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Supporting, Promoting, Respecting and Advocating: A Scoping Study of Rehabilitation Professionals' Responses to Patient Autonomy

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Pourtours et défis d'une éthique en réadaptation
Limits and Challenges of an Ethics in Rehabilitation

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Résumé de l'article

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Supporting, Promoting, Respecting and Advocating: A Scoping Study of Rehabilitation Professionals' Responses to Patient Autonomy

Emilie Blackburn[1,2], Evelyne Durocher[3], Debbie Ehrmann Feldman[2,4,5], Anne Hudon[6,7], Maude Laliberté[2,4,5], Barbara Mazer[1,2], Matthew Hunt[1,2]

Résumé

Contexte : L'autonomie est un concept central tant en bioéthique qu'en réadaptation. La bioéthique a mis l'accent sur l'autonomie en tant qu'auto-gouvernance et sur son application dans la prise de décision en matière de traitement. En plus de discuter de l'autonomie décisionnelle, la réadaptation met aussi l'accent sur l'autonomie en tant qu'indépendance fonctionnelle. Dans la pratique, la prise en charge des patients en perte d'autonomie est une composante importante des soins de réadaptation, mais elle engendre aussi des tensions et des défis. Notre objectif était de mieux comprendre les façons complexes et distinctes dont l'autonomie est comprise et maintenue dans le contexte des soins de réadaptation en examinant comment l'autonomie est abordée dans la littérature sur la réadaptation. ***Méthodes :*** Nous avons effectué une étude de la portée des questions d'autonomie dans le contexte de la réadaptation mentale et physique. Notre processus s'est déroulé en trois étapes séquentielles. Nous avons extrait et analysé des informations bibliométriques. Nous avons ensuite examiné comment l'autonomie était définie et conceptualisée. Enfin, nous avons examiné la façon dont les articles traitaient du rôle des professionnels de la santé en réadaptation dans l'autonomie des patients. ***Résultats :*** Les articles comprennent 16 rapports empiriques, 17 études de cas et 30 articles théoriques. Les récits conceptuels les plus courants sur l'autonomie s'appuyaient sur le principisme, les analyses fondées sur les droits et les analyses juridiques et les approches relationnelles/sociales. Nous avons identifié quatre grandes approches pour répondre à l'autonomie du patient : *le soutien*, *la promotion*, *le respect* et *la promotion*. ***Conclusion :*** Cet examen aide à clarifier certaines des ambigüités et des distinctions conceptuelles qui sous-tendent les discussions et les pratiques liées à l'autonomie en réadaptation. Il attire également l'attention sur un large éventail d'activités que les professionnels de la santé peuvent entreprendre dans le but de soutenir, de promouvoir, de respecter et de promouvoir l'autonomie des patients dans les soins de réadaptation.

Mots clés

autonomie, prise de décision, éthique, réadaptation, étude de la portée

Abstract

Background: Autonomy is a central concept in both bioethics and rehabilitation. Bioethics has emphasized autonomy as self-governance and its application in treatment decision-making. In addition to discussing decisional autonomy, rehabilitation also focuses on autonomy as functional independence. In practice, responding to patients with diminished autonomy is an important component of rehabilitation care, but also gives rise to tensions and challenges. Our objective was to better understand the complex and distinctive ways that autonomy is understood and upheld in the context of rehabilitation care by reviewing how autonomy is discussed in the rehabilitation literature. ***Methods:*** We conducted a scoping review addressing issues of autonomy in the context of mental and physical rehabilitation. Our process followed three sequential steps. We extracted and analyzed bibliometric information. We then examined how autonomy was defined and conceptualized. Finally, we examined how the articles discussed the roles of rehabilitation health professionals in responding to patient autonomy. ***Findings:*** The articles include 16 empirical reports, 17 case studies and 30 theoretical papers. The most common conceptual accounts of autonomy drew upon principlism, rights-based and legal analyses, and relational/social approaches. We identified four broad approaches for responding to patient autonomy: *supporting*, *promoting*, *respecting* and *advocating*. ***Conclusion:*** This review helps clarify some of the ambiguities and conceptual distinctions underlying discussions and practices related to autonomy in rehabilitation. It also draws attention to a wide range of activities that health professionals can undertake with the goal of supporting, promoting, respecting and advocating for patient autonomy in rehabilitation care.

Keywords

autonomy, decision-making, ethics, rehabilitation, scoping review

Introduction

Autonomy is a fundamental concept in bioethics, as well as in physical and mental health rehabilitation. Respect for autonomy is enshrined as a primary ethical obligation of health professionals towards their patients [1]. Within the field of bioethics, the concept of autonomy has traditionally focused on the capacity for individuals to make decisions concerning their medical treatment [2]. It has generally been conceptualized as encompassing an individual's capacity to self-govern and make and enact choices that are aligned with one's values and life goals [1,3]. Respecting autonomy also entails negative duties, such as non-interference with another person's actions and choices unless there are strong countervailing reasons for doing so [4,5]. More recent accounts have emphasized the relational, social and political dimensions of autonomy by considering individuals within their multi-layered past, present and future contexts [6]. For example, relational autonomy posits that individuals are shaped by, are inextricably linked to, and make decisions in light of, contextual features and relationships [7].

Since the mid-1980s there has been increasing discussion about the principle of respect for autonomy in the context of rehabilitation care, including many questions about the adequacy of an individualistic, rational account of autonomy in this context and about the adequacy of traditional care paradigms [8-13]. Caplan argues that it is "essential both for bioethicists and for those who deliver or receive rehabilitative services to identify the salient moral dilemmas and to determine whether ethical analysis based on emergency or acute care paradigms is adequate" [14, p. 3]. This thinking has contributed to a subfield of inquiry focused on rehabilitation ethics [14-18]. Such discussions are prompting increasing attention to ethical issues in rehabilitation and long-term care, including in relation to autonomy [8,14-17,19-25].

