



Editorial

For research rooted in the everyday reality of patient experience[☆]

1. Introduction

More than ever, patients want to play an integral role in their care. With the advent of interactive online tools, many of them use social media, blogs, and discussion forums to express themselves, quickly get answers to their questions, and manage their health online (Brouard, Bardo, Vignot, et al., 2014; LaCoursiere, Knobf, & McCorkle, 2005). No matter their level of autonomy and engagement, several express the need to better understand their diagnoses and the treatments they receive, know how to recognize their symptoms so they can react effectively, and be informed of alternative solutions to the recommended treatments so they can make informed choices (Woolf, Zimmerman, Haley, & Krist, 2016). An increasing number of patients wish to engage in a meaningful dialogue with health care professionals (Ledema & Angell, 2015); however, not all patients are in agreement. Some have difficulty expressing themselves and overcoming the dynamics of inherent inequality of dependence, power and knowledge between themselves and health care professionals (Fainzang, 2006). Consequently, supporting patients so they can become partners in their care is at the heart of contemporary issues in training and clinical practice in order to adequately meet the actual needs of patients and those of their loved ones (Lathlean, Burgess, Coldham, et al., 2006; Tremayne, Russell, & Allman, 2014).

The definition of the concept of “Patient partners” has evolved over the years, at the same time as a better-informed public began to exercise its rights, to gradually encompass more democratic and egalitarian principles (Gallant, Beaulieu, & Carnevale, 2002). In the current definition, patients are considered partners in their care. They are awarded the status of caregiver and expert in the organization of care (Comité sur les pratiques collaboratives et sur la formation interprofessionnelle (CPCFI), 2013). Patients' experiential knowledge and health care skills are recognized as equally valid as the experiential knowledge and expertise of health care professionals. The concerns of the health care team, previously centered on patient needs, are now centered on accompanying them towards the achievement of their life plans (Comité sur les pratiques collaboratives et sur la formation interprofessionnelle (CPCFI), 2013; Paul, 2012). The involvement of patients as partners in their care is recognized as a way to facilitate informed decision making in patients and preserve their human dignity and quality of life (Pomey, Flora, Karazivan, et al., 2015), yet its practical implementation in the field has been slow to become generalized. This despite the fact that empowering patients so they become partners in their care is highly desirable at the various stages of the continuum of care. Professionals also benefit, as they are more satisfied with the care services they

provide since interventions and clinical tools better meet the needs expressed by patient partners (Commission européenne, 2012; Pomey et al., 2015).

The higher level of engagement expected of patients as well as innovations in telemedicine and online communication now lead us to view the roles of professionals differently and to train them to support patients so the latter can learn to share their experiences and their experiential knowledge, make the decisions that affect them, and exercise leadership with regard to their health (Brouard et al., 2014; Comité sur les pratiques collaboratives et sur la formation interprofessionnelle (CPCFI), 2013; Lecocq & Lefebvre, 2017). However, the literature tells us little about the ways in which professionals can actually support patient partners in their bid for autonomy, nor does it help clearly define the outlines of the approach from the perspective of patient partners and of their family caregivers (also defined as partners) (Johnsen, Bjerg Eskildsen, Thomsen, et al., 2017). In this regard, academic settings and researchers increasingly rely on the new role of patients as partners in research to further develop knowledge in the field. As experts in living with disease and of the organization of care, patients as partners in research are viewed as the ones who can best communicate theirs and their loved ones' reality, interests, and needs (Johnsen et al., 2017; Orthmann, Rosler, Helbig, et al., 2017; South, Hanley, Gafos, et al., 2016).

This article aims to highlight the driving force of patients' participation as partners in a collaborative research carried out by the *Nursing network, a partner in care* (RIUPS) of the Université de Montréal (UdeM): *Developing a clinical innovation in oncology: For a better continuum of care and services for cancer patients*. A short review of the literature on patients as partners in research is first introduced followed by a description of the RIUPS project, and a patient support tool developed through the many exchanges and cooperative work of nurse clinicians, patients and researchers from the research team. The article concludes with the presentation of a model, in progress, of engagement of patients as partners in research.

