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Résumé de l'article

Introduction : La réadaptation est un service de santé axé sur le rétablissement et le maintien de la fonction et souvent entrepris par des équipes interdisciplinaires. Les prestataires de services de réadaptation sont confrontés à des questions et préoccupations éthiques qui requièrent une attention et une résolution. Les services d'éthique clinique (SEC) fournis par des consultants en éthique visent à soutenir les équipes confrontées à des défis éthiques. L'objectif de cette étude était d'explorer les expériences et les perspectives des personnes qui fournissent des SEC aux équipes interdisciplinaires de réadaptation dans les centres intégrés de santé et services sociaux du Québec.

Méthodes : Nous avons mené une étude qualitative descriptive et interrogé des personnes qui fournissent des SEC dans les 22 centres intégrés de la province de Québec. Les transcriptions des entrevues ont été examinées à l'aide de techniques de comparaison constante et d'une analyse thématique inductive.

Résultats : Les équipes de réadaptation ont demandé des SEC pour résoudre un éventail de problèmes, allant des conflits entre le maintien de l'autonomie et la sécurité du patient aux défis découlant des lacunes structurelles dans les trajectoires de soins. Cependant, les demandes aux SEC par les équipes de réadaptation ont été décrites comme étant beaucoup moins fréquentes que celles des équipes travaillant dans des établissements de soins aigus. Les formes de SEC fournies aux équipes de réadaptation comprenaient l'accompagnement, la délibération éthique et la médiation. Les participants ont souligné les difficultés rencontrées pour apporter un soutien éthique, notamment la visibilité limitée de leurs services au sein des équipes de réadaptation et l'insuffisance des ressources disponibles pour étendre la portée de leurs services.

Conclusion : Malgré les défis qu'ils rencontrent, les consultants en éthique offrent diverses formes de soutien aux équipes interdisciplinaires de réadaptation au Québec. D'autres recherches sont nécessaires pour mieux comprendre l'éventail des questions éthiques qui se posent en réadaptation, ainsi que l'impact que le soutien des SEC peut avoir sur le déroulement des situations éthiques et sur la façon dont elles sont vécues par toutes les personnes concernées.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Clinical Ethics Support Provided to Interdisciplinary Rehabilitation Teams in Quebec: A Qualitative Study

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Résumé

Introduction : La réadaptation est un service de santé axé sur le rétablissement et le maintien de la fonction et souvent entrepris par des équipes interdisciplinaires. Les prestataires de services de réadaptation sont confrontés à des questions et préoccupations éthiques qui requièrent une attention et une résolution. Les services d'éthique clinique (SEC) fournis par des consultants en éthique visent à soutenir les équipes confrontées à des défis éthiques. L'objectif de cette étude était d'explorer les expériences et les perspectives des personnes qui fournissent des SEC aux équipes interdisciplinaires de réadaptation dans les centres intégrés de santé et services sociaux du Québec.

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Mots-clés
services d'éthique clinique, réadaptation, soutien, enjeux éthiques, entrevues

Abstract

Introduction: Rehabilitation is a health care service focusing on the restoration and maintenance of function and is often undertaken by interdisciplinary teams. Rehabilitation care providers encounter ethical issues and concerns that require attention and resolution. Clinical ethics services (CES) provided by ethics consultants aim to support teams facing ethical challenges. The objective of this study was to explore the experiences and perspectives of individuals providing CES to interdisciplinary rehabilitation teams in Quebec health care centres.

Methods: We conducted a qualitative descriptive study and interviewed individuals who provide CES in all 22 integrated health care centres in the province of Quebec. Interview transcripts were examined using constant comparative techniques and inductive thematic analysis.

Results: Rehabilitation teams requested CES to address a range of issues, from conflicts between upholding patient autonomy and promoting safety to challenges arising due to structural gaps in care trajectories. However, ethics requests from rehabilitation teams were described as much less frequent than those received from teams working in acute care settings. Forms of CES provided to rehabilitation teams included accompaniment, ethical deliberation and mediation. Participants highlighted challenges providing ethics support, such as limited visibility of their services amongst rehabilitation teams and insufficient resources available to extend the reach of CES.

Conclusion: Despite encountering challenges, ethics consultants offer diverse forms of support to interdisciplinary rehabilitation teams in Quebec. Further research is needed to better understand the range of ethical issues arising in rehabilitation, as well as the impact that CES support can have on how situations unfold and how they are experienced by all involved.