Three broad features of rehabilitation services have been identified as shaping how ethical commitments, including the notion of respect for autonomy, ought to be understood. First, rehabilitation services require active participation by patients; in this

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sense, rehabilitation is done *with* rather than *to* patients [14,26-30]. The transition from acute care to rehabilitation typically involves patients becoming increasingly active agents in their own process of recovery [16,17,21,24]. This is particularly the case for individuals who have experienced a new disability due to injury or the onset or exacerbation of disease. Several authors have described how the experience and adjustment to new impairments challenges assumptions related to various conceptions of autonomy in bioethics and rehabilitation [21,23,25]. The dynamic process with which people respond to new or changing impairments raises several questions [18,22,24]: How should the process of seeking informed consent for treatment decisions account for an individual's evolving sense of self and personal identity? What implications might this process have for how and when information is shared with patients? How can health professionals best work with patients' family members throughout this process?

A second salient feature of rehabilitation is about relationships. Rehabilitation is often a long-term process. Patients tend to have longer lengths of stay and a higher frequency of treatment sessions in rehabilitation centres as compared to acute care facilities [24] thus enabling stronger relationships between rehabilitation health professionals and their patients, as well as with their families. This dynamic also exists in out-patient and home-based rehabilitation services which are often continued over longer periods of time. This approach contrasts with conceptions of autonomy that "presume medical relationships as being discrete, finite and episodic" [16, p.312]. Moreover, the ability of individuals receiving rehabilitation services to make choices is shaped by their functional and decisional capacities, and is also influenced by their multi-faceted social environments, including family relationships [11]. This social context may create or restrict opportunities for decision-making (e.g., through depth and types of relationships and networks, social expectations, socio-economic resources) [8,21].

Third, rehabilitation services are often provided within an interprofessional model of care. Rehabilitation teams tend to include many different professional perspectives, which greatly enrich the practice of rehabilitation. This diversity can pose challenges, however, because patients interact with many different professionals and it may be less clear how decision-making will take place. The size and diversity of rehabilitation teams may pose challenges for autonomy, as well as for other ethical considerations such as privacy of patient information [16,20].

Given how different features of the context shape the complex and distinctive ways that autonomy is experienced, understood and upheld in rehabilitation contexts, we asked: How is autonomy conceptualized in the rehabilitation literature, and how are the roles and approaches of rehabilitation health professionals discussed in responding to patient autonomy, especially in situations when patient autonomy is limited or uncertain?