2. Patients as partners in research

Researchers are relying more than ever on the involvement of patients as partners in research through various forms of engagement, as shown in numerous scientific studies (Ledema & Angell, 2015; Orthmann et al., 2017; South et al., 2016; Woolf et al., 2016). The partnership with patients in research can take many shapes, such as collaborating on the research design, its implementation and assessment, as well as sharing and exchanging knowledge through scientific

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activities (South et al., 2016). In the same ways as all other members of the team, patient partners are considered co-authors of the project. They are full members of the research team and participate at every step, from planning to knowledge dissemination (Lefebvre, Brault, Levert, Roy, et al., 2017; South et al., 2016; Woolf et al., 2016). They contribute to the initial formulation of research questions and ideas, the choice of outcome measures that are relevant and meaningful for patients, the resolution of ethical research dilemmas, the communication with patients, their recruitment, the collection and analysis of data as well as the dissemination of findings to the patient partners, the public, health care professionals, and researchers (Crocker, Boylan, Bostock, et al., 2016; Johnsen et al., 2017; Woolf et al., 2016).

In addition to playing a key role in several aspects of the project, patients as partners in research occupy a central position as experts on health care and the experience of living with the disease (Crocker et al., 2016; Ledema & Angell, 2015; Lefebvre et al., 2017). They contribute by sharing their knowledge of life with the disease (Lefebvre et al., 2017), service delivery, and the organization of services (e.g., wait times, intake process, discharge process, physical environments, communication of information) (Ledema & Angell, 2015; Pomey et al., 2015). As experts on living with the disease, their involvement results in the development of protocols that are based in the everyday reality of patients and their loved ones, which leads to the transformation of the research agenda and its perspective (Crocker et al., 2016; Lefebvre et al., 2017). They help motivate and encourage enthusiasm in researchers (Crocker et al., 2016), and their participation maintains the focus on the actual needs and the current concerns of patients (Lefebvre et al., 2017).

Enlisting patients as partners so they become actively involved in research implies that the research team must communicate effectively, in a respectful, open, collaborative manner and truly welcome the presence as well as the involvement of patient partners. Patients, clinicians, and researchers have the possibility of contributing, through their own stores of knowledge, to the co-construction of a shared research vision. The relationship that develops between partners is part of a dynamic process of interactions and co-learning in conjunction with exchanges of information (Lefebvre, Brault, Roy, et al., 2018; Lecocq & Lefebvre, 2017). The collaborative project conducted by the Nursing network, a partner in care (RIUPS) adheres to these research principles.

3. Description of the RIUPS project

The aim of the RIUPS project, an exploratory study which relied on a collaborative research design (Paillé, 1994), was to develop, implement, and assess an interactive web technology, the *Forum for Knowledge Exchange* (FKE), to support health care teams and contribute to the improvement of the continuum of care and services in oncology. The project called upon six (6) clinical teams from university hospital centers and integrated health and social services centers, both urban and regional (primary, secondary and tertiary care), which provided diversified oncological populations (adults, pediatrics, mental health with expertise in hospital discharge planning and care transitions) and types of cancers treated (e.g., breast cancer, pancreatic, acute myeloid leukemia). Its partners, bringing together researchers ($N = 4$), nurse leaders from clinical settings ($N = 6$), patient partners ($N = 4$), and professionals from the project team ($N = 5$), contributed to the co-construction of the FKE and supported its use as well as the realization of the collaborative work in the participating clinical settings in order to improve hospital discharge planning and transitions during the care process of patient partners (Lefebvre et al., 2018). Partners met on a regular basis as members of a knowledge user group (KUG) to share their experiences and solve the multiple problems associated with hospital discharge planning and care transitions in oncology. The project was assessed in spring 2016, an evaluation which relied on the analysis of the documentation necessary to the operationalization and promotion of the FKE by teams of leaders, on observation of the KUG

meetings, and on twenty-one (21) interviews conducted with the project's nurse leaders ($N = 7$), administrators from partner institutions ($N = 8$), and patient partners ($N = 6$). These findings shed light on the significant contribution of patients as partners in research, including providing a new outlook on hospital discharge planning and care transitions in oncology from the point of view of patient partners and their loved ones. This contribution led to the creation of a tool to support patient partners in order to improve transitions throughout the care process in oncology and support patients' bid for autonomy so they can become partners in their care. For the detailed description of the project and findings, see articles (Coulter, Parsons, & Askham, 2008).

