Ethical Perspectives on Knowledge Translation in Rehabilitation

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Abstract

Although the literature on the ethical dimensions of knowledge creation, use, and dissemination is voluminous, it has not particularly examined the ethical dimensions of knowledge translation in rehabilitation. Yet, whether research is done in a wet lab or treatments are provided to patients in therapeutic settings, rehabilitation professionals commonly use (as well as create) knowledge and disseminate it to peers, patients, and various others. This article will refer to knowledge creation, use, and transfer as knowledge translation and examine some of its numerous ethical challenges. Three ethical dimensions of knowledge translation will particularly attract our attention: (1) the quality of knowledge disseminated to rehabilitationists; (2) ethical challenges in being too easily persuaded by or unreasonably resistant to putative knowledge; and (3) organizational barriers to knowledge translation. We will conclude with some recommendations on facilitating the ethical soundness of knowledge translation in rehabilitation.

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Whether working in a molecular biology lab or conducting post-approval drug or device studies, investigators or clinicians using and applying relevant knowledge bases will inevitably encounter ethical challenges. Most prominently, any scientific or clinical knowledge that is publicly presented, used, or transferred rests on the presumption that it is true. Much rides on that belief, however, because if that knowledge is problematic or tarnished, then all of its users might suffer setbacks or harm. This article will explore these possibilities by examining the ethical dimensions of knowledge translation in rehabilitation.

Knowledge translation has been defined as the exchange, synthesis, and ethically sound application of knowledge, within a complex system of interactions among researchers and users, to accelerate capture of the benefits of research. Making liberal use of Rogers’ innovation decision process theory, we will focus on the ethical aspects of knowledge translation in the education and practice of rehabilitation professionals. We will offer ethical insights on knowledge translation as it proceeds through its (1) representation to potential rehabilitation knowledge users, who (2) consider whether they should be persuaded by that knowledge or not, such that they (3) include or reject its implementation in their professional practice. We will conclude this essay with some practical recommendations for improving knowledge translation in rehabilitation.

Ethical issues in knowledge dissemination

The words ethics and ethical have wide-ranging connotations and applications. Sometimes ethics refers to the corpus of moral philosophy authored by the likes of Plato, Aristotle, John Stuart Mill, John Rawls, and their kin. Alternatively, ethics might refer to the moral formation or virtuous character of moral agents. At other times, ethics might involve the resolution of difficult cases or problematic practices like stem cell research, allocating care, and end of life. Yet another branch of ethics analyzes problematic terms and policies involving rights, harms, benefits, and justice. As we explore the first issue in knowledge translation—namely, knowledge dissemination to potential users—our ethical interest will be a pragmatic one focusing on the quality of knowledge that is presented to rehabilitation knowledge consumers, especially as that knowledge claims to espouse the truth.

Quality of rehabilitation research

Our first ethical concern is whether the knowledge to which rehabilitationists are exposed—in their formal training programs...
leading to licensure or certification, or their continuing medical education programs, journal clubs, and the like—is valid and reliable. The ethical concern is obvious: to the extent that health professionals absorb and implement knowledge that is false or without adequate substantiation, they risk harming or defrauding their patients or clients. Unfortunately and as subsequently discussed, rehabilitation is not without significant criticism with regard to its practitioners’ implementing knowledge whose claims to truth or clinical effectiveness are questionable or that rest on dubious evidential sources.5

Certainly, the inherent challenge of performing valid and reliable rehabilitation research considerably explains this difficulty. If the criterion standard of clinical research involves the implementation of large, randomized, double-blinded, multicenter, placebo controlled trials, rehabilitation researchers will have an extraordinarily difficult time consistently accommodating these optimal expectations. Perhaps the most daunting methodologic challenge in clinical rehabilitation research is controlling variables that might affect a rehabilitation outcome, such as the patient’s severity, type, and location of injury, educational level, age, degree of familial support, coping mechanisms, and financial resources.8 Typically, these confounding variables would be controlled by randomizing large numbers of patients into various treatment arms of a study. But rehabilitationists are frequently without these large populations; indeed, the fact that no 2 neurologic injuries are anatomically or neurophysiologically identical would continue to compromise findings on rehabilitation effectiveness even if research participants could be purified of the confounding variables previously mentioned.7,8

