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Cover Page Footnote

The research team is extremely grateful to the patients, the parents and the relatives who participated in this research for their time and generosity. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

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Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced

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Abstract

This research focuses on the perception of patients who participated in Continuous Quality Improvement Committees (CIC) regarding their contribution, lessons learned, and challenges encountered. The committees are engaged in a care partnership approach where patients are recognized for their experiential knowledge and treated as full members of the clinical team. Based on patient interviews, we conclude that they bring a structured and thoughtful vision of their experience. They identify themselves as real partners in the care process and are grateful for the opportunity to improve the care provided to other patients by using their own experience and by bringing changes to the patient-professional relationship, particularly in terms of communication. They also become better acquainted with the complexity of the health system and its organization. However, their participation in CICs raised two challenges. The first was their availability, as their professional schedules did not always allow them to participate in meetings. The second was their frustration with the slow decision-making process and implementation of necessary measures for quality improvement of healthcare and services. This study highlights the contribution of successful patient participation to quality of care improvement.

Keywords

Patient engagement, quality and safety management, patient experience, patient partnership, quality improvement committee, quality of care, qualitative method

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Introduction

Over the last decade, patient engagement has been considered critical to improving the quality of care provided by the healthcare system.¹⁻⁸ Patient engagement can be defined as involvement of patients, their families or representatives, in working actively with health professionals at various levels across the healthcare system (direct care, organizational design and governance, and policy making) to improve health and healthcare services.^{9,10} The scientific literature suggests that patient engagement has become a cornerstone for quality of care improvement^{11,12} and is also a frequently stated goal for healthcare organizations aiming to control healthcare costs.^{6,9,12} At the organizational level, there are growing efforts to integrate patients in many areas to improve or redesign

service delivery, by incorporating their experiences¹⁴⁻¹⁶ and experiential knowledge, not only concerning chronic disease but also the services delivered by the system and the healthcare organization.^{12, 17}

Patients' perspectives are unique. Given their first-hand experience of every stage of the care pathway, they are legitimately positioned to evaluate the care and services received, in terms of whether their needs and preferences were met or not.^{18,19} However, quality of care and services was often evaluated by healthcare professionals, while patients' expectations, needs and perspectives, which were remarkably different,^{20,21,22} were not usually well understood.²³

A continuum of patient involvement has been identified, from the traditional view of the patient as a

passive recipient of services, to that of the patient as an integral member responsible for the re-design of healthcare²² in ‘partnership.’ The University of Montreal (UM) is recognized as a pioneer in ‘patient engagement,’ as much in healthcare as in training medical students and in research.^{10,24} Indeed, the idea proposed here is that the ‘patient partnership’ considers patients as full members - partners - of the healthcare team²⁵. They are full-time players in the care process, with expert status based on the skills developed during their experience²⁶ and on their experiential knowledge². This article thus focuses on the program developed at UM aiming to involve patients in quality improvement activities. Our research question was: what is the patients’ perception of their contribution as partners in the improvement of healthcare quality in organizations, while working with professionals as members of continuous quality improvement committees (CIC)?

Patient-as-partner: a new paradigm

For 20 years, paternalistic healthcare approaches have gradually given way to patient-oriented approaches that take into account patients’ differences, values, and experiences²⁷. Healthcare organizations, institutions, and universities around the world are increasing their efforts to involve patients and make their participation active using different forms of engagement²⁵ and various means of motivation.²⁸ However, recent initiatives such as shared decision-making²⁹ and some therapeutic education approaches,³⁰ maintain the healthcare provider’s monopoly on determining the course and outcomes of treatment.

The model of care partnership developed at the University of Montreal goes one step further by considering the patient as a full member of the care team, whose status is based on care expertise.²⁶ In the case of patients who are dealing with a chronic disease that cannot be completely cured, the disease’s evolution is closely linked to lifestyle. As patients have to live with the illness the rest of their lives, their experience becomes a rich source of knowledge essential for decision-making.³¹ The patient partnership is based on patients’ experiential knowledge, which is defined as “the knowledge a patient develops from the experience of health and psychosocial problems, from the trajectory of care and services, and the impact of these problems on his personal life and that of his relatives”³². Thus, from the perspective of patient-as-partner, decision-making and quality care actions are based on both professionals’ scientific and experiential knowledge and on patients’ experiential knowledge of living with the disease³².

Patients can be partners in many ways. For example, in healthcare patients-as-partners interact and share the

knowledge, acquired by their experience of living with the disease and its impact on their lifestyle, with multidisciplinary teams.³³ They also wish to share their experience with other patients to help them get through their episode of care. Such patients are here called resource patients; they are willing to use their experience to improve the organization of the health system.

