of rehabilitation

medicine have been examined. Ultimately, the goal of rehabilitation medicine is to ensure patient autonomy while striving to give the best care possible, at the same time respecting the wishes and guidelines of society as a whole.

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