Keywords
clinical ethics services, rehabilitation, support, ethical challenges, interviews

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INTRODUCTION

Rehabilitation aims to support individuals with a disability or potential to develop a disability to maintain, restore or optimize their functional capacities in interaction with their environment (1). Given this objective, rehabilitative care typically requires a patient's active participation (2). In this sense, rehabilitation care is done 'with' rather than 'to' or 'for' (3). It is also characterized by longer time periods compared to acute care (4,5), whereby patients and rehabilitation providers may work together for months or even years. Patients in rehabilitation may require comprehensive support that includes physical, psychological, social, emotional and vocational dimensions (6). Given the multiple needs of patients, rehabilitation is often delivered by an interdisciplinary team of health care professionals (5). The composition and organization of the rehabilitation team varies depending on the nature of the patient's condition and social needs, and on the structure of the health care organization or program. It is likely to vary between settings, for example home care, a rehabilitation hospital, or an outpatient clinic in the community. The members of these teams may include physical therapists, occupational therapists, speech-language pathologists, psychologists or neuropsychologists, nurses, physicians, and social workers, amongst others (7). An additional feature of rehabilitation teams is that they often reflect a less hierarchical and more horizontal structure among professions (8). Within team-based rehabilitation care, open, frequent and clear communication is emphasized amongst team members and with the patient on subjects such as goal setting and treatment (7,9,10).

Rehabilitation professionals encounter a variety of ethically difficult situations in their day-to-day practices (11-14). Common themes include concerns related to goal setting, team conflict, informed consent, discharge planning, confidentiality, patient autonomy, staff autonomy, patients' risky behaviour or choices, and resource allocation (11,12,15). In the face of recurrent ethical challenges or structural barriers to addressing them, rehabilitation professionals might also experience moral distress and a decline in job satisfaction (12,16), which could potentially result in attrition from the health care professions (17).

A range of strategies are used by teams to respond to ethically challenging situations (18-20). Teams may address ethical issues in the context of team or family meetings, during rounds or in informal discussions. They may draw on institutional or professional codes of ethics or organizational policies, seek input from peers, or solicit support from a coordinator or supervisor (20,21). In some situations, and in institutional contexts where it is available, rehabilitation professionals may seek assistance from a formal clinical ethics service (CES) (20-22). Drawing upon a CES can support the team to work through the situation by encouraging careful deliberation and reflection, providing exposure to alternative perspectives, and facilitating communication (22). These steps can also foster greater transparency and accountability in the decision-making process (23). Even where available, there may be barriers for rehabilitation teams accessing CES, including a lack of familiarity with the available support services, CES members being seen as "outsiders" by teams, or an actual or perceived lack of familiarity concerning the domain of rehabilitation care on the part of the individual(s) providing ethics consultations (24). Facilitators related to CES have also been reported, such as information on how to consult the CES being readily available and the incorporation of ethics education as part of continuing professional development, such as ethics rounds and seminars, which can help professionals be prepared to address ethical issues within their practice (24).

In the public health care system in Quebec, Canada, CES is available to interdisciplinary rehabilitation teams across health care centres. Before 2015, there were 182 separate health and social services facilities throughout the province of Quebec. In 2015, a health care system reform centralized all health care and social services into 22 integrated health and social services centres (named *Centre intégré de santé et de services sociaux)*. Each of these integrated centres consists of multiple health and social services institutions, such as hospitals, long-term care facilities, rehabilitation centres, and community health centres, under a single management structure. Nine of these centres have an affiliation with a university offering health care professional training programs (termed CIUSSSs in French), while the other thirteen are called integrated health and social services centres (CISSSs in French) and do not have a university affiliation. For simplicity, CISSS will be used in the text to refer to all health and social services centres. With the 2015 reform of the health care system and the creation of 22 CISSSs, CES was centralized in each integrated centre, though the form and structure of the CES service in each CISSS will vary. Each CISSS has a single CES structure which is typically based in an acute care hospital, but which has responsibility for all the programs and facilities under the management of the integrated centre. Where clinical ethics consultants are present, their activities include analyzing cases that raise specific ethical issues, developing or providing feedback on guidelines relevant to ethics, and raising awareness among practitioners and staff about ethics (25).

In a previous research project (yet to be published), we conducted focus groups with rehabilitation teams in two CISSSs, as well as interviews with team managers and ethics consultants. We aimed to understand how the teams engaged with ethical issues in their everyday practice. Some clinicians reported challenges and reticence to reach out to CES. To better understand the provision of CES to rehabilitation teams, and to look at this issue at the provincial level, we developed the study reported in this article. This study was approved by the Comité d'Éthique et de la Recherche en Réadaptation et en Déficience Physique du CIUSSS du Centre-Sud-de-l'Île-de-Montréal (MP-50-2022-1513) and institutional approval was received in each CISSS. Our objective was to explore the experiences and perspectives of individuals providing CES to interdisciplinary rehabilitation teams in Quebec health care centres and to better understand in which circumstances and how interdisciplinary rehabilitation teams access CES and what supports are provided.

METHODS

Design and Setting

A qualitative description methodology was used to guide the development of this study (26,27). This approach aims to provide a comprehensive account of a phenomenon using the common language and expressions of those involved (27). Qualitative description is well aligned with the exploratory nature of this inquiry which seeks to describe CES processes, including aspects that might function as enablers or barriers, as well as the types of cases or situations for which CES was sought, from the perspective of the individuals providing CES to interdisciplinary rehabilitation teams in Quebec.