Partnership in Care Program

To implement this new paradigm, a unit for patient collaboration and partnership (*Direction collaboration et partenariat patient* - DCP) was created within the Faculty of Medicine at University of Montreal, managed collaboratively by a patient and a doctor. This unit’s mandate is to engage patients 1) in medical students’ curriculum and in 12 training programs for health professionals; 2) in research work; and 3) in healthcare services. The inclusion of patients in these three fields is predicated on their partnership and is referred to as the Montreal Model. To carry out these activities, the DCP has trained 180 patients in the patient-as-partner approach.

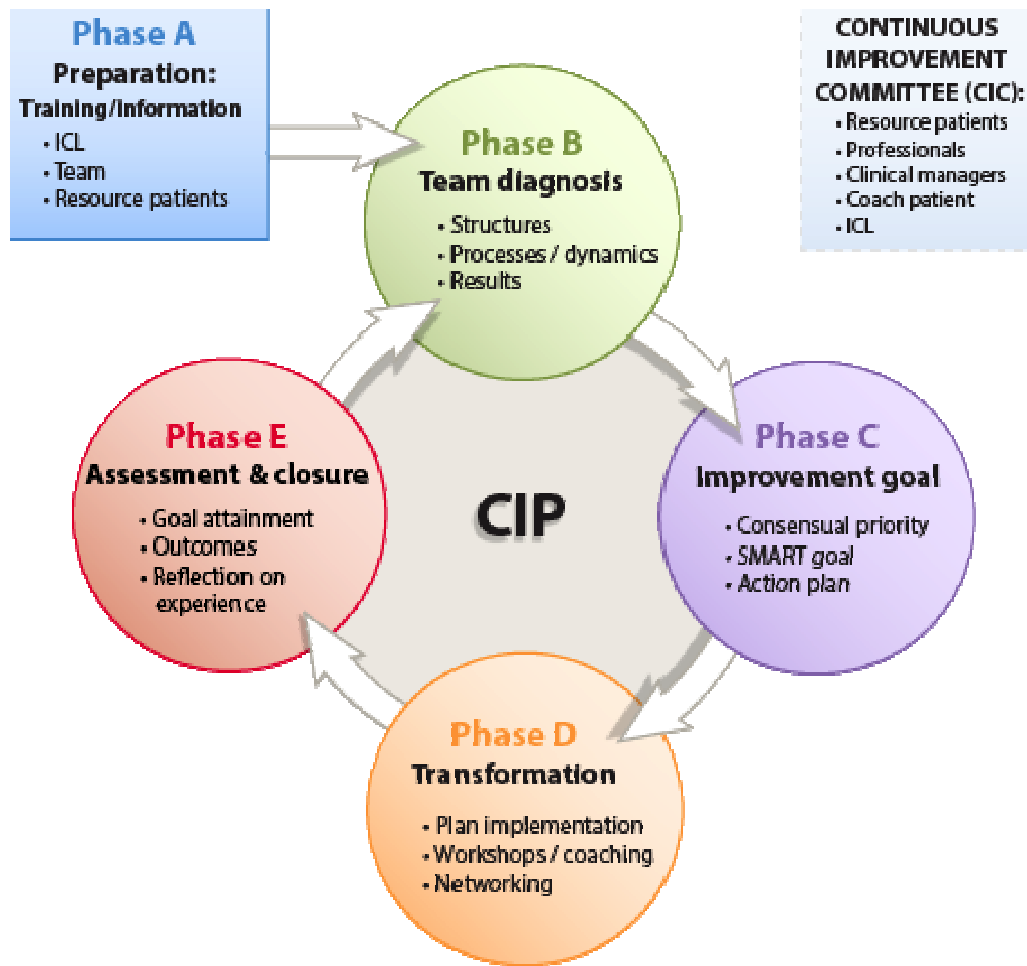
In the context of these healthcare service activities developed by the DCP, the ‘Partnership in Care Program’ (PCP) aims to develop a continuous quality improvement process through the implementation of interdisciplinary committees for continuous quality improvement (CIC), each including professionals and at least two resource patients.^{32,34,35}

Between 2011 and 2014, 26 teams were involved in this program on a voluntary basis in 16 health facilities in Quebec, with patients of different age groups and from various departments: General Medicine, Home Care, Long Term Care, Specialized Care (Mental Health, Oncology, Diabetes, Rehabilitation, etc.); various organizations (university health care centers, hospitals and integrated health and social care organizations) and various environments (rural, semi-rural, and urban). The program was funded by the Québec Ministry of Health and Social Services. The PCP consists of five phases that occur in sequence (see Figure 1).