Additionally, clinical rehabilitation research customarily involves what Whyte6 has called the “dynamic interplay” of therapist and client, which is another confounding variable. Such dynamics, as they are represented by the intersection and synergy of the therapist’s and client’s psychological characteristics and attitudes in treatment sessions, can powerfully influence patients’ outcomes over and beyond whatever intervention is being studied. Yet, they are virtually impossible to control. On a related point, no clinician-investigator providing an experimental rehabilitation modality will be blinded as to its nature, nor will that rehabilitationist be delivering a placebo. If a placebo in rehabilitation is essentially a nontreatment, then payors would balk at the idea of reimbursing a patient’s hospital stay, while our ethical sensibilities compel the rehabilitationist to offer some kind of accepted treatment to any patient seeking care.6

Of course, one can do a retrospective trial and compare persons who did not receive rehabilitation with ones who did. Clinical equipoise does not require a nonintervention. In any event, however, it is important to note that the difficulty of conducting rehabilitation research is not necessarily a moral failing among rehabilitation investigators—although it would be if the investigator published findings from data that he or she knew were seriously flawed.9 Rather, given that many if not most studies reported in the rehabilitation literature—and thus presented as putative knowledge—might have moderate if not considerable methodologic or design shortcoming or flaws, the clinicians who use this research are morally obligated to develop the analytic skills whereby they might assess the validity and reliability of whatever research they come across. Rehabilitation providers must, in short, become exquisitely sophisticated research consumers.10

This ethically entails that rehabilitation educators take considerable pains to instruct future rehabilitation professionals on critically assessing rehabilitation research; that journal clubs and grand rounds presentations pay keen attention to the methodology and design of any studies that are discussed; and that purveyors or disseminators of rehabilitation knowledge, especially as they might appear at national conferences, colloquia, and seminars, relate their findings objectively.2 This last requirement presents a particular ethical challenge.

**Conflicts of interest and rehabilitation research**

Although conflict of interest is a technical term of art—usually referring to a situation wherein an individual allows a secondary interest, such as an opportunity to increase one’s income, prestige, or standing to overtake a primary interest, such as a health professional’s prima facie duty to protect and foster his or her patient’s welfare1—researchers of any ilk frequently confront a conflict or temptation every time they gather and disseminate their findings. That temptation, whether conscious or unconscious, is to make those data appear as favorable as possible such that factors that might erode the persuasiveness of those findings are omitted or downplayed in their reports or presentations.12 For example, a ubiquitous methodologic problem in any kind of clinical research in statistically underpowered studies is usually owing to a small sample size or poorly matched controls. Additionally, some studies might ask too narrow a question, such as reporting an increased range of motion rather than some functionally meaningful outcome like dressing oneself. Other studies might forgo the use of established measures or scales and invent their own scale, which conveniently omits the very measures on which patients did not score well. And then there is the notorious technique of first shoot the arrow, then draw the target, wherein the research question is framed after the data are collected, such that the latter nicely support the former. Finally, a researcher might use some creative statistics that show a considerable effect but omit the finding’s confidence interval.13-15

Our point is that over and above the inherent challenge confronting rehabilitation investigators in designing and realizing methodologically sound studies, numerous factors can disturb their objectivity and even their ethical sensibilities. Consider especially the university-based researcher whose very career depends on persuading sources of research funding and peer-reviewed publications that his or her findings are compelling and merit continuing support and dissemination. The temptation to make research findings look better than they actually are is relevant at every stage of clinical knowledge translation from investigators working with animals, to clinical trials with human subjects, to third-party reimbursed clinical practice.15 Indeed, private interests, such as drug or device manufacturers, will frequently insinuate themselves in research environments and sometimes pressure researchers to validate their products.16 Consequently, researchers whose careers depend on the flow of research dollars, increased publications, or heightened professional visibility can easily be tempted to make claims for their knowledge that ultimately cannot be replicated or that turn out to be exaggerated. Consequently, the rehabilitationist as a knowledge consumer who is not alert to the possibility of a poorly designed study can be vulnerable to various forms of persuasion that hype the findings. We shall examine this phenomenon next.
Persuasion phase of knowledge translation