Participants and recruitment procedures

Given our aim to better understand CES provision to rehabilitation teams across the province of Quebec, we adopted quota and convenience sampling strategies and sought to recruit a participant from each of the 22 CISSSs who was responsible for providing CES to rehabilitation teams. These individuals could have different professional designations, such as a clinical ethics consultant, an ethicist, a chair or member of a clinical and organizational ethics committee, or some other form of ethics advisor. As part of the research ethics approval process, we contacted each CISSS to obtain institutional approval to conduct the study in their centre. During this process, the person responsible for granting approval identified one or several individuals who could potentially participate in the study, based on the profile of participants that we were seeking. These individuals were invited to participate in the study, either by the person who granted institutional approval or, at the direction of that person, by a member of the research team. Those who accepted to participate then signed the consent form and the interview was scheduled at a time that was convenient for the participant.

A total of 23 participants drawn from the 22 CISSSs participated in the study. In one CISSS, two individuals requested to be interviewed together as one had recently been hired in the position. Reflecting variability in the structures established across the CISSSs, participants had a range of professional titles. They identified their role using terms including “clinical ethicist”, “ethics consultant”, “ethics advisor”, “senior ethics advisor” and “ethics coordinator”. While all participants mentioned having a background in health (e.g., occupational therapy, nursing, and others), social services (e.g., psychology, social work, psychoeducation and others) or administration, 11 participants specifically mentioned having completed a training program in ethics or bioethics. The median amount of time participants had been involved in CES was 5 years (range: less than three months to more than 30 years). Amongst participants, 21 identified as women and two as men. To simplify the text, the term “ethics consultant” will be used to refer to all participants.

Interviews

We developed an interview guide based on a review of the literature and insights derived from the experiences in clinical ethics of the research team and our prior research on clinical ethics in rehabilitation hospitals. A pilot interview was conducted with a research team member who had previous experience working as a CES provider. This step led to the refinement and reordering of some questions. The interview guide included topics such as the participant’s background in clinical ethics, the nature of their current work in CES, procedures to access CES in their setting, the kinds of CES services they provide to rehabilitation teams, types of situations that had prompted requests for CES, and changes in CES provision stemming from the 2015 health care system reform and/or the COVID pandemic.

All participants signed the consent form prior to participating in the interview. Each participant took part in a semi-structured interview conducted in French or English via an online conferencing platform (Zoom or Teams depending on the preference of the participant) and with a mean duration of 62 minutes. Interviews were conducted by NT and JA who were master’s students at the time of the research, under the close supervision and guidance of experienced qualitative researchers. All interviews were audio recorded and transcribed verbatim by a member of the research team. Transcripts were reviewed for accuracy and anonymization by a different member of the research team.

Data analysis

An inductive thematic analysis approach and constant comparative techniques were used to compare within and between data sources (28). We initiated analysis as transcriptions were completed so that insights from earlier interviews could be integrated or tested in later interviews. The software QDA Miner (QDA Miner and QDA Miner Lite, Provalis Research, 2004) was used for the analysis process. Coding began with two team members independently coding two transcripts, assigning labels to sections of text in response to the questions: “What is going on here? What is this about?”. Coding was compared between the two coders and reviewed with other members of the team. We then established an initial codebook and used it to code the remaining transcripts with small additions or modifications made based on team discussion and consensus. Categories were then created to aggregate codes and identify patterns in the data. Another member of the team, JD, then reviewed all transcripts and coding to ensure coherence and completeness of the analysis that was developed. Excerpts presented in the following sections were translated from French to English, where necessary, by a bilingual member of the team.

RESULTS

Organization of CES

Since the 2015 reform, CES has been available across all CISSSs in Quebec. Overall, participants reported that the services offered in their centre were available to all programs and facilities, though there was a variation between CISSSs in terms of the structures and processes of CES provision. A participant underlined the universality of CES in their CISSS but described how they tailored their response to the needs of those requesting it: "*No, it is always the same set of services. People, they write to me for what they need, then I adapt the services offered in response to their needs, but the service is the same for everybody*." (P19)

In most CISSSs, a single ethics consultant was responsible for providing CES, while in other settings ethics consultants worked in pairs to respond to requests for support. Most participants reported that there was a clinical ethics committee with whom they collaborated, and a few described working with multiple committees, such as an organisational ethics committee and a clinical ethics committee. These committees were typically composed of health care professionals, managers, lawyers, and community or patient representatives. Members included individuals with an interest in ethics or expertise aligned with the specific role of each committee. For example, clinical ethics committees were more likely to include members with expertise in patient care and clinical decision-making, while organisational ethics committees included, but were not limited to, individuals with experience in policy development, administration, and more systemic issues. Participants described the committees as providing input on CES referrals, engaging in mediation or deliberation around particularly challenging cases, offering ethics training for clinicians and managers, and developing or reviewing policies, such as updating the centre's Code of Ethics. Participants also described the visibility of the clinical ethics committee within an institution as resulting in an increased awareness of ethics across their institution.