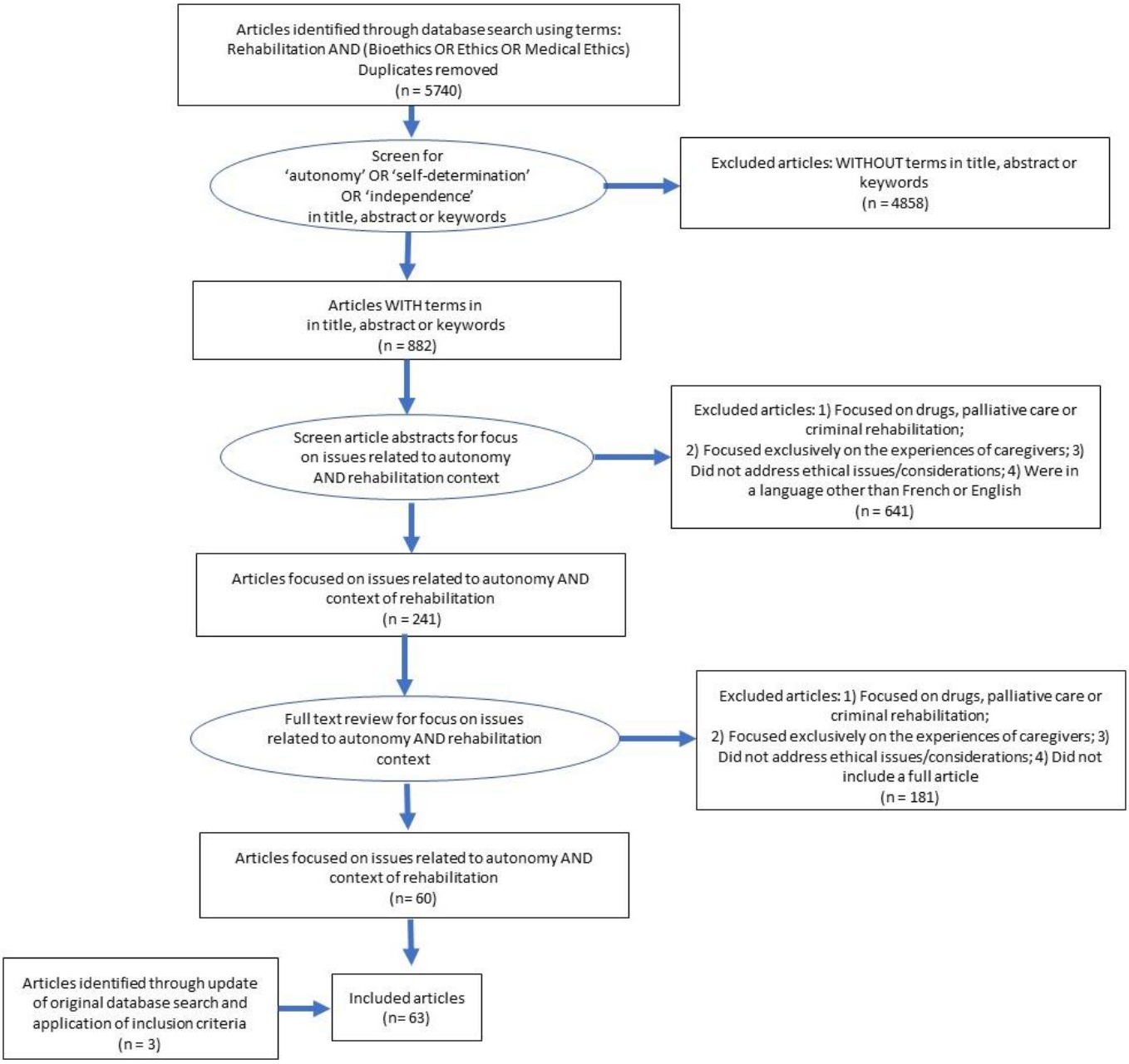
Methods

We conducted a scoping review of the literature following the framework developed by Arksey and O'Malley [31] and incorporating recommendations proposed by Levac et al. [32], with the goal of better understanding how the concept of patient autonomy is defined, theorized and discussed in the rehabilitation literature. This approach involved five stages: identifying the specific research question; identifying relevant studies while balancing "feasibility with breadth and comprehensiveness" [32, p.5]; selecting relevant studies; extracting pertinent data from the selected documents; and collating and summarizing the data through a qualitative analysis, as well as a compilation of quantitative bibliometric data about the reviewed articles.

The scoping review process is presented in Figure 1 using a modified PRISMA flow diagram format (CONSORT, 2010). We consulted with a medical librarian at multiple steps in the design and implementation of the search strategy. We began our review by searching the following databases: AMED, BELIT, Embase classic, Ovid MEDLINE (1946-present), Philosopher's Index and PubMed. These databases were selected based on their prominence and the alignment of their content with the research questions. An initial search was conducted in July 2014 and updated in April 2016. The databases were searched using the terms rehabilitation AND (bioethics OR ethics OR medical ethics). After removing duplicates, this search yielded 5740 articles. We then searched the retained articles for those that included the search terms 'autonomy OR self-determination OR independence' in the title, abstract or keywords, resulting in 882 articles being selected.

The titles and abstracts of the 882 articles were reviewed and articles were retained for further analysis if they addressed issues related to patient autonomy (including independence and self-determination) in the context of rehabilitation (including physical or mental health rehabilitation). Articles were excluded if they: 1) did not address physical or mental health rehabilitation (e.g., focused on drug rehabilitation, palliative care or criminal rehabilitation); 2) focused exclusively on the experiences of caregivers; 3) did not address ethical issues/considerations (e.g., focused only on technical aspects of assessing independence); 4) were in a language other than English or French; or 5) did not include a full article (e.g., conference abstract or short commentary). Following this first application of exclusion criteria, 241 articles were retained. The full texts of these articles were then reviewed by applying the inclusion and exclusion criteria and 60 articles meeting the inclusion criteria were identified. When we performed an updated search in April 2016, three additional articles that met the inclusion criteria were identified, for a total of 63 articles included in the review (see Figure 1).

Figure 1. Modified PRISMA flow diagram



From the 63 articles, we extracted three types of data. First, we extracted bibliometric information related to authors, publication dates, types of journals and methods used in the articles. Second, we gathered information related to the settings where rehabilitation took place (e.g., rehabilitation centre, outpatient physiotherapy department, community health organization, home care), the impairments (e.g., stroke, spinal cord injury, burn injury, traumatic brain injury) and rehabilitation health professions (e.g., speech language pathology, physical therapy, occupational therapy, nursing) that were discussed in each article. Third, we extracted information related to how autonomy was defined, conceptual or philosophic frameworks used, ethical issues reported in relation to autonomy, and recommendations made by the authors related to autonomy. The extracted data were organized into a conceptually clustered matrix following the guidelines suggested by Miles, Huberman and Saldana [33]. Organizing the data in such a format enabled comprehensive storage and easy manipulation. Data manipulation in the analysis included the creation of sub-tables and concept maps [34] to facilitate clustering similar ideas related to the response of rehabilitation health professionals toward patient autonomy. We particularly focused on data related to ethical issues practitioners faced in relation to patient autonomy and recommendations made by the authors on how they managed, or recommended others to manage, different issues of autonomy. Through this iterative process and team discussion, we inductively developed four categories of response to patient autonomy: *supporting*, *promoting*, *respecting* and *advocating* for

autonomy. Before presenting this analysis in detail, we provide a bibliometric overview of the 63 articles retained through our scoping review, and a brief summary of how autonomy was conceptualized across the articles.

Results

Bibliometric overview

The 63 papers included in this review were published between 1987 and 2016, and consisted of 16 empirical studies, 17 case studies and 30 theoretical articles. Empirical articles included both qualitative and quantitative research. Case studies typically examined a specific ethical dilemma arising in rehabilitation services and presented a case narrative. Theoretical papers included conceptual analyses of issues related to autonomy in rehabilitation. The included articles were published in a wide range of journals. Forty-three articles (68%) were published in a rehabilitation journal (21 different journals), 11 articles (18%) were published in a general medical journal (11 different journals), and 8 articles (13%) were published in a bioethics journal (4 different journals).

When viewed from a chronological perspective, more recent articles are increasingly international (i.e., authors are from a greater number of countries), include more empirical studies, and present more diverse theoretical perspectives of autonomy. Articles from 1987-1999 were almost all authored by US-based authors, and were mostly theoretical articles focusing on issues of capacity and consent, or patient-provider relationships. From 2000 to 2009, articles were increasingly diverse in terms of subject matter. Examples include articles on the ethics of safety and risk, autonomy in relation to specific impairments such as spinal cord or burn injuries, autonomy and assistive technology, rehabilitation processes such as goal setting or discharge planning, or specific concepts such as independence or self-determination. They also introduced additional professional perspectives, including nursing, occupational therapy and physical therapy. Articles from 2010-2016 continued the trend of internationalization and increasing rates of empirical research. They included authors from 11 countries and one third of these articles presented empirical research findings.