Phase A: Preparation of Health Institutions

During this phase, the PCP is submitted to the Executive Committee of each institution to obtain a commitment from senior management. In addition, members of the CIC are selected and a doctor–nurse team is identified to coordinate the CIC. Team members consist of professionals and patients. Professionals are representatives of different professions (physicians, nurses, physiotherapists, social

Figure 1. The Partnership in Care Program cycle



workers, etc.) who have been chosen on a voluntary basis. Patient participants are selected by the DCPD from a list of names suggested by their departments, according to special criteria applied to patients with chronic illness: 1) having significant experience of living with an illness and of using healthcare services; 2) being in a period of stable health; 3) having a constructive critical attitude and a certain distance from one's own story; 4) having good personal communication skills; 5) being willing to help people by working with both patients and health professionals; and 6) being available and motivated enough to be involved for the entire duration of the project. Subsequently, the selected patients meet with the UM team to confirm their interest in participating in this type of approach.

All team members (professionals and patients) receive training, provided by both a patient and a professional

from the DCPD, on the concept of healthcare partnership and the recognition of experiential knowledge of patients and/or families. In addition, a patient with more experience in partnership working for the DCPD, referred to as a 'patient-coach,' is available to guide other patients during the process. As for professionals, a leader in quality improvement in the organization assists the team while applying the phases of the Deming PDCA quality improvement cycle.

Phase B: Team diagnosis for collaborative practices in patient partnership.

The DCPD drafts a report on the department where the CIC is implemented, using standardized tools developed by UM, to identify strengths and opportunities for clinical teams in regard to quality of

care and 'partnership-oriented' practices. Clinical teams are assessed on three dimensions, in line with several basic evaluation models in health sciences: 1) team structure and organization, 2) team collaborative processes and dynamics, and 3) monitoring quality indicators. At the end, a report (of approximately 15 pages) is produced for each team, containing the teams' general clinical context, major strengths and weaknesses on the three assessed dimensions, as well as major recommendations. This report is then presented to the Continuous improvement committee (CIC) during its first meeting.

Phase C: Definition of goals for quality improvement

During the CIC second meeting, members comment on the report, make recommendations, and are invited to submit their suggestions for improvement based on their experience within the team and on principles of healthcare partnership. A brainstorming session follows, usually giving rise to dynamic exchanges and discussions on problems encountered, on opportunities to improve the care team or unit, and on proposals to address the problems. Particular attention and reinforcement is granted to the patients' perspectives, which often match the professionals' concerns. After discussion, deliberation, and the exchange of views, priorities are chosen by consensus and translated into a SMART goal (Specific, Measurable, Attractive, Realistic, and Time-bound) that can be carried out in three to four months. Following this phase, the members draft a project development template³⁶.

Phase D: Implementation of action

The CIC carries out the processing activities described in the action plan. A third meeting is held six to eight weeks after the second meeting of the Committee, to ensure monitoring and follow-up of activities. The specific topics covered include: input from a resource patient, distribution of tasks, work progress, inclusion of healthcare partnership dimensions, and coordination between members. If necessary, the action plan may be revised. Meanwhile, to further develop skills and learning related to partnership-oriented practices, UM offers the teams workshops in areas such as training patients to conduct interdisciplinary intervention plans (IIP) and learning how to manage inter-professional meetings. All workshops are facilitated by both an expert patient and a clinician.

Phase E: Assessment of the impact of actions and preparation of a new cycle of improvement

In a time frame of eight to ten weeks following the CIC's third meeting, the team pursues and completes its transformation activities. Four months after the first meeting (phase B), a fourth meeting of the committee is held to assess achievement of goals and share members' comments on their experience in the committee, in a focus group format. Topics covered during this assessment include: facilitating factors (conditions promoting strong inclusion of patients in the committee); obstacles encountered during this cycle and how they have been addressed; learning acquired; direct and indirect impacts of the project; participants' satisfaction and opportunities for improvement. At the end of the cycle, an official certificate of acknowledgment of the team's achievement is handed out in recognition of members' work and as an incentive to continue with improvement cycles. In addition, preparation for the following cycle is initiated.

Materials and Methods

Description of the study

This study was conducted over a period of three months from November 2014 to January 2015, during which all healthcare organizations participating in the PCP completed two cycles of quality improvement. A qualitative research approach was used for this project, based on a set of semi-structured telephone interviews, with patients or patients' parents, about their experience of participating in the CIC and the impact of their contribution on the process of continuous care improvement.