Six participants mentioned that a "Hub-and-Spokes model" had been or was being implemented in their CISSS. Participants described how this model includes the establishment of a clinical ethics office (the Hub) supported by regular collaborators from across the CISSS with different backgrounds and who were situated in varied locales (the Spokes). Collaborators, also called "ambassadors", or referred to as functioning as "satellites" of the CES structure, were recruited for their interest in ethics and were trained to provide support to the members of teams within their clinical setting who were grappling with ethical issues with the goal "…*that they would be local ethics representatives who could, I imagine, one, increase the visibility [of the CES service] and, two, be responsible for more straightforward cases*" (P4). These participants highlighted that the model of using ambassadors was useful and relevant for their practice, though it was described as still in development in several settings. This form of CES was described as helping clinicians realize, "*OK, we're there, we're in the ethics zone, this is about values.*" As the participant emphasized, this timely recognition encourages clinicians to "*ask for help right away because otherwise the suffering will continue and it will just grow*." (P16)

While CES was present in all CISSSs, it varied considerably in form, and in many cases multiple approaches were used in an integrated manner. Structures such as clinical and organizational ethics committees, hub-and-spoke ambassadors, and satellite sub-committees were described as valuable mechanisms for enhancing the work and reach of CES.

CES provision

Participants described the process for clinicians, including interdisciplinary rehabilitation teams, to seek CES. In some cases, clinicians must first contact their managers who then have the responsibility of requesting CES, while in other settings, clinical teams fill out a webform to request CES. A participant described that they had sought to reduce the administrative steps to access CES in their institution by encouraging clinicians to contact them directly:

> *Many of the preoccupations at that time […] was all the paperwork, uh, it was actually pretty complicated to have access [to CES]. So, to really simplify things for people who have a request, they can contact me directly, by email, on my cell, or using Teams, so we can talk and from there we can look at it together.* (P18)

Once the participants received a request for CES, they assessed if they were best placed to provide support to the team and, if not, redirected the request. A participant described such a situation in which they redirected a team:

> *if I judge that it isn't an ethics case then I redirect that person. […] If the person has a very specific question, for example about confidentiality and charting, and it is a very focused question, then I redirect them to the medical records department.* (P18)

In some situations, the participants reported that they discussed an ethical question with the team prior to the initiation of a formal CES process. If needed, they would set up a virtual meeting to get more details, which might lead to a formal CES consultation, as described above.

If a CES process was initiated, the delay for responding to the request varied based on whether it was assessed to be an urgent situation. For non-urgent situations, participants reported a delay of a few days to a few weeks, depending on factors such as whether multiple individuals needed to be convened to discuss the situation. For urgent cases, the process was initiated within three days of receiving the request. Participants described a range of ways that they provided CES, and that

these approaches were similar for rehabilitation teams and teams from other clinical sectors. The most frequently mentioned approach was “accompanying” (*accompagnement* in French) those involved in the ethically challenging situation through a relatively informal process of coming alongside the team as they work through a particular challenge. Participant 12 described how they “*accompany the clinicians in certain choices and decisions, raise awareness of ethics [… and] support stakeholders*”. Through this approach, the participants promoted a shared exploration of ethical issues with the aim of supporting the team to develop a deeper understanding of the ethical issue and possible responses, and to empower teams through the development of skills and knowledge to navigate ethically complex situations.

The second approach described by participants was to organize a formal ethical deliberation meeting. This meeting typically involved an interdisciplinary group of health care professionals, the ethics consultant, and sometimes other members of the ethics committee, who came together to explore in depth the nature of the ethical challenge faced by the team, consider different perspectives on the questions raised, and evaluate possible responses and the ethical rationales for and against different options. The intent was that following such an exchange, the team would be better oriented and equipped to move forward in their process of decision-making. Following the session, the ethics consultant shared a written summary of the main ideas that were discussed. Several participants mentioned following up afterwards to see how the situation evolved and to provide ongoing support if needed. A participant jokingly described this as offering “*after-sale service*” and that if the follow-up showed that more support was needed, they would not “*back down so long as we haven’t reached the end of it*” (P11) and so would continue to work with the team towards a resolution of the situation.