Of the 63 articles, 41 (65%) did not focus on a specific patient population or age group within rehabilitation. When a specific condition was identified, traumatic brain injury (16% of all articles) and spinal cord injury (8% of all papers) were the most common. Eight percent of the articles focused on children/youth and 19% on older adults. Articles focused on the older adult population often addressed concerns related to discharge planning and making risky choices. Thirty-nine of 63 articles (62%) focused on inpatient rehabilitation, with other papers considering contexts such as outpatient care, homecare, or addressed issues across the care continuum.

Conceptualizations of autonomy

The papers included in our review can be grouped into three broad categories related to autonomy: 1) principlist accounts, 2) rights-based and legal analyses, and 3) relational/social approaches; the principlist approach and its application to ethical issues in rehabilitation or to specific cases being the most frequent [14,19,25,35-49]. A common feature of articles drawing upon principlist accounts is to discuss the principle of respect for autonomy in light of other principles, including beneficence, non-maleficence and, less frequently, justice. Authors take different approaches in arguing for balancing amongst principles, or for prioritizing respect for autonomy relative to other principles, though not all authors argued for this prioritization; Kraft [50] proposes that beneficence take precedence over respect for autonomy. Other articles that drew on a principlist account emphasize the application of autonomy through the practice of informed consent [16,18,20,51], avoiding paternalistic approaches [15,17,18,52] or the use of a fiduciary, education-based model [26,52-59]. The second most common category of conceptual accounts includes rights-based and legal perspectives. Major concerns addressed in articles centering on this approach include case studies related to the rights of incompetent patients, or those with diminished capacity, to make care decisions or refuse treatment [24,60-67], and the evaluation of capacity [5,23,36,37,68-70]. The third conceptual approach to autonomy emphasizes interdependence, family and social relationships, and the social and political location of the individual. It includes relational autonomy [8-13] and patient-centred or family-centred approaches [14,26-30]. The authors of articles that adopted these viewpoints seek to challenge conceptions of the person as an isolated rational decision-maker to actively promote a broader account of agency and autonomy, and negotiated and shared decision-making. Multiple articles in this category also address issues related to divergent cultural perspectives among patients, families and care providers [27,71-74].

Four categories of responses to patient autonomy in rehabilitation

Through an inductive analysis process, in the articles included in this review, we identified four main categories of how authors discuss rehabilitation health professionals' responses to patient autonomy: *supporting*, *promoting*, *respecting* and *advocating*. These categories represent responses to autonomy that are given a positive valence by the authors, often presented as recommendations for health professionals, and sometimes contrasted with approaches that are presented in a negative light, such as acting in ways that are dismissive, disengaged, or overly paternalistic. These categories are discussed in detail below. Recommendations associated with the four responses to autonomy are presented in Table 1.

Table 1. Recommendations associated with the four main professional responses to patient autonomy

Supporting	Promoting	Respecting	Advocating
By acknowledging the importance of relationships • Develop knowledge about family relationships. • Increase opportunity for dialogue between practitioners and patients and choice (informed consent and knowledge about multiple alternatives). • Look for creative ways to include family members in the rehabilitation process. **Through effective teamwork** • Ensure clear communication between rehabilitation team members for how to support patient autonomy. • Be consistent in who is interacting with the patient. • Document the process of supporting autonomy. • Help the patient and their family understand the process and limits of how the rehabilitation team makes decisions.	**Through addressing psychological needs** • Monitor psychological health • Consider referring to professionals offering psychosocial support. • Incorporate an awareness of perceptual and emotional factors. **By providing patient education** • Being responsive to patients' knowledge, values and interests. • Provide information about local resources, the implications of different treatment options and about patients' rights. • Be transparent about how patients' private information is protected, as well as informing them of any potential conflicts of interest between different stakeholders. **Through active participation** • Encourage patients to participate in the decision-making process. • Allow patients to make autonomous choices in daily routines. **Through open communication** • Calibrate communication of information to match patients' and families' information needs and capacities to integrate. • Ensure that patients have sufficient and proper information. • In circumstances involving communication impairment, identify relevant experts who can help develop communication skills.	**Through sound and thorough assessment** • Appraise any evidence that patient wishes and best interests are incompatible. • Select appropriate evidence-based competency assessment tools. • Gather information concerning patients' life situations to help identify alternative ways to engage with patients. • Re-evaluate the role of surrogate decision-makers over time. **Through collaboration and by engaging with different cultural perspectives** • Build trust to develop greater understanding between different conceptions of care. • Include the culturally relevant decision-making unit in the rehabilitation process. • Inquire about specific cultural norms and beliefs. • When an evaluation of capacity is needed, consider patients' history and background, and share this information with the rehabilitation team.	**Through involvement in policy changes that are supportive of autonomy** • Take action within healthcare institutions to encourage policy development. **Through better training for rehabilitation professionals to respond to autonomy** • Advocate for changes to the training of future clinicians. **Through advocating for societal change** • Engage in discussion and debate to draw greater societal attention to health promotion.

