Review Article

Ethical Issues in Rehabilitation Medicine

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ABSTRACT

Within the past few decades there has been a tremendous increase in the knowledge and awareness of ethical issues and dilemmas within the medical profession. However, until more recently, the problems of chronic illness, and more specifically of rehabilitation-related issues, have received relatively little attention. We reviewed a large amount of literature concerning various ethical dilemmas that occur specifically within the context of chronic care and rehabilitation medicine. The review was done through extensive searching of databases between January and June of 2018. The search was confined to Google Scholar, HINARI and PubMed published articles. Besides, some institutional guidelines were taken into consideration. Keywords used for searching were 'rehabilitation', 'rehabilitation medicine', 'chronic disease', 'chronic illness', 'disability', 'ethics', 'ethical issues' and 'ethical dilemma'. After meticulous scrutiny, a total of 21 journal articles and 3 guidelines were selected for this review. The goal of this review 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 practitioners.

Keywords: *Ethical issue, ethical principles, rehabilitation medicine, chronic illness, disability*

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INTRODUCTION

Within the past few decades there has been a tremendous increase in the knowledge and awareness of ethical issues and dilemmas within the medical profession.[1] However, until more recently, the problems of chronic illness, and more specifically of rehabilitation-related issues, have received relatively little attention.[1,2] Physical medicine and rehabilitation physicians need to master a complex body of knowledge and skill and use that responsibly in rehabilitative care settings.[3] Rehabilitation physicians are trained to care for patients with several complex medical conditions, e.g., brain injury, neuromuscular disorders, spinal cord injury, musculoskeletal injuries, pain syndromes and cardiopulmonary disorders.[2-6] As a leader of an interdisciplinary team or sometimes as a member of the team, physicians related to rehabilitation medicine should be accustomed to actively engaging in decision making as well as facilitating and empowering patients in the decision-making processes.[2-5] Since this unique paradigm is not typically employed in many other areas of medicine, it is imperative that rehabilitation physicians must have firm understanding of the possible ethical issues or dilemmas they may come across in their professional practice.[1-3,6] In recent times, there has been a tremendous increase in the amount of literature concerning various ethical dilemmas that occur specifically within the context of rehabilitation medicine. However, there is a scarcity of literature, discussion paper, or guidelines on ethical dilemmas in clinical practice of physical medicine and rehabilitation (PM&R) in Bangladesh. Moreover, there is no formal bioethics education and training available in the country. Hence, we proposed to do a

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review on ethical issues in rehabilitation medicine based on available literature. The goal of this review 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 practitioners in the country.

METHODS

We reviewed a large amount of literature concerning various ethical dilemmas that occur specifically within the context of chronic care and rehabilitation medicine. The review was done through extensive searching of databases between January and June of 2018. The search was confined to Google Scholar, HINARI and PubMed published articles. Besides, some institutional guidelines were taken into consideration. Key words used for searching were 'rehabilitation', 'rehabilitation medicine', 'chronic disease', 'chronic illness', 'disability', 'ethics', 'ethical issues' and 'ethical dilemma'. We selected the articles and guidelines through the following inclusion criteria:

1. Literature published in English language;
2. Literature published between 1991 and 2018;
3. Articles that discussed ethical issues on rehabilitation medicine (having narratives, or qualitative components and discussion rather than having only quantitative opinions); and
4. Ethical issues not conflicting to the cultural norms and values relevant to diverse communities of Bangladesh (e.g., medical assistance in dying to minimize suffering in longstanding incurable disease is not legal in Bangladesh, and communities are resistant to it due to socio-cultural norms and religious beliefs).

This review of literature included both original research and review articles, book chapters and some western professional association's guidelines. Only relevant documents were downloaded after going through the abstracts and we did an extensive review of the downloaded papers and documents. After meticulous scrutiny, a total of 21 journal articles and 3 guidelines were selected for writing this review paper.

RESULTS

In a dynamic and growing field like physical medicine and rehabilitation (PM&R) in the country, it is relevant and important to examine the ethical challenges faced by the practitioners in the specialty. Our literature review has identified "four specific areas" of PM&R practice that are inevitably associated with ethical principles and considerations. These are: 1) ensuring informed consent and determining decisional capacity, 2) addressing patients who refuse or discontinue the treatment or procedures, 3) providing patient centered care and justice, and 4) rehabilitation research and education. These points are not always separated, rather there are much overlapping when we elaborate along with specific scenarios in PM&R practice.