A third course of action was mediation. In this approach, the ethics consultant typically acts as a mediator among health care professionals who are grappling with an ethical challenge and have conflicting perspectives. Although not all ethics consultants reported that they included patients and families in mediation processes, in certain situations, mediation was conducted with the health care professionals, the patient, and their family:

> *An ethicist very often takes the role of this neutral party, I don’t represent one or the other [perspective], I represent a mediation effort to try and break through that impasse, but in the best interest of the decision makers; the family or the patient in order to move forward in this situation.* (P7)

In most CISSSs, ethics consultants also provided ethics education to clinicians. The focus of these educational activities was often informed by the ethical issues that were raised by clinicians during formal or informal consultations with the ethics consultants, especially when an ethical challenge was identified as recurrent or widespread. In this sense, ethics education functioned as a more upstream means of responding to ethics concerns identified by teams. Educational initiatives included in-service lunchtime talks or webinars, as well as the development of reports or pamphlets on specific ethical issues that were then made available to all staff through the CISSS’s website.

CES requests from rehabilitation teams

Participants reported that they received fewer CES requests from interdisciplinary rehabilitation teams than teams working in other sectors (e.g., acute care, mental health). Strikingly, several participants stated that they had had very few or no CES requests from a rehabilitation team. An ethics consultant reported that they had had only “*one request in four years that came specifically from a rehabilitation professional.*” (P2) In contrast, a participant who worked in a large CISSS with a very active CES reported a high number of requests from rehabilitation teams, though still considerably fewer than from other services:

> *In rehab, we must have, I’d say at least 20 per year, for physical rehab. […] but they are not among our big requestors. Rehab is amongst our low requestors. Our three biggest are support for the autonomy of the elderly, mental health and addiction, and intellectual disabilities.* (P6)

Participants described a range of ethical challenges that were the source of CES requests from interdisciplinary rehabilitation teams. These challenges can be grouped in five main categories: 1) tension between safety and autonomy, 2) gaps in continuity of care, 3) tension between the treatment team and patients’ families, 4) refusal of treatment, and 5) communicating about prognosis.

Situations where clinicians experienced tensions between promoting the patient’s safety and respecting their autonomy were the most common category of ethical challenge. A participant described these ethical issues as “very broad” in scope and gave multiple examples, including situations when a patient drove a motorized wheelchair recklessly, non-compliance with recommendations to avoid a dangerous sport that was contra-indicated due to their health condition, and “*a smoker who puts other people at risk because he was negligent and risked starting a fire.*” (P15)

Issues related to patients’ care trajectories were also frequently reported as ethical challenges faced by interdisciplinary rehabilitation team and prompting ethics consultations. These issues were particularly challenging when there were gaps in available care or uncertainty about discharge options and continuity of care once the patient left the rehabilitation centre.

Third, ethical challenges also arose in situations when there was tension between families and the clinical team, including situations when families opposed recommendations made by the rehabilitation team. In other cases, tension arose in relation to how the patient’s progression was perceived and disagreement about the rehabilitation interventions that were being offered.

For example, a participant described challenges when a patient's functional gains reached a plateau quite quickly: "*patients who have trouble adapting to the situation and sometimes, but often also more with relatives, they do not accept the prognosis and then well, they insist that there are different rehabilitation treatments and services that they should receive.*" (P17)

The fourth category of ethical challenge was situations when a patient refused to participate in some aspect of their rehabilitation. For example, a participant described a situation where a patient declined to participate in certain therapeutic exercises due to fatigue and rejected the suggested rehabilitation plan because he could not understand its benefits. This situation was distressing for the treatment team as they felt caught between respecting the patient's autonomy and their professional responsibility to ensure the patient received appropriate care.

The fifth category of ethical challenge was mentioned less frequently by the participants. It relates to communicating about the patient's prognosis and the likelihood that they would achieve functional gains as a result of their rehabilitation. In some cases, these issues arose in relation to communicating with patients whom the clinical team assessed as having limited potential to benefit from rehabilitation. Clinicians struggled in situations when they felt they had to balance honesty about the prognosis with the need to maintain hope and motivation for the patient, while also managing the emotional impact that such conversations could have on both the patient and their family. This challenge was also linked to constraints in the health care system, including limited resources for rehabilitation and long waiting time for rehabilitation services in some areas. It introduced considerations of equity as clinicians may feel pulled between continuing to provide rehabilitation services for a patient who has reached a plateau in their recovery or taking on a new patient from the waiting list who has yet to receive services.

Factors that support or impede CES for interdisciplinary rehabilitation teams

Participants mentioned several elements that they viewed as facilitating the delivery of CES to interdisciplinary rehabilitation teams. Interestingly, most of the elements that were raised were related to the characteristics of rehabilitation teams themselves. Several participants mentioned that the rehabilitation teams that they had worked with had a "culture of ethics" and took time to talk about challenging cases in team meetings. A participant described that the rehabilitation teams "*share a lot of information, so it's already part of the culture to take five minutes, to sit down, to discuss a situation together. Those teams already have that culture.*" (P22) Participants highlighted the positive effects when teams have support from a clinical coordinator or manager who ensures that there are opportunities to exchange about ethical issues on a regular basis.