Supporting Autonomy

Many individuals receiving rehabilitation services have experienced a sudden life-changing event. Others experience more gradual processes resulting in a loss of function. A major injury, the progression of a degenerative disease, deteriorating functional abilities for individuals with a congenital condition, or the onset of a disabling medical condition may all result in changes to life roles, capacities, identities and goals [14,16,53]. What we identified as *supporting autonomy* are efforts made in light of these changes to foster patients' abilities to make and enact choices that are consistent with their values and their (sometimes evolving) sense of self. Approaching patients in this way is frequently presented in the reviewed articles as an effort or opportunity to go beyond merely respecting patients' choices. This approach includes attempts to create decision-making environments conducive to supporting autonomy. The reviewed articles present two primary contexts for supporting autonomy: within family and social relationships, and through effective teamwork in healthcare settings.

Supporting autonomy by acknowledging the importance of relationships

In the past decade, increasing emphasis in the rehabilitation literature has been placed on the importance of practicing patient-centred and family-centred care, or of using relational approaches to rehabilitation [8,9,12,14,27,30,41,55,60,66]. For example, Hunt and Ells suggest that supporting autonomy requires that those involved in rehabilitation acknowledge "the ways that individuals are interdependent with others for support and care in a myriad of practical and emotional ways" [12, p.964]. These authors also suggest that most people experience relationships as an important resource for autonomous choices and actions. The experience of a disabling condition not only affects individuals with an impairment, but can also result in significant economic and psychological stressors for others in their family and social networks [24,48]. For these reasons, it is important for rehabilitation health professionals to develop a sound understanding of a patient's "local social world" [12, p.965]. Other authors also discuss how patients' social contexts and networks can shape their capacity to make choices consistent with their values and identity [8,14,16,23,27,30,41,52,56,66]. To support autonomy, Dill recommends "increasing the opportunities for dialogue and choice" [8, p.1298]. However, not all patients wish to have their family involved in their care, and patients should be able to make decisions about their family's roles [30,42]. Sim describes that knowledge about familial relationships "may give some indication as to how the professional can mediate between apparently conflicting perspectives" [66, p.8] and as such, rehabilitation health professionals might help patients to look for creative ways of including family members [42].

Supporting autonomy through effective teamwork

The functioning of healthcare teams is also important for supporting autonomy. As teams communicate about how to support patient autonomy, they will be better able to work towards this goal [40,52] and to create environments that are supportive of patients' autonomy. Haas proposes training and counselling for rehabilitation professionals and family members to "maintain consistency on the part of all who interact with the patient" [63, p.13]. Documenting the process of supporting autonomy may also allow health professionals to be "more conscious about their role in the decision-making process and the extent to which their clients' values and wishes were considered" [58, p.309]. Helping the patient and their family understand the process and limits of how the rehabilitation team makes decisions may also be helpful. Caplan and colleagues argue that "patients should have certainties about the nature of authority and responsibility in the provision of treatment" [14, p.316] and should know how the healthcare team will work with them to support their autonomy. This includes working as a team in protecting patients' private information [14]. Effective teamwork in the care of a specific patient requires that "team members know the patient well. Teams that focus on patient identity have a strong foundation for choosing among alternatives in the face of regulatory constraints" [57, p.330]. Effective inclusion, collaboration and communication between the patient, involved family or caregivers, and healthcare team members enable patients' autonomy to be supported.

Promoting Autonomy

Approaches that *promote autonomy* encompass interventions aiming to restore autonomy that has been diminished and to enhance patients' internal capacities to make and enact decisions, including regaining lost capacities or developing new ones. Promoting autonomy includes activities related to skill development, patient education and enhancing participation. The approach to skill development and efforts to enhance capacities for autonomy are presented in the reviewed articles as being shaped by features of rehabilitation, including participatory approaches where patients take active roles in therapy sessions and in setting care goals, the interdisciplinary nature of rehabilitation, and the length of time (often extended) over which therapy takes place [17,23-25,53].

Promoting autonomy through addressing psychological needs

Rehabilitation health professionals can promote patient autonomy as part of the therapy process. There are wide variations in the experiences of individuals with a disabling condition, whether the condition is long-standing or results from a more recent, sudden event. For some individuals, autonomy is limited by a lack of knowledge related to the degree and scope of their impairments, including the extent of their treatment needs [14,16,53], as well as by feelings of ambivalence, expectations that may be unrealizable, or a fear of treatment [65]. Rehabilitation services that include the monitoring of these psychological aspects can help identify opportunities to promote autonomy [8,14,23,25,27,43,50,66], including referral to professionals offering psychosocial support [43], which could include psychologists, social workers, chaplains, and sexologists, among others. Incorporating an awareness of perceptual and emotional factors will also help rehabilitation professionals to promote their patients' decision-making capacities by tailoring their approach to the patients' realities and needs [27,43]. For instance, several authors discuss the 'intermittent interdependence model' [14,16,17,27,47,52], which suggests that "individuals have different methods of adjustment, and each phase of rehabilitation generates choices and strategies for maximizing autonomy and participation" [27, p.972]. This model accounts for the different and sometimes fluctuating types and degrees of a person's impairment. From this perspective, working with patients may require more back and forth between autonomy and paternalism. In other cases, authors suggest that the goal of promoting autonomy over the long term may require letting patients experience feelings of helplessness in the initial phase of rehabilitation [47,53].

Promoting autonomy by providing patient education

Many authors describe patient education as an important aspect of rehabilitation services and a means to promote both functional and decision-making autonomy [10,12,14,16,18,23,53,61]. Durocher and Gibson noted that "incomplete information or the inability to understand information can result in undue persuasion, hindering the client's ability to freely choose among options" [10, p.5]. Considerations for the provision of autonomy-promoting education include responsiveness to patients' knowledge, values and interests [18] and could involve providing information about local resources (e.g., availability of publicly and privately financed homecare or the types of meal services available in a particular neighbourhood), which could facilitate patients being able to consider a wider range of options in their decision-making [10,30]. The provision of information could also involve open discussions with patients and family members (when appropriate) about the implications of different treatment options [26,55]. Autonomy may furthermore be promoted by providing information to patients about their rights [57], including their rights to make treatment decisions and about stakeholders' potential conflicts of interest [8,12,17,20,42,51,71].