DISCUSSION

Informed consent and decisional capacity are very much inseparable and together they constitute the foundation for ethical clinical practice in all disciplines. Informed consent represents crucial interactive relationship between the patient and his/her attending physician performing the any examination or intervention.[8] This process provides patients with information regarding the purpose of treatment, treatment options, risks and benefits of the procedure, and the opportunity for them to indicate their understanding prior to giving or withholding consent.[2-5,8,9] Once consent is provided, a document reflecting this discussion is signed by both patient/surrogate decision maker and physician and is included in the medical record.[7] Now the other aspect of consent is consent for research, which is necessarily obtained to carry out research studies in a clinical setting. Research consent should be an informed one, which means description of the investigational study, possible risks and benefits, contact information for study staff, and approval by an institutional review board are presented in front of the study participants (patients), and written consent is sought.[10-12] It is important to note that both informed and research consent are for ensuring patient safety and allows the patient or healthcare proxy to partake in the decision-making process in modern healthcare.[10,11]

Competence and capacity are often used interchangeably in clinical practice, but we feel an importance to distinguish them in our review. Competence is obviously a legal concept which can be determined formally through legal proceedings. In contrast, capacity is determined by a physician and, of course, is an essential element in the informed consent process for medical treatment.[13] In some cases, e.g., elderly people with gross cognitive

impairment (dementia), mentally ill patients, and/or mentally disabled adults; patients with head injuries; and patients who object to a recommended treatment, etc. individual's capacity to make medical decisions is commonly questioned and falls under scrutiny.[13-15] Hence, competence is said to refer to legal judgments whereas capacity is said to refer to clinical judgments, which is more in our concern as physicians.[15] We must admit that a patient is not necessarily globally incapable for all treatment or interventions. Sometimes an individual may be capable of consenting to some treatments and not others. However, it is the physician's responsibility to thoroughly assess capacity when the patient's condition is serious, and treatment options are relatively dangerous. In day-to-day practice, physicians may also experience that in some cases the patient's capacity may fluctuate and require repeat assessments. A person is capable of consenting to treatment if the person is able to: "understand" the information that is relevant to making a decision about treatment, and "appreciate" the reasonably foreseeable consequences of a decision or lack of a decision.[13] Generally speaking, a person is presumed to be capable with respect to treatment unless reasonable grounds to suspect incapacity exist.[13,16] Some of these patients require alternative communication and interpretive strategies, while others simply cannot adequately participate.[17] In patients without decisional capacity, a surrogate decision maker is utilized based on either patient's previous wish/direction or as directed by legal authorities (country's rules or regulations). Practitioners usually follow that; however, they should not hesitate to consult legal representatives or a bioethics team of the hospital when conflicts and contradictions ensue in shared decision making.[16-18] Another ethically problematic conflict is raised by the patients with stroke who refuse nutritional treatment or severely injured patient asks for withdrawal of life-saving therapies like ventilators; these patients' autonomy should be respected, while also considering beneficence, i.e., prognosis, options for maintaining fluid and food intake or life expectency and quality of life and act on the best interest of the patient.[19-21]

Another important issue is maldistribution of health resources and the divide between the rich and poor which seems a major ethical and political issue when considering rehabilitative treatment for severe accidental injuries like brain or spinal cord injuries. Those treatments are expensive and time consuming, which their livelihoods. In the western countries, compensation given by the insurance company may facilitate them by having access to home modifications, equipment, care, and support and have greater social and financial security for the rest of their lives. However, in low-income countries like Bangladesh, those facilities are almost absent, and most the treatment expenses are made out-of-pocket.[22,23] Hence, physicians sometimes need to deal with justice issues regarding bed occupancy, advanced therapy options, hospital stay, and rehabilitative support from the hospital for those patients, etc.[21-25] This is clearly inequitable and deprives the society of the valuable contribution that the poorly supported patient might make with more support.[22,23]

In such conditions, physical medicine and rehabilitation practitioners also need to develop and maintain knowledge, personal awareness, sensitivity, and skills and demonstrate a disposition reflective of a culturally competent professional while working with diverse client populations.[26,27]

In 1978, the Belmont Report[10] was published which outlined three main bioethical principles which ultimately became accepted by all medical fields to ensure quality and safety in healthcare as well as in research involving patients: i) respect for persons (autonomy for those with decisional capacity and protection for those who lack that capacity), ii) benevolence and non-maleficence (doing good, doing no harm), and iii) justice (equal treatment regardless of social status, financial ability, sexual orientation, or cultural factors). These are crucial and need to be followed by one who is in PM&R practice. Similarly, few years later, Beauchamp and Childress[28] came up with the '*Principlism*', consisting of four principles of biomedical ethics in which different approaches could generate and sustain a common set of ethical principles for bioethical discourse and practice in the field of medical science. Those principles are: patients' autonomy, beneficence, non-maleficence and justice. However, the authors tried to fulfil the need for an approach that recognized the value of ethical theory for practical judgments; they did not impose a single type of theory or promote a single principle over all others. There is a known obligation to follow all four principles, *prima facie*, unless principles conflict. Conflict of principles is common particularly between beneficence and autonomy and in those situations

finding common ground leads to beneficence encompassing autonomy, where the patient's best interest is inherently linked to their preferences.[10,26,29] We all know that ethical and moral decisions are made in our day-to-day practice 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, while many others, however, are more complex and difficult in nature, and may involve the participation of several different people. Some issues are very specific to the specialty, while some need interdisciplinary intervention.[30] From above discussion, we have seen that the principles of autonomy, beneficence, non-maleficence, and justice must be considered in PM&R practice, and as applicable in different situation, an attempt to strike a balance among those principles must be made.[26,29]