Recruitment of participants

A theoretical sampling approach^{37,38} was used to select and recruit participants. This approach is based on the assumption that 'intense cases,' i.e. patients who participated in a CIC are good candidates for this object of study, as they have a wealth of information regarding their experience.

We randomly selected 16 of the 26 teams to include patients from various healthcare sectors representing 10 different institutions (university healthcare centers, urban healthcare centers, rural and semi-rural healthcare centers, pediatric hospitals).

We then contacted team leaders to ask whether patient members in their teams would agree to participate in our study. The 17 patients and parents who were contacted by the institutions agreed to meet with us. We followed up by email; three patients did not respond despite three attempts to contact them. We thus obtained a response rate of 82% (14/17). The respondents included six patients and eight parents.

They were given the choice of being interviewed by telephone or in person.

Data collection

The interviews were conducted between November 24 and December 5, 2014, and they lasted for an average of 30 minutes (they ranged from 20 to 64 minutes). They were carried out by two members of the research team (MPP/HH). Thirteen interviews were conducted by phone and one in person. The interview questionnaire (see Table 1) consisted of 13 questions structured around three topics: 1) the contribution of participants on professional teams (Q.1-4); 2) the learning from their experience in CIC (Q.5-9); and 3) the obstacles encountered (Q.10).

issue, but also to build a cohesive idea or theory about an investigated phenomenon as it emerges from the collected data.⁴¹

Each interview was digitally recorded and transcribed; none were returned to participants, as all recordings were clearly audible. Transcripts were imported into NVivo 9 for Windows (QSR International) for data coding. In compliance with criteria for methodological rigor in qualitative research,^{38,42} two techniques were used for coding: primary open coding followed by thematic and selective coding. Data analysis was carried out concurrently with data collection, as per the grounded theory approach.⁴¹ Two authors coded the first three interviews independently. After the first

Table 1. Interview Questionnaire

1. How at ease did you feel in joining the Continuous Improvement Committee (CIC)?
 - a. What was your perception of the welcome by the team (respect, language, fairness, and understanding)?
 - b. Have you felt a full member of the team?
 - c. Were you comfortable communicating and enforcing your point of view / your opinions?
 - d. To what extent did you feel that your views / opinions were taken into account by other members of the CIC?
2. What has helped your participation in in the CIC the most?
3. What do you most appreciate about your contribution within the CIC?
4. What are the greatest impacts on patients (users) that will result from objectives set up by the CIC?
 - e. At what degree do these objectives meet the needs of patients (users)?
5. In your opinion, what did you bring to the team / to the CIC?
6. What personal benefits (gains) have you derived from your participation in the CIC?
 - f. What skills have you acquired during this experience?
7. What are the advantages of contributing to “Partnership Care Program” PPS activities at the healthcare facility?
8. What is your overall satisfaction with your involvement in the CIC?
 - g. Meetings of CIC
 - h. Processing activities (implementation of the SMART goal)
9. Have you received support from a patient-coach? If so, what was his/her contribution?
10. What are the greatest challenges/obstacles related to the implementation of PPS activities/the engagement of Resource Patients in the CIC?

All interviews were recorded and transcribed.³⁴ Qualitative sampling requires that sufficient data be generated to adequately explore the phenomenon under investigation. Theoretical data saturation occurred after the first ten interviews when no more new ideas emerged; the four interviews that followed reinforced the stability of the process.³⁵

Data Analysis

We used constructivist grounded theory approach for data analysis.⁴⁰ Like most qualitative analysis methods, grounded theory is based on the concept of emergent themes. These themes are used not only to explore an

phase of primary coding, the group discussed the data and reached consensus on an initial coding tree. Coding categories were discussed and agreed to by all authors; divergent issues were discussed until the group reached agreement.

In a second phase of thematic coding, links between different codes were analyzed and discussed to create a thematic coding structure. Through a constant comparative process,⁴⁰ selective coding was used to generate and refine categories (coding groups), leading to a conceptual map of the patients' perception.

After five interviews, concepts and categories were applied to all interview transcripts. Coding categories were subsequently populated with quotes to ensure grounding of the data and representation across the study sample, thereby providing an integrated account of participants' practices and how they view patient-partnership.

Ethical considerations

This study was approved by the University of Montreal Health Sciences Research Ethics Committee (certificate # 13036- CERES-D).

Results

Our study focuses on 14 patients, whose characteristics are summarized in Table 2. There are 10 women and four men who participated in CIC, eight of whom were parents. Based on interviews, we present the results in terms of patients' perception of their contribution to CIC and of their input to the teams, then we present what they learned during their participation and finally, we report the challenges they encountered during their involvement in the committees.