Another enabler mentioned by participants was the range of experiences and skillsets amongst team members. This diversity was seen as contributing to rehabilitation teams' capacities to discuss and respond effectively to ethical challenges, as well as working effectively with CES providers. A participant described that for "*the exchange [of viewpoints] at the ethical level. I think the diversity of experiences and perspectives is a plus, I think it's an advantage that these teams have, the way they are created.*" (P8) Participants also described the benefits when there is one or several members of a team who have developed expertise in addressing complex cases: "*Sometimes, I've seen that in some settings there is a person who is seen by their peers as having good judgment or [as having] a well-developed competence in ethics, who becomes an informal reference point for others.*" (P13)

One of the barriers to providing CES was misunderstanding amongst some health care teams regarding the role of ethics consultants and CES. Participants reported that this misunderstanding was not limited to rehabilitation teams but a wider challenge they faced in their work. In some cases, clinicians expected the ethics consultants to take over a situation and provide a definitive answer or quick resolution of the situation:

> *People sometimes expect solutions, a magic solution in the sense that they want "okay, tell me what to do". But that isn't our role. And sometimes you have to clearly define the role we have in terms of [supporting] reflections, but that we won't impose our point of view, because imposing our point of view wouldn't be ethical.* (P9)

In response to this misunderstanding, participants pointed to the value of having ambassadors across the institution who could increase awareness and understanding of the role of ethics consultants and how CES could help health care providers in their centre.

Barriers to CES were also the result of human resource issues and time constraints. Many of the approaches employed by the participants require bringing together stakeholders to deliberate around an issue yet convening them was often difficult due to their varied schedules and extremely high workloads. This situation was also intensified due to high staff turnover in some rehabilitation centres. A participant described the challenge of convening people to discuss ethical issues as being more difficult in rehabilitation settings due to the high number of people involved:

> *The real challenge is to get the clinicians together at the same time [for] 90 minutes, and I find it difficult to do it in less than that for a formal consultation, with stakeholders. To get the stakeholders together, the doctors, the high-level specialists who work in rehabilitation, that's really the main challenge of all this.* (P11)

Features of the CES service or institutional structures also functioned as barriers. Several participants reported that a lack of visibility of CES contributed to fewer requests from rehabilitation teams. The reduced visibility of CES was compounded by difficulty recruiting qualified personnel to CES roles and reduced funding for ethics services in some CISSSs. As a result of these factors, some participants stated that they were alone or had a very small team who were responsible for managing all CES requests. In this light, several participants said that they experienced tensions when trying to engage in visibility efforts for their CES because they worried that if the number of requests increased too much, they would be unable to adequately support the teams making the requests due to a lack of CES resources: "*A barrier is that we are not so well known. But we don't dare to be recognized too much because we will be overwhelmed. And then we don't necessarily have the budget to increase the number of people in ethics.*" (P15)

Several participants also reported that it is important to ensure that the administrative process for accessing CES is not an impediment and that there is adequate flexibility and responsiveness. Generally, participants viewed their services as being accessible and mentioned that they put a lot of effort into achieving this objective: "*Look, first, call me, then I'll fill in the form for you, or I'll explain it to you. As for your ethical challenge, I'll help you structure your thoughts, and then we'll present it to the committee clearly*." (P8) Many participants reported adapting procedures to request CES in order to avoid this part of the process being a barrier to accessing support.

DISCUSSION

Our study describes the provision of CES to interdisciplinary rehabilitation teams in Quebec following a health care reform which mandated and centralized the availability of CES in all CISSSs across the province. Before the creation of the CISSS structure, CES was provided by local ethics committees in rehabilitation hospitals. However, not all rehabilitation hospitals had an ethics committee, and those that did tend to be larger institutions in urban settings and with university affiliations. For those hospitals that had an on-site ethics committee, it is possible that there was greater awareness of ethics support services and more integration into the daily workflow of rehabilitation teams. Following the reform, all rehabilitation hospitals now have access to CES but this is centralized within the CISSS and typically based in an acute care hospital. While this structure enhances broad access, it may also create more of a sense of distance for interdisciplinary rehabilitation teams towards the CES service (especially in settings where this was previously an intramural resource).