3.1. Contribution of the patient partners in the RIUPS project

Patient partners¹ participated in numerous project activities. They were actively involved in the regular meetings of the KUG (2 to 4 patient partners per meeting) and contributed to decision making regarding the project methodology, to the resolution of difficulties related to implementation, and ideas on strategies to mobilize clinical settings. They participated in the co-development of the architecture and content of the FKE as well as in the planning of the activities associated with the platform. They co-produced video clips on various themes (e.g., living with cancer and its treatments, the prospect of death, fatigue, role of the patient as partner), made presentations during two one-day conferences organized by the RIUPS, participated in webinars, in visits to clinical settings, and in symposiums and conferences. Some wrote content, shared articles, or participated in discussions on the FKE.

Their active participation in the research was the driving force of the project and helped mobilize partners around collaborative work. Even though several administrators and nurse leaders interviewed sometimes felt unsettled by their remarks, they nevertheless appreciated their frankness, emphasizing that patient participation led to a fresh way of thinking and clarified certain things, which in turn led to innovative ideas or even opened up new perspectives on the standardized ways care is approached. Patient participation also raised awareness of patient needs throughout the care process and of their expectations regarding the health care system. Researchers, patient partners, and leaders from the clinical settings learned to communicate and work together without feeling threatened.

Patient partners recognized the positive effects of their participation, some mentioning a greater capacity to maintain emotional distance from the experience of cancer or even a better understanding of the functioning of the health care system. One patient partner appreciated being able to step outside the role of patient and leverage, during project activities, his personal and professional skills and expertise.

3.2. Creation of a tool to support patient partners during care transitions in oncology

The RIUPS project's many discussion forums raised awareness and informed partners of the multiple challenges associated with hospital discharge planning and care transitions as well as the importance of finding solutions, in addition to encouraging discussions on the use of conclusive data. They led to the creation of a common discourse on certain aspects of the practice and to an awareness of different perspectives and administrative practices related to care. The project was

¹ Of the eight (8) patient partners recruited, 3 men and 1 woman were very active (two men were referred by the *Direction partenariat et collaboration patients* of UdeM; one man was referred by a nurse leader, and himself referred a woman who was on a committee with him). The three other patient partners were recruited by the clinical settings; two participated, on occasion, in activities organized by the project, and two others never participated (1 because he went back to school and the other because his team never met after he was recruited).

tested and revisited in light of the issues encountered in the clinical settings and the insight patient partners brought to these challenges, which gradually led to changes in outlooks on the ways to comprehend hospital discharge planning and care transitions in oncology from the point of view of patients and their loved ones. Partners gradually agreed that it was important to provide patients with the opportunity to ask questions and request information from professionals on areas of concern, and to encourage the latter to focus on the needs and expectations of patients. While respecting the pace of each individual (finding the right moment to intervene), it was important to support patients who were hesitant to assert themselves, inquire, or ask their questions by providing a way for them to exercise greater control over their health and their experience of living with the disease, in close collaboration with health care professionals, so they could become partners in their care. A project to improve hospital discharge planning and care transitions in oncology began to take shape, the approach culminating in the development of a tool to support patients viewed as partners in the oncological care process.

3.2.1. The development process of the tool

The development of the support tool relied on the model created by Van Meijel and collaborators (2004; 22), which guides the development and validation process of complex interventions, in particular those where the experience of patients and their loved ones plays a determining role. This model served as a framework for the co-construction of the tool at different stages of its development, from defining the problem (e.g., exploration and verbalization by the patient partners of the difficulties faced throughout the oncological care process), creating a first outline of the intervention (tool developed in stages that were supported by the literature), establishing the foundations (guiding principles of the tool), determining the when and how of its implementation (e.g., prioritizing the professional approach, organizational aspects to consider in order to provide support), to analyzing its validity and feasibility.