Promoting autonomy through active participation

Many authors have recommended adopting a partnership or shared decision-making approach as a means of not only respecting autonomy, but also as an opportunity to help promote or restore the capacity for decision-making [13,17,24,27,44,52,58]. For example, Taylor and Adelman suggest that children who are receiving rehabilitation services be encouraged to participate in the decision-making process as it can help with the acquisition and development of decision-making skills, increase children's sense of independence and encourage understanding of what competency and self-determination mean and feel like [56]. Many inpatient rehabilitation settings are highly structured, however, allowing patients to make autonomous choices in daily routines could be beneficial, especially in relation to tasks that patients value highly [27]. For example, patients with diminished decision-making capacities might be given more latitude to decide about their wake-up time, or which type of recreational activities they will pursue in an inpatient rehabilitation setting [47-49,51,52]. Enacting such choices could promote the ability to make autonomous choices that are more consequential in other areas of their lives.

Promoting autonomy through open communication

Clear and open communication has also been suggested to promote patient autonomy [8,12,19,20,27,30,68,71]. Rochette and colleagues state that "communication abilities of health professionals emerged as a key factor to foster respect and confidence" [30, p.386] in interactions between patients and care providers as well as to access important information that will help promote autonomous decisions [20-30]. Rehabilitation health professionals should seek to calibrate their communication of information related to treatment plans and goals to match patients' and families' information needs and capacities to integrate it [10,20,30], especially for patients with communication impairments who "may have difficulty in conveying their desires and intentions to the health professional" [29, p.5]. In some circumstances, it would be valuable to identify relevant experts, for example speech-language pathologists, who can help develop communication skills to promote autonomy [67]. A strong understanding of patients' values and clear communication can promote patients' autonomous participation.

Respecting Autonomy

The third response to autonomy involves *respecting* (and not undermining) an individual's autonomy, and includes respecting the goals that an individual wishes to pursue, the values they hold to be important, and the choices that they wish to make. The rehabilitation literature also discusses several limits and constraints for respecting autonomy in these ways. Broadly, respecting autonomy is understood as allowing individuals to make choices for themselves without undue outside influence [4,5]. Particular concerns in the rehabilitation literature, however, relate to the justification of actions aiming to persuade or influence patients to make less risky choices [12,58], or of limiting autonomous choices in the early phases after a disabling injury has occurred [47,53]. Caplan reports that a more common challenge for rehabilitation health professionals may not be how to obtain informed consent from their patients, but to determine "what steps and activities, and with what degree of persuasion or even coercion, are morally permissible in the hope of restoring autonomy" [16, p.315]. Two topics that were addressed in relation to respect for autonomy were issues related to assessment and collaboration.

Respecting autonomy through sound and thorough assessment

Strong ethical justification is needed to limit choices [14,16,20,70]; rehabilitation health professionals should remain vigilant so as to not inadvertently undermine autonomy and to "be aware of when and how their actions might result in limiting patient autonomy" [60, p.6]. Given the importance of defining the quality of a person's decisional capacity, assessments can play an important role in respecting autonomy, as these can help determine the scope and degree of a patient's insight and capacity to make autonomous choices. A major concern is that health professionals may assume that a patient's decision-making capacity is weaker than it really is, and thus may limit the patient's opportunities to act autonomously. Caplan and colleagues maintain that rehabilitation health professionals' efforts to assess levels of decisional capacity and competency must be "ongoing and zealous" [14, p.12; 16, p.316]. On the other hand, and in light of the significant and potentially detrimental impact that being identified as having lost decisional capacity can have on patients, considerable efforts must be made to appraise any evidence that patient wishes and best interests are incompatible [18, p.67]. These efforts include selecting appropriate evidence-based capacity assessment tools [5,20,58,63,70]. Mauk states that, at the very beginning of a patient's admission, a careful and thorough assessment should be conducted to gain a sound understanding of "past decision-making patterns or habits" [46, p.64]. Gathering information concerning a patient's life situation, such as their medical condition or the types of assistance to which they have access, may also help identify alternative ways to engage with patients [12]. Surrogate decision-makers will play important roles in the care of patients who are assessed as having limited decision-making capacity or as being incompetent. Given the evolving nature of disability and incapacity for many patients in rehabilitation, in many cases the role of surrogate decision-makers will need to be re-evaluated over time [61,70].

Respecting autonomy through collaboration and by engaging with different cultural perspectives

Authors have discussed respect for autonomy in relation to enhanced collaboration, consensus and problem solving, and engagement of patients in the decision-making process [10,12,58]. Respecting autonomy also entails engaging with the cultural perspectives of individual patients, including expectations and views related to decision-making, interdependence, dependence and families [27,43,73,74]. For example, in some cultural communities, older adults may be less (or not) involved in decision-making processes about their own health; autonomy may also be understood as being collective [27,73,74]. In light of these different perceptions and expectations, several authors propose focusing on building trust among the patient, family and rehabilitation team in order to develop greater understanding between different conceptions of care [73] and with the intent of including "the culturally relevant decision-making unit" within the rehabilitation process [71, p.16]. Mauk recommends that when health professionals are not familiar with a patient's culture, they could ask the patient about specific cultural norms and beliefs [46]. When an evaluation of capacity is needed, the patient history and background should be considered and shared with the interdisciplinary team [46].