Physicians face ethical dilemmas every day in deciding about choice of treatment, continuation of treatments, events near the end of life, conflicts of interest, and risk management.[26] Recently, Atanelov et al. specified "five ethical considerations for practicing in the field of rehabilitation", as per endorsement of American Medical Association (AMA):[4]

1) Scarce resource allocation and the potential for discrimination against disabled people;
2) The ethics of accommodating people with disability and chronic neuromuscular disorders, including medical settings;
3) Identifying optimally inclusive nomenclature and terminology (e.g., using the word "physical diversity" rather than "disability");
4) Conflict between the goals of promoting acceptance and accommodation for persons with disability on one hand and securing resources for restoration of functional efficiency and meaningful mission on the other hand; and
5) The ethics of rehabilitating persons with neurological and behavioral disorders e.g., anosognosia (deficits of awareness), in which maximizing rehabilitation may mean abandoning or overriding patient autonomy.

In modern medicine, patient-centred care is a philosophy for organising and delivering healthcare based on patients' needs, preferences and experiences,[30,31] which is very crucial in rehabilitation medicine, as rehabilitation occurs across the care continuum (e.g., in inpatient, outpatient and community settings) and over a long period of time, where patient's needs may change along the way and require changes in how practitioners and services work, for instance, moving from reducing impairment to compensating for a loss of function or even for the development of any new capacity or function, beyond those actually lost.[30,31] Hunt and Ells[32] developed the Patient-Centered Care Ethics Analysis Model for Rehabilitation (PCEAM-R) in 2013 to guide ethical rehabilitative care given the complexity of the care team, patient's degree of impairment/disability and a variety of possible interventions. The six steps of the PCEAM-R are:

1) *Identify the ethical issue(s) to address:* What is at stake and for whom?
2) *Collect information:* What do we need to know to be able to evaluate the issue(s)?
3) *Review and analyze:* Do we need to reformulate the issue(s) and what can help us better understand it?
4) *Identify and weigh options:* What are our options and what rationales support them?
5) *Make decision(s):* What is the best option and how should we implement it?
6) *Evaluate and follow-up:* What was the outcome and how can we learn from it?

This six-step process for ethical decision making is theoretically grounded in the International Classification of Functioning Disability and Health (ICF)[33] and has a sufficiently detailed list of questions to provide a comprehensive and balanced assessment of each patient's situation.[32] This may be one of the best methods for the practice of physiatry to ensure justice for all patients of differing abilities.

To our knowledge and understanding, all those ethical considerations as we discussed are important to address as they help to ensure highest standard of care and foster patient and public trust in physicians and the profession as well as in health system of the country. Besides, they construct part of our public health policies promoting greater diversity, tolerability, and functionally appropriate environments for patients who are often poor, underserved, marginalized, and physically disabled.

Finally, we would like to remind all current and future practitioners that the physician owes a duty of loyalty to protect and act on the patient's best interests and goals of care by using his/her expertise, knowledge, and prudent clinical judgment.

CONCLUSION

Rehabilitation professionals must establish and maintain ethical standards consistent with the specialty and national standards. Professional ethics and patient safety are intertwined fundamental concepts in all fields of medicine. The code of ethics and duty of service to patients, that are very foundational, must be followed by all physicians and medical students. It actually falls upon the senior faculty members and largely on the institution to teach these attributes to the trainees/residents. Teaching through ethical grand rounds, case discussion, role play, workshop and mentoring as well as role modelling can help trainees learn ethical principles, how to handle ethical dilemmas, ensuring empathetic care and meet the expectations set up for their practice in rehabilitation medicine. Besides, online resources for ethics education and discussion may be warranted.