The development process was initiated, on this foundation, within the framework of a discussion forum on the FKE, which led to 115 interactions bringing together nurse leaders, patient partners, and researchers ($N = 14$ participants) with, alternately, in person meetings of the collaborative committee ($N = 5$ meetings). A list of themes and sub-questions was first created by a patient partner in response to a first question posed in the Forum: **What are the most important questions/needs/concerns of cancer patients that should be addressed by the tool?** The list was commented and reworked, and questions, of a specific and general nature, were added. Here are a few examples: **Are there other aspects not included in the list that should also be considered? How could the list be organized according to the different stages of the patient's care process? What are the needs of patients at the time of the announcement of the diagnosis that the tool should meet? What are the aspects that the tool should include at this stage regarding the professional's approach and the organization of care in order to provide optimal support?** Scientific articles were gradually recommended to further reflection (e.g., taxonomy of the announcement of the diagnosis, reflection on the notion of survival). A shock video was shared, depicting a difficult return to the home in order to encourage discussion on the optimal support that should be provided, accompanied by questions: **What are the most important needs of patient partners upon their return to normal life once the active treatment stage is completed? What are the thoughts of our patient partners? How can you, as clinicians, help at this level?** The order of the questions was reorganized, as were the questions themselves, and some were deleted or reworked.

Lists of questions were gathered in tables for each of the stages and transitions of the care process, in light of the experiences of the patient partners, the experiential knowledge and expertise of the nurse leaders, and the scientific expertise of researchers. These lists were submitted to colleagues in the field and the comments that were collected were discussed on the Forum and during in-person meetings. The tool was

improved accordingly. A draft of the tool was developed, commented on, and improved, as was a humanist collaborative support approach to guide, inform, and reassure patients throughout the process. The wording of the tool, its format, and the content of the tables by stage and transition in the care process were discussed during in-person meetings of the collaborative committee. These meetings were considered essential by the partners, who agreed that they anchored the thought process and helped maintain motivation.

3.2.2. Description of the support tool

The aim of the collaborative support tool is to fulfill patients' need for information and equip health care and social services professionals in terms of approaches, strategies, resources, and organizational support so they can meet this need. It seeks to address all the questions and concerns of patients considered partners and their family caregivers may have at any given stage in their care or during the transition from one step to another, as well as the concerns of the health care professionals involved in their care (e.g., nurses, doctors, pharmacists, social workers, psychologists), and of the organizations they work for, in order to offer proper support to patients throughout the care process. It provides a series of questions the patient partners can ask professionals and also offers support to professionals to open up discussion, in partnership with patients, on a subject chosen together. The tool is co-developed around four sections: *Information*, *Follow-up/procedures*, *Support/resources*, and *Preparing patients for the next stage in their care process*. For each section, there are main themes, composed of sub-questions, which include key components identified by the partners (Table 1). Examples of key components identified for every stage of the care process) to guide the support approach of professionals and organizational support. Much like selecting from a menu, the patient, alone or with a professional, can choose, at any time during the care process, one or more questions to ask and discuss with the health professional.

The first draft of the tool covers several stages: screening/investigation; announcement of the diagnosis; the beginning of treatment and the end of active treatment; and the different transitions from one stage to another. The tool's themes and their sub-questions are mainly representative of the physical, psychological, social, economic, and spiritual needs of patient partners, and focus in particular on aspects associated with: *the patient's experience of health/disease and their life plan* (e.g., announcement of the diagnosis and support for loved ones, work management, housing, costs, management of complications at home and/or signs to look for, support during appointments, preparation for the next stage in the care process, management of information and emotions: fear, worries, anxiety, waiting for results); *professional support* (professional on file to contact if necessary); and *organizational* (e.g., flow of information concerning the patient, organizing commutes to and from appointments). The tool also covers aspects that are more sensitive for patients (e.g., refusing treatment and the associated consequences, uncertainty related to the recommended treatments and possibility of discussing them with a professional, accessing their medical records, patient rights and responsibilities).

For every question or group of questions in the tool, teaching materials will be co-developed to better equip professionals to support patients according to best practices. Types of organizational support for every stage and transition of the care process will also be co-determined. The objective is to provide quality services, at the right place and time, in a care setting that is considerate, coordinated and friendly, where patients and their loved ones have easy access to their primary, secondary and tertiary care teams. The tool will be available in a paper or online version according to the patient's needs. Each clinical setting will determine the extent of its use and the most suitable application according to local reality.

The tool's approach puts forward, for every stage and transition of the care process, the importance of considering patients in their entirety, recognizing them as people in their own right within the context of living with the disease. It recognizes that supporting patients at every

Table 1
Examples of key components identified for every stage of the care process.

Screening and investigation stage:

When cancer may be a possibility, the partners agreed that it is essential to show patients that they are part of a rapid, coordinated care process.

- Importance of reassuring patients, showing that they are part of a rapid, coordinated care process, that their case is well in hand and that an effective follow-up will be offered.