Obviously, for potential knowledge consumers to even consider incorporating some knowledge claim into their belief or practice systems, they must be persuaded by it to some degree.17 Within a clinical rehabilitation context, this clearly means that a professional who delivers a particular treatment modality will believe in its effectiveness. In turn, his or her consistent deployment of that intervention implies that in some way—whether in his or her formal training or through some alternative learning venue like continuing education seminars—the rehabilitationist was exposed to the associated knowledge base and became confident that its claims to clinical effectiveness are true.

Now, at least 2 ethical considerations follow from this. The first concerns a therapist’s consistent use of rehabilitation knowledge that is known to be unproven, doubtful, or foundationless. As previously noted, given that many rehabilitation modalities are without the kind of criterion standard evidence or support enjoyed by other clinical disciplines—that typically evaluate very discrete interventions (eg, a drug) against a very well-defined and easy to measure outcome (eg, mortality)—the rehabilitationist is ethically obligated to be judicious in adopting new modalities.18 Alternatively, if he or she adopts an unproven intervention nonetheless, one might argue that the rehabilitationist is duty bound to inform the client about the lack of evidence to justify the intervention. If readers blanch at such a disclosure requirement, they should be aware that it follows straightforwardly from a professional’s informed consent obligations, wherein patients have the right to know about the material risks of the treatment they will receive, especially when knowing about those risks might prompt the patient to refuse the treatment.4 Obviously, a reasonable rehabilitation consumer might find a significant absence of empirical justification for a particular treatment disturbing and reject it per his or her autonomous right to do so.

A second ethical problem, however, consists in an opposite scenario wherein a rehabilitationist might be confronted with a treatment intervention that boasts impressive evidentiary support, and yet he or she refuses to deploy that intervention. Let us consider each of these issues.

Ideationally vulnerable rehabilitation provider

One of us (J.D.B.) vividly recalls the markedly enthusiastic reception of Bobath interventions among physical and occupational therapists in the 1980s. Bobath theory and its techniques, named after its creators Karl and Bertha Bobath, were often taught by instructors who studied overseas with the Bobaths themselves or with therapists taught by them.19 Some of these Bobath instructors were rather charismatic individuals who mesmerized and sometimes terrified audiences of physical and occupational therapists attending training sessions that certified their learning of Bobath techniques. Despite decades of Bobath instruction and popularity, which was called in 2009 “the most popular treatment approach used in stroke rehabilitation,”20(p89) 2 recent literature reviews suggest that there is no compelling evidence that substantiates Bobath’s clinical superiority to other treatment modalities.

For example, a 2004 literature review that examined outcomes from Bobath treatment for upper limb recovery after stroke analyzed the literature from 1966 to 2003 and identified 8 articles that addressed outcomes.21 Five of the studies were randomized controlled trials, another used a single-group crossover design, and 2 were single-case design studies. None of the studies found that Bobath-based interventions were superior to other therapy approaches. Similarly, a 2009 study of the overall effectiveness of Bobath in stroke rehabilitation identified 16 studies comparing Bobath with other therapies and concluded that “there was no evidence of superiority of Bobath on sensorimotor control of upper and lower limb, dexterity, mobility, activities of daily living, health-related quality of life, and cost-effectiveness.”20(p89)

Now, we do not quote these studies to impugn Bobath theory, its related interventions, its instructors, or its therapist-advocates. Instead, we wish to point out that if rehabilitation research is plagued by numerous challenges that compromise data integrity, then some rehabilitation therapists might easily fall prey to hype.22 Of course, claims for some drug, device, or intervention that are not substantiated by good data are hardly new, and the associated claims are not necessarily false. But an uncritical acceptance of such claims or, in the language of this article, a too ready translation of knowledge into practice is ethically worrisome for the simple reason that consumers of the intervention or product may be receiving therapy whose claims are untested and whose benefits may be less than touted. Clearly, professionals who perform treatments for only self-serving reasons, for example ease or convenience, greater reimbursement, and refusing to learn something new, are placing their interests and needs above the patient’s and, possibly, are providing the patient with less than what he or she is owed.4 Our next example is a case in point.