Contribution of patients to the teams

All the patients perceived CIC as a structured entity that was not demanding and was centered on the search for practical solutions, mainly to improve communication with healthcare professionals through the development of simple and effective tools (Table 2). They also found that the participation of professionals in this process of continuous quality improvement led to a better understanding of patients' expectations and highlighted the interdependence of various professionals within a given situation. The most valuable thing that patients got from participating in the CIC was sharing their vision and experiences regarding the care process and having them taken into account in various ways. For example, Camille considered her contribution as an opportunity to share the *"personal point of view of someone who does not know the system."* Rita also explained: *"I brought my inquiries, my own particular and distinctive vision as a parent of a patient."* Similarly, Sylvie explains, *"I brought the perspective of patients (...) with real examples, with felt experiences."* This perspective is particularly relevant as it comes from the inside:

"When you're a professional, you are trained to listen, but from a professional point of view. However, none of them is the parent of a child with cancer, so, what we bring is the perception of the storm from the inside. When you are an observer of one or more storms, you see phenomena from the outside. Taking the example of a tornado, we see flying things and the whirlwind,

we understand the phenomena, but we are not in the eye of the cyclone. So, I think that what I bring is the perception from inside, such as what you feel when a doctor tells you your child has cancer. Moreover, (...) who is that child? Only his parents know him."
Laurence

Patients also made it clear that the number of years that they lived with a disease gave them a unique perspective worthy to share:

"My experience is of the patient's perspective of the healthcare system, while healthcare providers do not see things the same way as the people who receive the services. My case is special, since I have been dealing with the healthcare system more or less continuously for more than 30 years. I was also part of a foundation; I met with people, researchers. So I think my contribution is complementary." Sophie

Many patients identified the need for means of communication between healthcare professionals, patients and volunteers:

"To identify problems, the CIC developed a questionnaire. I presented our project to volunteers and asked for their help in assisting patients with completing the questionnaire. I was the link between the two." Jacques

Similarly, to establish simple ways and solutions for communication between patients and professionals, to facilitate contact with services, Jeanne said:

"I highlighted a basic flaw in the system: how hard it is for people at home to reach the right person in the right home care service. Up until then, it was almost impossible. The solution was to have a single phone number..."

To meet the needs of families by using simple tools enabling them to track what happens while they are not there, Camille, daughter of a geriatric patient, suggested introducing a logbook to record what has been done with her mother on a daily basis:

"The patient was my mother, and my mother forgets everything. To know what is done during the day, I need details. Practically speaking, it was difficult to find someone to talk to, which made me frustrated and anxious. Eventually, they realized that I needed feedback concerning what was done with my mother, and the idea was to have a logbook for tracking."
Camille

A further area in which the contribution of patients appeared crucial was in the organization of care, which

often does not take human needs into account. Here, in the context of home care, certain actions have a direct impact on personal comfort and the ability to receive effective care:

“Despite the implementation of an intervention plan, the lack of coordination persists. It leads to a lot of wasted effort, for poorly adapted services. For example, baths are given in the morning and not in the afternoon, as patients are tired in the afternoon, while in the morning they are fresh and ready. You have to act accordingly and adapt your services.” François

Learning Acquired by Patients

The main learning acquired by patients concerned their personality and behavior, in addition to learning about their disease and care procedures employed. Their participation also allowed them to improve their communication with professionals.

For the participants, this learning process was supported by the responsive, sensitive, and open climate created by professional members of the CIC:

“I found that the team gave us an important position, and that we were more important than we thought. Although we keep criticizing the system, I realized that everyone wants to change and improve, which motivated me to get more and more involved.” Marie

“Why was CIC created? So that the patient is not at the top or the bottom of a pyramid but rather in a circle, and to open up the communication network, to make patients feel that they can express their needs and that they are involved in their own treatment. Partnership means that all users must be partners.” François

This openness within the CIC has a more direct impact on care and changes the attitude of patients towards their health professional. As Florence observes: *“I realize that we patients have the right to take our place in the decision-making, a more active place.”*

These behavior changes involved patients and professionals taking on greater responsibility to achieve the best results:

“I think that everyone wins through teamwork.(...) The health professionals’ job is to cure cancer, and that of the parents is to rebuild their child. You must get the parents to recognize their own expertise and get professionals to recognize the parents’ expertise.” Laurence

This participation has also allowed patients to develop self-confidence:

“I was in a period where I wanted to have more self confidence and the fact that I was involved in CIC was very beneficial. I had to speak in front of people and I noticed that they appreciated me. It was also mentally beneficial because it kept me busy as I had a job to do and it also allowed me to leave the house and meet people as well.” Aude

Another type of personal learning focuses on the participant’s sense of usefulness, their ability to change and to improve things by communicating on an equal footing with professionals through an experience that was initially painful:

“I learned many things, but for once I felt that what I had experienced served a purpose. I felt I was improving the system for other patients. I really felt I was being useful, giving meaning to something that was originally relatively negative.” Sophie

Participants emphasized that they had developed an ability to listen more attentively and to perceive the important role of family and friends:

“It’s teamwork, I learned to listen to the views of others, and we understand that there may be several points of view on a issue, that of nurses or doctors; and if the rules were well established and we realized that nobody was going to be attacked, we could reach our goals.” Sylvie

“It taught me many things; how it is essential to have family or friends around. I understood my brother’s environment and I forged relationships. I figured out the roles and the importance of each person and of working together.” Rita

Patients also highlighted that their participation in the CIC improved their knowledge of their illness and thereby strengthened their role in maintaining their own health. These experiences helped them become familiar with certain types of terminology and identify different roles in the healthcare process. This generated an awareness of patients’ vital role in the management of their own illness:

“I properly valued my contribution as a patient. I personally discovered my illness. I did not know its cause. I discovered that it was not the health profession that is responsible for dealing with my disease, to make me healthy, but it is my own responsibility, I had to know my illness to work accordingly.” Alexandro

This also led them to change their relationship with healthcare professionals, especially with their doctor:

“My involvement in the CIC had such an impact not just on my own care but also on my relationship with my doctor. The experience has given me more self-confidence to speak frankly with my doctor.” Marie

This learning also involves a better understanding of the internal dynamics of the health system and its complexity. Through their participation in CIC, patients have achieved a better understanding of organizational constraints, the complexity of tasks in the field, and difficulties encountered on a daily basis by health care teams.

“I learned that the process for accessing information from my doctor is more complex than I had thought, and that it is not a matter of just picking up the phone: the nurse has to make a report and forward it to the doctor, who will review it and follow up on my request. This is a complex process and a lot of work will be required to improve it. It's hard, it often seems as if things are prevented from moving forward, we have worked on 20% of the problem, but it's not finished ...” Jeanne

“It was very positive to define simple goals. At first I found them too simple, but eventually I realized that, although refining them is more complicated, it brings great benefits.” Sylvie

Another direct impact on patients from their participation in the CIC is the pride of having helped to improve care and services:

“My greatest satisfaction is when I see a change, while revising a document with the team, that has been adapted according to my comments. That's very rewarding. We see the finished product.” Jacques

We also found that the participants developed, through their learning, a feeling of gratitude towards the institution and the team. They also had the impression of being able to give in exchange for what they had received:

“This is a social commitment to give back to my institution what they gave me, to contribute to a better future. I have the feeling of paying off my debt. I will be eternally grateful for the care of my child.” Lise

And finally, seven out of the 14 interviewees benefited from the support of their coach–patient who prompted and encouraged them to express themselves, to put their views forward, and to articulate their expectations, which helped their learning:

“He helped me express myself and facilitated discussions to make me feel more at ease, that is what I appreciated.” Camille

“He is someone very nice, his presence could be very reassuring, I learned a lot from him.” Sylvie

“It's thanks to her that I was able to talk and open up. She would write me little notes. It's not easy; it made me cry, I had many difficulties in the beginning. It's a very hard exercise.” Jeanne

Thus, people who participated in the CIC were able to identify many positive learning outcomes that gave meaning to what they went through on a personal level and transformed their painful experiences into a source of creativity, sharing, and practical solutions for improving care and services.

Challenges of participation

The main barrier to participation noted by all patients was the time factor. Indeed, they commented not only on the difficulty in finding time for the activities but also on the slowness of decision-making in healthcare facilities.

Regarding the time needed for activities, all patients were aware that it was not only hard for them to find time, but also for professionals. For example, Florence, Sophie, Stephanie, and others noticed:

“I'm very surprised at the commitment of the members; it's not easy to find a time to get everyone together. The real challenge was their availability. But still, it's amazing, as sometimes they joined by phone even if they could not attend. (...) In addition, it's hard to justify to the employer. Otherwise, I see no other obstacles.” Florence

“Basically, the only thing that I had to deal with and that was an obstacle was the issue of scheduling. For someone who works full time, it's difficult to travel to meetings...” Sophie

“For parents, it's the matter of time, depending on their schedules. Some parents cannot take time off. It's hard sometimes.” Stephanie

They also expressed a lot of frustration regarding the time taken by teams to reach decisions and regarding their own lack of familiarity with operational procedures in health facilities.