Announcement of the diagnosis:

Learning the cancer diagnosis is a trying experience for patients. They need to be comforted, trust the professional(s) that participate in the announcement of the diagnosis, and feel that procedures are quickly initiated for their treatment.

- Announcement of the diagnosis in a calm setting.
- Importance of communication. Professionals must engage in a dialogue with the patient and ensure that the information shared is understood. They need to encourage patients to verbalize their fears and concerns, and ask them whether they have any questions. Since the specialist does not always have sufficient time to engage in a lengthy discussion with patients, a nurse or other professional should be on hand to take over if necessary.
- Taking into account the patient's reality (support of loved ones, how to announce)
- Importance of efficiency. Process initiated immediately for the quick planning of treatment appointments.

Beginning of treatment:

Partners observed that an important need at the beginning of treatment was associated with information and being able to consult the care team if necessary.

- Importance of properly communicating information (clearly defined treatment steps and procedures, possible complications and side effects of treatments).
- Help patients properly manage the different treatment options recommended.
- Help patients feel they are an integral part of a well coordinated care team (being able to consult one or several professionals, as needed, to once again discuss the recommended treatments; giving themselves the possibility of reconsidering their decision about a given treatment; breaking down the information received with the professional; or obtaining psychosocial support).

End of treatment:

The end of active treatment followed by a return home (survival stage) can be a difficult experience as patients find themselves suddenly without professional support. Some patients may also find it difficult to live with the idea of recurrence.

- Clinicians feel bereft when patients are in remission; the therapeutic relationship is cut off. Patients can feel abandoned and professionals can also find this transition difficult.
- Importance of supporting patients to help them gain independence from the assistance of health care professionals when they must learn to cope with their disease alone.
- Deal with recurrence (the remission stage has ended, but in actuality it is not over for patients) and provide support.
- Support loved ones.

step of their care process entails much more than simply taking into consideration the physical or organic aspect of the disease. This support also presupposes continuously revisiting their life plan. Professionals must seek to understand what patients know about their disease, their expectations, their needs, the level of engagement desired, their health literacy, their personal life objectives (at the family, professional, and socio-economic levels), and their concerns (e.g., worries, mourning, other health or socio-economic problems) to help them better manage and cope with their disease. They need to adjust their approach accordingly. The human dimension is at the heart of the approach. The professional's approach is personalized and individualized, to reflect the fact that every patient is different, their experience of the disease is unique, and they cope with it in their own way using the skills acquired throughout their life and according to their values, beliefs, and cultural heritage. This human approach focuses on knowing the patients and recognizing their particular identity, as key actors, during a transitional period in their life, the approach shifting according to the new expectations and needs of them. The organization of services thus provides support to patients. Flexible and coordinated procedures within

health care facilities are prioritized (e.g., grouping the many appointments to reduce commutes, reduced waiting times) as is the flow of information to avoid patients having to repeat personal and medical information to every professional they meet with. Here are some excerpts of comments made by patient partners during project committee meetings.

“...We really got both sides of the story, so it wasn't just us professionals sitting there sharing what would be best; we had immediate input. Sometimes, this allowed us to really realign things in the setting.”

(22; Nurse leader) (Free translation)

“When there is a patient partner, it changes a team, it changes the way of thinking, for sure. First, because we have to explain terms, and then because we have to explain why things need to be done the way they are when the patient would prefer another way. Sometimes, the patient just wants an explanation.”

(4; Administrator) (Free translation)

The tool seeks to support patients in their bid for autonomy on the basis of two poles of action. These poles were established during project committee discussions and elaborated from the definitions proposed by the patient partners of the project. They are: 1) *the personal pole related to the patient's experience of health/disease and their life plan*, which focuses on supporting patients in their experience of the disease (e.g., showing themselves kindness during the progression towards a new identity-integrity), accomplished through reassurance, emotional support, support in understanding and perceiving the disease, as well as at the level of the mobilization of the patients' personal resources and those of their environment consistent with their life plan, and 2) *the pole of patients' self-determination of their care*, which focuses on helping patients gain more control over their health (e.g., self-management, self-monitoring) and their care. Professionals engage in a process of self-determination with patients by recognizing and reinforcing their literacy in the field of health care as well as their decision-making power. This is also accomplished by encouraging patients to act in their own interests by co-creating their health care plan with the professionals involved in their care, to ask any questions they may have, and to inquire about their care, by engaging in a dialogue with patients, and by making patients participate in decision making as well as the planning and follow-up of their care.