REFERENCES

1. Haas JF, Mackenzie CA. The role of ethics in rehabilitation medicine. Introduction to a series. Am J Phys Med Rehabil. 1995;74(1 Suppl):S3-6.
2. Kirschner KL, Stocking C, Wagner LB, Foye SJ, Siegler M. Ethical issues identified by rehabilitation clinicians. Arch Phys Med Rehabil. 2001;82(12 Suppl 2):S2-8.
3. Caplan AL, Callahan D, Haas J. Ethical & policy issues in rehabilitation medicine. Hastings Cent Rep. 1987;17(4):S1-20.
4. Atanelov L, Stiens SA, Young MA. History of physical medicine and rehabilitation and its ethical dimensions. AMA J Ethics. 2015;17(6):568-74.
5. Blackmer J. Ethical issues in rehabilitation medicine. Scand J Rehab Med. 2000;32(2):51-5.
6. Scofield GR. Ethical considerations in rehabilitation medicine. Arch Phys Med Rehabil. 1993;74(4):341-6.
7. Sliwa JA, McPeak L, Gittler M, Bodenheimer C, King J, Bowen J; AAP Medical Education Committee. Clinical ethics in rehabilitation medicine: core objectives and algorithm for resident education. Am J Phys Med Rehabil. 2002;81(9):708-17.
8. Carlisle JR. Informed consent in physical medicine and rehabilitation. The physician/patient relationship – the doctor as a fiduciary. Phys Med Rehabil Clin N Am. 2002;13(2):213-24, viii.
9. Purtilo RB. Applying the principles of informed consent to patient care. Legal and ethical considerations for physical therapy. Phys Ther. 1984;64(6):934-7.
10. Department of Health, Education, and Welfare; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. J Am Coll Dent. 2014;81(3):4-13.
11. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013;310(20):2191-4.
12. Manti S, Licari A. How to obtain informed consent for research. Breathe (Sheff). 2018;14(2):145 52.
13. Albala I, Doyle M, Appelbaum PS. The evolution of consent forms for research: a quarter century of changes. IRB. 2010;32(3):7-11.
14. Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. N Engl J Med. 2007;357(18):1834-40.
15. Fields LM, Calvert JD. Informed consent procedures with cognitively impaired patients: A review of ethics and best practices. Psychiatry Clin Neurosci. 2015;69(8):462-71.
16. Lo B. Resolving Ethical dilemmas: a guide to clinicians. 2nd ed. Baltimore, MD: Williams and Wilkins; 2000.
17. Brody H. Shared decision making and determining decision-making capacity. Prim Care. 2005;32(3):645-658.
18. Venesy BA. A clinician's guide to decision-making capacity and ethically sound medical decisions. Am J Phys Med Rehabil. 1994;73(3):219-26.
19. Sandman L, Agren Bolmsjö I. Ethical considerations of refusing nutrition after stroke. Nurs Ethics. 2008;15(2):147-159.
20. Sharp HM, Genesen LB. Ethical decision-making in dysphagia management. Am J Speech Lang Pathol. 1996;5(1):15-22.
21. Ohry A. Ethical questions in the treatment of spinal cord injured patients. Paraplegia. 1987;25(3):293-5.
22. Rosenfeld JV, Bandopadhayay P, Goldschlager T, Brown DJ. The ethics of the treatment of spinal cord injury: stem cell transplants, motor

neuroprosthetics, and social equity. Top Spinal Cord Inj Rehabil. 2008;14(1):76-88.

23. Wyndaele JJ. Ethics, healthcare and spinal cord injury: research, practice and finance. Spinal Cord. 2011;49(2):161.
24. Stein J. Ethical issues in inpatient rehabilitation length of stay determination. Top Stroke Rehabil. 2012;19(1):86-92.
25. Bach JR, Barnett V. Ethical considerations in the management of individuals with severe neuromuscular disorders. Am J Phys Med Rehabil. 1994;73:134-40.
26. Jonsen AR, Siegler M, Winslade WJ. Clinical ethics: a practical approach to ethical decisions in clinical medicine. 7th ed. New York, NY: McGraw-Hill; 2010.
27. Purtilo RB. Ethical issues in teamwork: the context of rehabilitation. Arch Phys Med Rehabil. 1988;69:318-22.
28. Beauchamp TL, Childress JF. Principles of biomedical ethics. 6th edition. New York, NY: Oxford University Press; 2008.
29. Haas J. Ethical considerations of goal setting for patient care in rehabilitation medicine. Am J Phys Med Rehabil. 1993;72:228-32.
30. Elements of Patient-Centered Care. NEJM Catalyst. What is patient centered model? [Internet] https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559. Published January 1, 2017. Accessed June 6, 2018.
31. Collins A. Measuring what really matters: towards a coherent measurement system to support person-centred care. London, UK: Health Foundation, 2014.
32. Hunt MR, Ells C. A patient-centered care ethics analysis model for rehabilitation. Am J Phys Med Rehabil.2013;92(9):818-27.
33. World Health Organization (WHO). International classification of functioning, disability and health: ICF. Geneva, Switzerland: WHO; 2001.