While the reform established CES across CISSSs, there remains considerable variability in the way it is organized and deployed. Kaposy et al. (29) described four broad structural models for organizing ethics consultation: 1) the lone ethics consultant model, 2) the ethics committee model, 3) the capacity-building model and 4) the facilitated model. All four are present to some degree across our participants. As is the case in many other health care systems, the first two models are the most commonly used. Alongside these approaches, participants also used the latter two models. In the capacity-building model, the ethics consultant is not directly involved in consultation activities, rather they train ethics committee members or practitioners (29). For example, the capacity-building model can be used to train a team from a smaller hospital in a rural area so that they can manage most ethics challenges independently. Many participants in our study discussed the Hub-and-Spokes model (30) and discussed its current or potential implementation in their organizations. This model is particularly interesting in settings such as the CISSSs with CES based at a central hub but with the mandate to provide services across many institutions, sometimes spread over a large geographic area. It has been implemented in health care organizations to increase access to ethics consultations, share best practices, and standardize consultations across a health care system that includes both large teaching hospitals and small community hospitals (31,32). It also presents risks, including congestion at hubs, which can occur if requests towards the hubs are not well coordinated (33). For example, if a new spoke is created, the hub will have to devote more effort to it, which could affect the service to the other spokes. Other risks include overextension of spokes and staff dissatisfaction if they feel disconnected from the hub. Such challenges can be addressed by assuring good communication and strong linkages between the hub and the spokes (33). The fourth model of ethics consultation, the facilitated model, focuses on convening appropriate stakeholders to participate in meetings to make decisions about ethically challenging situations and ensuring that adequate resources are in place (29). Many of our participants adopted multiple models of ethics consultation in their practice, depending on the circumstances, reflecting a pragmatic and responsive strategy for CES support.

Our findings highlight the adaptability of ethics consultants in Quebec as they sought to facilitate access to their services. Although participants did not describe a standardized procedure across settings, the basic steps were consistent, including clarifying requests, assessing the appropriateness of the request for CES, and subsequently offering tailored services. These steps are similar to the initial phases outlined in the National Center for Ethics in Health Care (23) model for ethics consultation known as CASES: 1) Clarifying the consultation request; 2) Gathering relevant information; 3) Synthesizing the information; 4) Articulating the synthesis of information; 5) Supporting the consultation process (for example, by evaluating how the process is unfurling and making adjustments as necessary). A desire for clear and consistent administrative and deliberative processes has been reported in prior research on clinical ethics committees (34). In contrast to the goal of having a clear set of standardized processes, our findings suggest that flexibility is crucial for responding to the diverse needs of those requesting services and being attentive to their specific situations. Striking a balance between rigorous processes and adaptability is important for successfully providing CES (35). Gaudine et al. (36) underscore the importance of extending CES support not only to health care professionals but also to patients and their families. In our study, participants mentioned the involvement of patients in mediation cases; however, no explicit emphasis was placed on their role or whether requests originated from them.

Many participants reported receiving fewer requests from rehabilitation teams compared to other sectors, such as intensive care units (ICUs), where ethical consultations are reported in the literature to be more common (37,38). Strikingly, several participants had not received any referrals from rehabilitation teams. When requests were received from rehabilitation teams, the most frequent issue that led to these consultations were situations where there was tension or conflict between respecting patient autonomy and protecting safety. This category of ethical challenge included situations when patients insisted on risky behaviours or refused recommended treatments, creating tension between supporting independence and avoiding harm to themselves or others. This topic has been identified as a prominent source of ethical challenges in studies of ethical issues experienced by rehabilitation teams (11-14). Additionally, issues related to the patient's care trajectory, especially during discharge planning and continuity of care, posed significant challenges. Discharge planning from a rehabilitation hospital is especially difficult when services are lacking in the community (39,40). Conflicts with families, particularly disagreements around goal setting and treatment plans, further complicated these situations (39).

The issues identified as giving rise to CES consultations by rehabilitation teams underscore the complexity of ethical decision-making in rehabilitation settings (15). Rehabilitation frequently necessitates sustained and intensive interactions between care providers and patients. This ongoing engagement often leads to the development of deep, complex relationships where trust, understanding, and communication are crucial. Within this context, ethical considerations are intricately tied to how values, goals, and priorities are interpreted, negotiated, and managed within these care relationships (11-14,41). The prolonged nature of these interactions means that ethical concerns can evolve over time, as both patients and providers must continuously navigate shifting needs, expectations, and challenges in pursuit of the best possible outcomes. This longer timeline may also lead to lower use by rehabilitation teams of CES where ethically challenging situations appear more prolonged and less urgent. In contrast, ethical challenges in ICUs and other acute care settings often revolve around time-sensitive and critical issues, including end-of-life decision-making or where complex decisions about life-sustaining treatments need to be made. The urgency and gravity of decision-making in intensive care settings may lead clinical teams to seek ethics support on a more frequent basis.