Failure to implement evidence-based therapy for self-serving reasons

The traditional ethical theories of the west, ie, deontologism, utilitarianism, and virtue theory, rest on a signal concept: each understands the ethical act to nourish or foster the welfare of another or, at least, the agent’s acting in a principled and respectful way toward another (eg, keeping promises, telling the truth, respecting another’s privacy). According to these theories, an act that is motivated and performed for purely self-serving reasons cannot be called ethical. In all cases, the other person is the one to whom health professionals are ethically obligated and to whom they are accountable.4

Although rehabilitationists might take umbrage at the allegation that therapists sometimes act in purely self-serving ways, it is difficult to know what else to make of a 2009 study on the refusal among some Dutch therapists to adopt evidence-based practice guidelines for treating low back pain.17 These guidelines were developed by the Royal Dutch Society of Physiotherapy in collaboration with the Dutch Institute of Allied Health Care and were based on the best available scientific evidence. The guidelines themselves advised physical activity rather than bed rest, exercise therapy, and “a hands-off policy...for patients with acute low back pain.”17(p222) In fact, the overall thrust of the guidelines “is the lower importance assigned to the management of patients’ impairments.”17(p222)

When Dutch investigators sought to determine the degree to which the guidelines were actually being implemented in treatment environments, they were disappointed to find only a moderate degree of acceptance. Interviews with therapists found some indifferent to the guidelines, others pleading that absorbing the related knowledge was too time-consuming, and others
claiming that some of the guidelines’ terminology was too vague (eg, nonspecific low back pain).

What is especially noteworthy, however, were certain therapists’ refusals to implement or translate the guidelines into practice for self-serving reasons, such as therapists feeling the guidelines were too professionally constraining (eg, “What would be left of your independence, your own competence, your own practice?”), too threatening to an existing knowledge base (eg, “I completed my education only 5 years ago, and I learned things that the guidelines say I shouldn’t do. Am I to conclude then that my training was useless?”, or too cumbersome (eg, “It simply does not fit in with the way I normally work.”)).

None of these therapists expressed that the guidelines were too vague or that they were only of theoretical interest (eg, nonspecific low back pain).

Consequently, the rationales previously given for refusing to implement what Dutch authorities believe are evidence-based therapies are ethically worrisome and, to the extent that they might be representative of a larger population of therapists who resist evidence-based practice, they are very unsettling. Motives for refusing to deploy low back pain interventions because they threaten a therapist’s need to feel autonomous, or lessen the value of his or her previous instruction, or disrupt the therapist’s work habits are ethically unacceptable.

But suppose a clinician is asked by a researcher to help recruit patients for the researcher’s clinical trial that will evaluate a new, experimental rehabilitation treatment. How should the clinician respond, especially as the proposed treatment is (1) only in a research phase such that (2) its value in comparison with the standard or traditional therapy is clinically undetermined (as should be the case if equipoise exists), and (3) the clinician is quite satisfied and comfortable with the intervention that he or she has been using for some time?

For the clinician to acquiesce—and clearly, there should be instances when he or she does to propel rehabilitation translational research forward—we suggest that the investigator be able to secure the clinician’s trust by showing compelling (albeit preliminary) data speaking to the experimental treatment’s effectiveness. Borrowing from Kimmelman’s work on reducing the amount of translational distance between preclinical and clinical models, we recommend that the investigator be able to show that his or her data boasts good internal and external validity, that findings from preclinical animal studies tightly correspond to the experimental treatment’s objectives, and that measures are in place to control for optimism bias.

We list some ways to implement these considerations in Table 1, borrowing again from Kimmelman. Ultimately, though, the situation envisioned here involves distinguishing blind from warranted trust in initiating rehabilitation research. As previously discussed, rehabilitationists as well as clinicians from other disciplines must not only guard against hype, but be astute research consumers such that they do not thwart rehabilitation research that deserves to proceed. Alternatively, they should be extremely wary about novel therapeutic interventions whose supporting data lack methodologic rigor, a reasonable animal model, a nonvalidated research hypothesis, or a nonvalidated research method.