“The greatest obstacle in any movement for change lies in those resisting change who want to continue doing things the same way. Sure, it takes some time, but it is also important to show that new ways are being implemented.” Sylvie

“I realized how resistant the structure was. It took a lot of energy for people to endorse a project. They fought

and fought and nobody came on board. There was little support. I saw a resistance to change within the organization, professionals were like fighters united in a sea of resistance to change.” Sophie

“The first obstacle is the hospital environment. We don’t know the rules or the mechanisms from the caregiver’s perspective. I was completely lost. I didn’t know who was managing the project, etc. I find that they are not moving at the speed that I want or that I would expect.” Laurence.

Another challenge reported by patients concerns change management and the availability of sufficient resources to implement desired transformations, as highlighted by Marie: *“I suggested changing the furniture in the rooms, but this was not possible due to lack of resources ...”* Rita takes up the same idea:

“The biggest issues are austerity measures, financial resources, human resources and will. Especially in these areas undergoing cuts, the challenge is to have people in place to be able to carry on...As for barriers to patient involvement, there are those who do not have families or are not able to express their needs. I think of my brother, I have to look after him, but I changed and told myself I have to take the time to take care of him. We are not there to watch, we have to get involved in different ways. To try to communicate frequently with them.”

Another barrier that was revealed was the communication skills of those involved in ‘continuous improvement activities.’

“I think that in neonatology, certain criteria must be taken into account before selecting parents and patients to participate. There was a dynamic that developed between me and the other mom; I have a Master’s degree and she is a lawyer, which facilitates the exchange of ideas. While, for example, those who are timid, are afraid to speak or of being judged would not be a good choice. The personality of the parents can become an obstacle. I have not noticed any other obstacles.” Lise

Discussion and Conclusion

The aim of this study is to gain an understanding of patients’ experience as partners in quality improvement committees, by presenting their perceptions of their contribution to quality teams, of their learning, and of the challenges encountered during the process.

It is interesting to note that, although patients had different healthcare experiences and came from different health facilities, there were no significant

differences in their perceptions, which led to reaching theoretical saturation quickly. However, a limitation of this study is that it focuses only on patients’ perceptions. It would have been interesting to conduct a cross-analysis with professionals’ perceptions.

Our results corroborate studies carried out in other contexts that demonstrate the appreciation of patient participation in quality committees.^{43,44} However, our results go beyond these studies, as they show that patients did not only feel ‘listened to’ or ‘heard,’ but had the sense of being full members of the team, contributing on an equal footing with professionals while analyzing dysfunctions, choosing themes to prioritize, searching for possible solutions, and implementing them. Sometimes patients even took the lead in choosing themes and suggested solutions that were, in many cases, simpler to implement than those proposed by professionals.

Another particularity of this study is that there was no problem recruiting patients, even though strict selection criteria were applied, such as their ability to be objective concerning their illness and period of care, their ability to speak in public, and their availability to attend meetings. These criteria are different from those found in other articles,^{45,46,47} particularly with regard to the reflexive capacity of the patients involved. This reflexivity seemed to enable patients to work together with professionals and to get the professionals to respond in kind. This mutual contribution of professionals and patients also had an impact on their relationship. It was found that patients had a desire or a need to give back, in some way, what they had received from the system. Patients were motivated and felt privileged to participate. Thus, contributions provided by patients and families created a healthcare partnership with professionals that led to practical solutions rooted in their experiences.

Such a positive perception by patients of their involvement is probably due to the CIC’s particular context. In fact, this participation is part of a broader model, referred to as ‘the Montreal model,’¹⁰ implemented by the UM, which has developed expertise in getting professionals to work in collaboration with patients in clinical practice,³² in training health professionals,²⁴ and in research projects.¹⁰ This has been made possible notably by having patients select other patients, by having patients jointly train patients and professionals, and by recognizing the complementary scientific and experiential knowledge of professionals and patients.

Another important dimension highlighted by patients was the change in their relationship with professionals and the health system as a direct result of their participation in the CIC. We also sensed in this case

that these types of activities can become meaningful in the therapeutic process of mourning and acceptance of a life without illness. All of this enables patients to continue their self-reflexive work and to move their relationship with professionals to a more equal footing, on a partnership basis³³. And finally, their participation in CIC gives them a better understanding of the complexity of the healthcare system and thus of the environment they are dealing with.