Advocating for Autonomy

The final response to autonomy that was identified in the reviewed articles is *advocacy,* which encompasses actions taken by rehabilitation health professionals to address broader social and institutional structures that limit autonomy. Several authors note that advocacy is one of the professional competency areas of many rehabilitation professions [14,18,26,38,39, 58] and that "practitioners have an obligation to appeal to society" [63, p.15], to advocate for adequate responses to the needs of patients. However, not all practitioners feel comfortable with this role [14]. Advocating for autonomy might also create tension or conflict among rehabilitation health professionals, other stakeholders, and/or patients and families [18,66,70].

Advocating for autonomy through involvement in policy changes and training

Advocating for autonomy can involve actions within a healthcare institution to encourage policy development that is supportive of autonomy and to ensure that rehabilitation services are planned, designed and evaluated to better protect patient autonomy [18]. Rehabilitation health professionals might also advocate for changes to the training of future health professionals so that they are better equipped to respond to patient autonomy, including "the utilization of ethical principles to reinforce protection of patients' rights within the rehabilitation treatment setting" [43, p.28]. Some authors noted that it will be difficult for individual health professionals to effect broad changes, and that collective effort is needed; Garlikov and Jackson observed that "it may be beyond the ability of individual care providers or even institutions to effect such changes; but if any changes might be demonstrably effective, then efforts should be made to get larger groups (government, private donation, private labor contributions, etc.) and to bring them about" [39, p.8]. Caplan and colleagues suggested that rehabilitation professionals should advocate for greater societal attention to health promotion [14].

Discussion

As demonstrated by this review, discussions of decision-making autonomy in the rehabilitation literature have been ongoing for over forty years. During this time, the range of perspectives (e.g., from different professions and countries) has widened, as have ways of conceptualizing autonomy. Overall, however, theoretical analyses of autonomy have predominated, with fewer empirical investigations of this topic and a limited number of papers providing concrete recommendations for how health professionals ought to respond to patient autonomy. A challenge associated with this trend is that "philosophical treatments of autonomy typically rely on idealized examples that are far removed from the ordinary actions that make up everyday experience" [75, p.125]. However, many papers brought together careful philosophical analysis with realistic case discussions, presenting implications for practice and policy [5,10,12,14,17,19,20,54,67,68,70].

Only 16 of the articles included in this review examined autonomy using empirical methods; these included social science approaches to investigate patient perceptions and experiences [8,9,11,25,28-30,38,42,47,49,52,53,71,72,74]. While we may have missed other articles due to our search strategy, the predominance of theoretical over empirical research in this area suggests an important gap in current knowledge. For example, many theoretical articles discussed how identity, self-conception and the capacity for autonomy evolved in the time period following a disabling injury, hence how autonomy might change over time. However, there is limited evidence about how autonomy might change or about what persons with disabilities might learn about their own autonomy through the course of their life, or through their experiences of care. This gap may contribute to uncertainty for rehabilitation professionals in how best to respond to their patients' needs in this area. Research exploring the challenges and facilitators to adequately respond to patients' autonomy and explore patient's experiences related to autonomy over the course of their illness/disability or across the rehabilitation care continuum, might shed further light on important aspects of this complex issue.

There is also considerable variation in the rehabilitation literature regarding conceptualization of autonomy, as well as in the vocabulary that is used to discuss them. Collopy described the bioethics literature on autonomy as being characterized by conceptual plasticity, a "loose system of inter-orbiting concepts that trace out the varied paths of self-determination" [4, p.10]. As noted, many terms are used interchangeably in the literature analyzed in this review; this trend may be even more pronounced given the intersection of decisional autonomy and functional autonomy in rehabilitation. This diversity provides a distinctive flavour to the discussion of autonomy in rehabilitation compared to other healthcare domains, and reflects the more holistic approach of this model of care. At the same time, it may give rise to distinctive tensions. For example, when decision-making autonomy is discussed in a narrower sense as self-governance, it may be at odds with the rehabilitation context which requires attention to social and environmental features that shape decision-making possibilities. In contrast, relational approaches to autonomy have greater coherence with these characteristics of rehabilitation care and thus seem particularly relevant.

As demonstrated by this review, responding to patients' autonomy requires effort and diligence on the part of health professionals. There are a range of opportunities for rehabilitation professionals to *support*, *promote*, *respect* and *advocate* for the autonomy of patients with whom they work. These actions are summarized in Table 1 (above). There is also a range of barriers associated with responding to patient autonomy. One of the challenges relates to the creation of sustainable collaboration with patients and their families. Doing so was a central component of how the authors of the reviewed articles described supporting and respecting patient autonomy. Yet, despite rehabilitation professionals espousing patient participation in decision-making as highly valuable, establishing a partnership with a patient and their family is often difficult. For example, participation requires that power dynamics be rebalanced to be more equitably shared between patients and professionals. Clinical encounters will also need to include sustained opportunities for meaningful discussions about patients' goals, values and aspirations.

Features of clinical environments (e.g., the time allocated for discussion, the level of privacy allowed by physical spaces, the scheduling of regular team meetings) also play facilitating or limiting roles for health professionals to get to know their patients, and for providing opportunities to foster their patients' capacities to make their own decisions and enact informed choices. In this way, healthcare environments may fail to be supportive of patient autonomy. For example, the culture of the healthcare context, budget cuts, time constraints and busy caseloads can make it difficult for health professionals to achieve these

objectives [76-81]. Several of the articles in this review discuss these barriers [9,30,51,57]. The empirical research papers found in this review are especially valuable in drawing attention to how autonomy is addressed in real world settings, including institutional or system-level constraints that influence the capacity for health professionals to support, promote, respect and advocate for their patients' autonomy [8,9,29,30,38,42,66,51]. Of the four categories of responding to patient autonomy, advocacy was the least discussed response within the reviewed literature. We note, for example, that little was said about more localized advocacy efforts, such as ways that health professionals could advocate for change within their own rehabilitation centre or hospital to, for example, improve accessibility. Advocacy represents an important opportunity for rehabilitation professionals to address structural and systemic issues that limit autonomy [82-84], efforts that can be directed at more local or broader levels (e.g., developing better advocacy skills among rehabilitation professionals, and highlighting and supporting advocacy efforts by professionals in their clinical context to also address some of the barriers to patient autonomy identified in this review).