Of course, most rehabilitationists work in environments that do not conduct formal rehabilitation research and, hence, do not face these technical considerations. For these care providers, ethical worries about knowledge transfer often target organizational variables that are beyond the therapist’s control but that nevertheless inhibit his or her access to and use of evidence-based knowledge. In such events, the moral onus for failure to translate evidence-based knowledge into practice may well fall on whoever is responsible for failing to eradicate such barriers. We will discuss that possibility next.

### Organizational barriers to the implementation of evidence-based knowledge

Rogers’ final stage of knowledge diffusion is the adoption process, which, and to a significant extent, will often require that certain organizational structures be in place to facilitate the benefit of knowledge translation to the end user. Rogers’ innovation decision process identifies implementation factors, such as training change agents and opinion leaders, forming professional networks, providing management support and planning to overcome cultural and organizational obstacles to translation, and...
tasking certain personnel and especially leadership to champion innovation.\textsuperscript{17}

These factors are ethically important because data suggest that the difficulties involved in translating knowledge to practice are sometimes over and beyond what individual clinicians can reasonably overcome on their own. For example, a 2009 study by Schreiber et al.\textsuperscript{2} on strategies to promote evidence-based practice in pediatric physical therapy found therapists complaining that the knowledge material was not only difficult to comprehend but especially difficult to apply, for example, “it’s very difficult to take a blanket statement about cerebral palsy and apply it to any of the kids or take results from a piece of evidence that you might get and apply it.”\textsuperscript{26} Another problem that confronts therapists interested in applying evidence-based guidelines is the sheer difficulty in accessing those guidelines given the constraints of their daily routines.

Most therapists in Schreiber’s study,\textsuperscript{2} however, mentioned time limitations as the major impediment to their implementing evidence-based guidelines. As one therapist noted, “how many times is it going to take me—45 minutes or an hour—to find something when I just don’t have that time to give.”\textsuperscript{27} In such instances, ethically based obligations to provide evidence-based care collide with organizational concerns and economic constraints that prioritize a reasonable income flow. Indeed, as leadership might sometimes understand its primary role as profit generation, little incentive might be offered to therapists to implement new knowledge, especially if that implementation threatens diminishing revenue streams. Without those incentives and supports, though, it seems unrealistic to expect many therapists to enthusiastically overhaul their current treatment approaches in favor of new practice knowledge derived from compelling research data.

Consequently, barriers to knowledge translation stemming from comprehension factors, lack of available knowledge sources (or difficulty accessing them), time constraints, and a leadership indifferent to research-based knowledge shift a large part of the moral onus for inadequate knowledge translation to organizations. If rehabilitation consumers are to achieve the kind of quality care that their providers frequently promise in their marketing materials, then therapists must come to understand that new research will necessarily destabilize their old way of doing things and embrace it rather than be threatened by it. Remaining mired in the old way of doing things constitutes a moral failing in the rehabilitation industry (or any health care delivery system) to live up to the quality care it promises its consumers.

Glimpsing the future: the problem of morally tainted knowledge

Today, health care is perched on a wave of potential technologic implementation whose size, impact, and benefit might be unprecedented in human history. Gene therapies, nanotechnologies, and neurotechnologies are only some of the mechanisms that rehabilitationists might implement in the 21st century. Yet, it might be the case that not all of these technologies will be equally embraced and used. Some might be resisted, because they violate the ethical sensibilities of certain health professionals who perceive their knowledge bases as morally tainted. A case in point is stem cell transplantation after neurologic injury.