Certain ethical challenges seem to be generalized across all health care settings, including rehabilitation. These include issues related to communication and interaction with patients and families as mentioned in our study but also elsewhere (38,42). Participants also highlighted concerns about equitable access to care, particularly in relation to limited resources and discontinuity of care, which can create ethical challenges across health care sectors (38,42). Some participants suggested that rehabilitation teams were less likely to access CES due to their ability to resolve ethically challenging situations internally, in particular when the team, or some members of the team, has developed expertise in addressing such situations. Others suggested that some rehabilitation teams did not seek CES because they had less familiarity with identifying and discussing ethical challenges. Both of these observations underscore the importance of developing ethics awareness and moral sensitivity, as highlighted in other studies (20,24,34). Moral sensitivity enables health care professionals to recognize and navigate ethical challenges (43,44). Molewijk et al. (20) conducted interviews with mental health care professionals, including nurses, nursing assistants, social workers, psychiatrists and psychologists. Most appeared to have a general understanding of an "ethical challenge," often using words like "problem," "dilemma," "emotion," "discussion," "reflection," or "thinking around." However, they reported that they do not specifically label such experiences as an "ethical" challenge, referring to it simply as a challenge or a professional challenge. Thus, if professionals have difficulties identifying and recognizing ethical challenges, they may struggle to address these situations effectively but may also be less likely to seek CES support. Doran et al. (21) and Molewijk et al. (20) found that most health care professionals will consult a colleague when they are concerned about an ethical situation. Doran et al. (21) reported, however, that only 38% of participants indicated that they would consult with a clinical ethics committee or another source of external ethics expertise when encountering an ethical issue. Our results show that rehabilitation teams in Quebec infrequently access formal CES, despite efforts to increase flexibility and accessibility of these services, as also noted by Pedersen's study (34). Further research is needed to better understand the development of moral sensitivity in rehabilitation teams and how they address ethical challenges, including knowledge of the role of CES as a potential source of support.

Rehabilitation is not solely concerned with physical or functional maintenance and/or recovery but also encompasses the holistic well-being and integration of individuals into society (2). It recognizes the need to ensure the participation of individuals within their social contexts. Participants in our study suggested that the nature of rehabilitation as a health care service had an impact on how interdisciplinary rehabilitation teams addressed ethical aspects of their work. Some participants mentioned that ethics consultations with rehabilitation teams were more effective because of the interdisciplinary nature of the teams. This interdisciplinary approach allowed for a more comprehensive understanding of the ethical challenges and was supported by the values, beliefs, and principles that underpin the delivery of rehabilitation services (45). Participants also described the ethical culture amongst many of the interdisciplinary rehabilitation teams with whom they worked as being strengthened by their diverse backgrounds and the autonomy they had developed in addressing ethical challenges specific to their practice. Sinclair et al. (46) conducted a study on interprofessional collaboration in rehabilitation teams and highlighted key aspects of team culture, including leadership, care philosophy, relationships, and the context of practice. These authors stated that the core values of the team's culture focused on exchanging information, co-learning/teaching, and shared rather than separate practice (46). These values provide a solid foundation for fostering a culture of ethics within rehabilitation teams, enabling them to support one another when encountering ethical challenges. On the other hand, when there is entrenched or unresolved conflict amongst members of an interdisciplinary rehabilitation team, or when teams are incomplete due to staffing issues, addressing ethically challenging situations will be rendered considerably more difficult (15).

As noted by our participants, the recruitment of qualified personnel and funding for the development of CES varies among CISSSs. The lack of human and financial resources was identified in our study as one of the barriers that made it challenging to meet current and potentially increasing demand for CES. Some participants expressed concern that the CES could be overwhelmed if the demand for their services increased and they thus hesitated to heavily promote the visibility of CES within their CISSS, which typically had several thousand employees, across dozens of institutions, and spread over a large geographic area. Several participants also expressed feeling isolated in their CISSS, bearing sole responsibility for handling all referrals for CES. Collaboration and networking among ethics consultants were emphasized by participants as means to address these challenges and to promote the sharing of resources and expertise, including through a provincial network of ethics consultants to facilitate knowledge exchange and shared professional development opportunities.

Our study has several limitations. Despite successfully recruiting participants from every CISSS in Quebec, several were new to their positions, potentially affecting the depth of the data obtained. We did not undertake member checking with participants but did provide them with a summary of provisional findings while the analysis was ongoing. Our study provides insight into CES provision for rehabilitation teams from the perspective of ethics consultants. To obtain a comprehensive picture of CES within the CISSSs in Quebec, it would be interesting to collect data from other groups of stakeholders, such as patients, clinicians, managers and other staff.

CONCLUSION

Our study sheds light on clinical ethics services provided to interdisciplinary rehabilitation teams in Quebec CISSSs. The ethical challenges prompting requests for CES support include concerns related to patient autonomy versus safety, gaps in patient care trajectories, conflicts between family expectations and team recommendations, refusal of care, and prognostic transparency and communication. Despite encountering difficulties, such as limited visibility and misunderstanding of the ethics consultant's role among teams, the effectiveness of CES is facilitated by experienced rehabilitation teams with a strong ethical culture. However, rehabilitation teams infrequently request clinical ethics support, indicating a need for further research and collaboration between rehabilitation teams and ethics consultants to understand underlying reasons. This study enhances the understanding of CES in the Quebec health care system and suggests avenues to improve support for rehabilitation teams in addressing ethical concerns.

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