However, patients were particularly frustrated by the slow pace of decision-making and of implementation of quality improvement actions. To our knowledge, this study is one of the first to illustrate the gap between the time recognized as reasonable by patients to make changes and the time, perceived as reasonable, taken by healthcare organizations. This gap may be a cause for patients' lack of motivation. Therefore, it is important for professionals to keep in mind the feasibility of decisions taken with patients and the possibility of implementing these decisions within a reasonable time frame, so that patients can see the effects of their involvement as soon as possible.

In conclusion, patient involvement in quality committees is complex. This research shows that a change in the philosophy of patient-professional relationship beyond patient centered-care to engagement or even partnership in healthcare services, recognizing the patients' experiential knowledge and their role as full members of the team, becomes a powerful lever for service quality improvement. It also shows that the contribution of patients to this approach depends on selecting patients well and training the whole team. The PCP experience can be a source of inspiration for healthcare organizations wishing to change their philosophy of care and willing to benefit from their patients' experience to improve their processes and results.

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Table 2. Patients' characteristics

Aliases	Resource person	Sex	No. of yrs w/disease	Unit/ Program	Type of Healthcare facility	Nature of the Project	No. of cycles of involvement in CIC
Marie	Patient	F	6 y.	Family Medicine Unit FMU-FMG-Cree (mental health)	Urban	Developing a welcome process and tools to inform patients about the clinic's operating procedures (residents and trainees' rotation, filmed interviews, etc.) and to accept terms smartly, as care and education partners.	2C
Alexandro	Patient	M	11 y	Hemodialysis	Urban and University	From the perspective of care partnership, conduct a survey of patient needs for at least 30 patients (20% of total no.). Monitor the out-patient hemodialysis unit, compiling and analyzing the results.	2C
Jeanne	Close	F	16 y	Family Medicine Unit FMU/home care	Rural	Design a sheet dealing with a fast access procedure, for physical needs of users whose medical care is provided by the FMU	2C
Rita	Close	F	3 y	Long term care & Nursing home	Urban	Develop a process to facilitate the involvement of residents and their relatives in the development of their intervention plan.	2C
Camille	Close	M	7 y	Geriatrics	Urban	Develop and implement a 'log book' to facilitate communication between patients and families and stakeholders in the geriatric unit, for the purpose of care partnership.	2C
Stéphanie	Mother	F	3.5 y	Transplantation hematopoietic cells	Urban – Pediatric University	Remake all documentation submitted to families during the entire transplant process, from notification until returning home.	3C
Laurence	Mother	F	11y	Transplantation hematopoietic cells	Urban – Pediatric University	Remake all documentation submitted to families during the entire transplant process, from notification until returning home.	3C
Sylvie	Mother	F	3 months	Neonatology	Urban – Pediatric - University	From the perspective of 'how to look after the baby together,' co-develop a survey questionnaire to collect care partners' perceptions on 'what parents can do' in neonatology	2C

Aliases	Resource person	Sex	No. of yrs w/disease	Unit/ Program	Type of Healthcare facility	Nature of the Project	No. of cycles of involvement in CIC
Florence	Patient	F	5 y	Thyroid cancer	Urban and University	Make a customer satisfaction survey on the diagnosis of thyroid cancer and present the results to the members of the thyroid cancer interdisciplinary team	2 C
Aude	Patient	F	25 y	Day hospital	Rural	Outline and complete patient's transition process from the referring service (Psychiatry 8th floor in-patient unit, emergency room, or treating psychiatrist) to the day hospital, to facilitate patients' integration into the day hospital, by promoting a sense of continuity and security, in a partnership perspective	3C
François	Close	M	30 y	Home support	Rural	Define categories of essential information to be shared on a regular basis between patients, professionals, and stakeholders, as well as possible formats for information dissemination in the context of homecare and care partners.	3C
Sophie	Patient	F	30 y	Inflammatory bowel diseases	Urban and University	Implement 'interdisciplinary intervention plan' IIP meetings in the presence of a patient and/or relatives, if desired, for patients with inflammatory bowel disease from a pediatric hospital or having a complex clinical situation at a bio-psycho-social level	2C
Jacques	Patient	M	9 y	Transplantation hematopoietic cells	Urban and University	As part of the out-patient hematopoietic cell transplant team, in preparation for medical visits: 1) Create a tool for patients and their families to identify symptoms and concerns; 2) Develop a tool for patients and families to update their forms.	3 C
Lise	Mother	F	2 months	Neonatology	Urban – Pediatric University	From the perspective of 'how to look after the baby together,' co-construct a questionnaire to survey the perception of care partners on 'what parents can do' in neonatology	2C