Future research

Our review suggests that there are gaps in the current knowledge related to patient autonomy in rehabilitation. We note that settings such as homecare and outpatient rehabilitation have received less attention compared to inpatient rehabilitation. With increasing efforts to emphasize early discharge, community participation and remote monitoring and tele-rehabilitation, it is important to focus on these contexts of care in future autonomy-related research. Some components of the rehabilitation process have also received more attention, including goal setting and discharge planning, and some patient populations have been more extensively discussed (e.g., traumatic brain injury, spinal cord injury and older adults). Widening the analysis to other components of rehabilitation and other groups is warranted. For example, Thomasma has noted that issues related to restoring autonomy are very different in young adults compared to older patients [85]. Also, patients experiencing the effects of a stable congenital impairment, a degenerative condition, or a sudden injury will vary considerably. Analyses that investigate the range of lived experiences will be especially important. Overall, expanded empirical research will also be beneficial, including studies that seek perspectives of different stakeholders, including patients, family, and health professionals. While our discussion of responding to autonomy focused on the actions of health professionals, we believe that it is critical to expand the understanding of patient and family perceptions and experiences. Indeed, future empirical research could include in-depth investigation of how efforts to *support*, *promote*, *respect* and *advocate* for autonomy are experienced by patients and families.

Limitations and strengths

We note several limitations related to this review. The first limitation relates to our two-stage search process. We initiated our search by identifying articles that addressed ethical issues in rehabilitation. We then focused in on those papers which discussed autonomy. This process led to the selection of papers whose primary focus was on ethical dimensions of functional or decision-making autonomy in rehabilitation. However, we were less likely to include articles in which ethical dimensions were a secondary consideration. It is possible that these articles would have drawn attention to other facets of autonomy in rehabilitation. A second limitation to the review is that we limited our search to articles published in French or English as these are the languages understood by the research team. Finally, even though scoping review methodology generally includes both grey and academics literature, we did not review the grey literature. This decision reflected our research question, which sought to assess how autonomy was discussed in the academic rehabilitation literature, and pragmatic considerations related to the scale of the project.

Several strengths associated with our review can also be highlighted. First, the diversity of perspectives on the research team was a strength that enriched the analysis. The seven-team members include individuals with training in the areas of bioethics, occupational and physical therapy, clinical rehabilitation practice, and anthropology. A second strength of our review is that in an effort to be as comprehensive as possible and to explore the concept of autonomy in depth we did not limit the timeline of the search with the earliest articles being from 1987. This approach enabled a thorough examination of how discussions of autonomy in the rehabilitation literature have evolved over time.

Conclusion

The concept of autonomy is understood and approached in multiple ways in rehabilitation. By drawing attention to different ways that health professionals can and do respond to issues related to autonomy, we can help enrich dialogue and discussion about the importance of patient autonomy in rehabilitation relationships, and the roles of health professionals in advancing autonomy. Distinguishing amongst efforts to *support*, *promote*, *respect* and *advocate* helps to provide a more nuanced articulation of these different modes of action and points towards specific approaches that address varying aspects of autonomy. From the perspective of supporting autonomy, relationships are highlighted, including an understanding of how enhanced communication and teamwork between patients, families and healthcare teams can support autonomy. Efforts to promote autonomy emphasize the importance of tailoring responses to individual patients, including communication, addressing patient needs, providing patient education and promoting active participation in rehabilitation and decision-making. Respect for autonomy is likely the most familiar way to frame a response to autonomy in the wider literature. In the reviewed literature, respect for autonomy included considerations related to the completion of thorough, evidence-based assessments in order to not unduly limit patient participation, and by considering patients' cultural and social perspectives. The final approach to autonomy was that of advocating for autonomy, in particular through involvement in policy changes and health professional

training. This approach, however, was the least discussed in the literature, and may present challenges for health professionals who may not feel that they are in a position to inform or enact such changes.

A common thread in all approaches was that of engaging patients and considering their unique contexts. However, we identified few empirical studies examining how autonomy was understood and upheld (or contravened), offering little concrete recommendations related to approaching patient autonomy. Empirical studies are needed to provide the evidence for guidelines and recommendations for clinicians in their approach to patient autonomy and may further broaden how autonomy is conceptualized and upheld in a variety of rehabilitation settings and circumstances.

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Maude Laliberté était auparavant éditrice de section dans *BioéthiqueOnline* (maintenant la *Revue canadienne de bioéthique*). Elle n'a pas participé à la sélection et au processus éditorial. Bryn Williams-Jones, éditeur en chef de la RCB, faisait partie de l'équipe de recherche financée par les IRSC ; il n'a pas participé à cette étude en particulier, ni à l'évaluation ou l'approbation de ce manuscrit.

Conflicts of Interest
Maude Laliberté was previously a section editor at *BioethiqueOnline* (now the *Canadian Journal of Bioethics*). She was not involved in the selection and editing process. Bryn Williams-Jones, Editor-in-chief of the CJB, was part of the CIHR funded research team; he was not involved in this specific study, nor was he involved in any part of the evaluation and approval of this manuscript.

Responsabilités des évaluateurs externes
Les évaluations des examinateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme examinateur n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de *Revue canadienne de bioéthique* assument la responsabilité entière de l'acceptation finale et la publication d'un article.

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