Stem cell therapies have the potential to revolutionize rehabilitation medicine. Although that potential is not yet realized, stem cells might ultimately prove a rehabilitative and regenerative panacea, serving as cures for paralysis and as seeds for replacing damaged cells and organs anywhere in the body at any time. The capacity of stem cells to differentiate can theoretically be exploited in a large fraction of all rehabilitation referrals—afflicting any situation where new cells and tissues would be beneficial, from relatively minor cases like strained or torn muscles, to chronic, debilitating cases of cell death and tissue degeneration, for example Parkinson’s disease, stroke, spinal cord injury, and heart disease.\textsuperscript{25-28}

Physiatrists and therapists are already participating in clinical trials involving stem cell therapy or in providing traditional rehabilitation therapies to patients who have undergone stem cell therapy.\textsuperscript{29} Indeed, the success of stem cell therapies will overwhelmingly depend on the degree of functional improvement they provide, rather than how well basic scientists are able to isolate, grow, and control the differentiation of the cells. But a common source of these cells is in vitro fertilization clinics’ unused human embryos. Consequently, many individuals presently associate stem cell therapies with homicide because deriving such cells requires the in vitro creation of a human embryo and then destroying it at its blastocyst stage to secure its stem cells.\textsuperscript{30} Thus, for his first televised address in August 2001, then President George W. Bush asserted he would ban federally funded research on these cells, except for the handful of cell lines that had already been developed to that point.\textsuperscript{31} In 2008, some members of the Georgia legislature went considerably further in introducing House Bill 1358 to make it law that “the creation of an in vitro human embryo shall be solely for the purpose of initiating a human pregnancy (19-7-61)...and an in vitro human embryo exists as a legal person (19-7-62)...who is not the property of the fertility physician or the facility which employs the physician or the donors of the sperm and ovum (19-7-65).”\textsuperscript{32} In effect, this bill would understand stem cell transplantation that uses human embryonic stem cells as homicide and seek to punish those involved. Although the bill did not pass, it or legislation like it will almost certainly be resurrected in future legislative sessions whether in Georgia or in other states.

Stem cells derived from human embryos present a case where religion and politics cross over into science and raise important ethical questions.\textsuperscript{33} Although stem cells present these questions in an especially dramatic way, any biomedical research and application might disturb the ethical sensibilities of any number of persons, including rehabilitation providers. Should, then, physiatrists and therapists participate in clinical trials or therapies in which human embryonic stem cells are used? How does the promise of human embryonic stem cells weigh against what many see as the destruction of human life? Are there moral limits to making someone with disease or disability better? Should scientists and rehabilitationists categorically avoid the use of human embryonic stem cells and search for alternative approaches?

We surmise that many rehabilitationists might balk at treating patients who are undergoing stem cell transplantation—which would probably occur simultaneously with their therapy—just as many health professionals refuse to participate in abortions. Knowledge implementation, therefore, might not only be resisted for psychological and organizational reasons, but for pronounced ethical reasons that understand certain kinds of knowledge as morally tainted.

Conclusions

We conclude with an ethically based plea that evidence-based practice and its challenges occupy center stage at all levels in
rehabilitation education and delivery. This would begin in training programs where future care providers are not only taught the critical tools to differentiate methodologically superior from questionable research findings, but are also supplied with the ethical bases and justifications to champion evidence-based practice throughout their careers. 

Furthermore, most rehabilitationists will work in some sort of organization and might be challenged, for the reasons previously given, to implement evidence-based care. One can only hope that such organizations will take their mission statements—that almost invariably state a commitment to high-quality care—to heart and do everything reasonable to champion the cause of evidence-based practice, such as including an ongoing and scientifically informed program of continuing education, and the selective hiring of individuals with superior credentials. In this regard, we applaud the profession of physical therapy for advocating the doctorate degree, because its associated requirements almost always include a heavy research component infused with, one hopes, ethics instruction.

Finally, we contemplate the possibility that some rehabilitationists might resist the implementation of certain scientific knowledge for ethical reasons. But as other articles in this issue argue, the entire system that produces biomedical knowledge has an ethical nature that requires constant evaluation or peer review. Knowledge discovery, analysis, and implementation are inevitably infused with ethical considerations that prompt the attention and oversight of institutional review boards, an ever vigilant and infused with ethical considerations program of continuing education, and the selective hiring of individuals with superior credentials. In this regard, we applaud the profession of physical therapy for advocating the doctorate degree, because its associated requirements almost always include a heavy research component infused with, one hopes, ethics instruction.

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