A research project will be developed in order to continue the validation of the tool, more specifically to assess its acceptability and feasibility. This project will help improve the tool and recommend avenues for reflection on the best ways to encourage patient partners in their bid for autonomy by providing support throughout the care process. It will also outline the supportive approach implemented within the experimentation framework and identify the aspects to focus on and/or co-develop for professionals (e.g., guiding principles of the support process, of the teaching materials to support professionals) and at the organizational level (possibility of applying the tool, most favorable care setting).

4. Towards a model of engagement of patients as partners in research

Partners in the RIUPS project are now convinced of the importance of ensuring the participation of patients as partners in future projects to co-construct clinical practices. All agree that collaborative research with patient partners that is based in practice settings provides an avenue that should continue to be pursued. Several nurse leaders indicated their intention of implementing the philosophy of the collaboration with patients they experienced with their team and of including them in future clinical projects. They committed to sharing their experiences during future meetings of the RIUPS in order to identify the different shapes this participation can take as well as the facilitating factors and challenges. This sharing will complement a process of reflection, which has already begun and aims to outline a

Implication and contributions of patient-as-partner in research in the research process

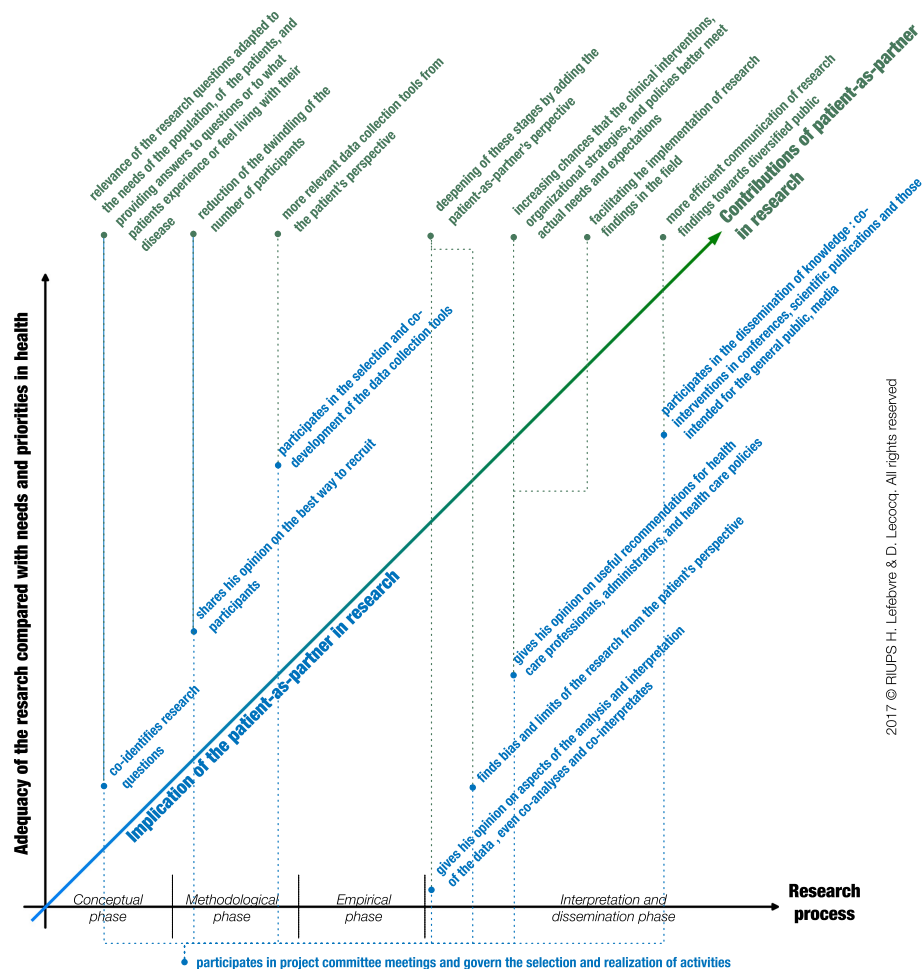


Fig. 1. Contributions of patient-as-partner in research.

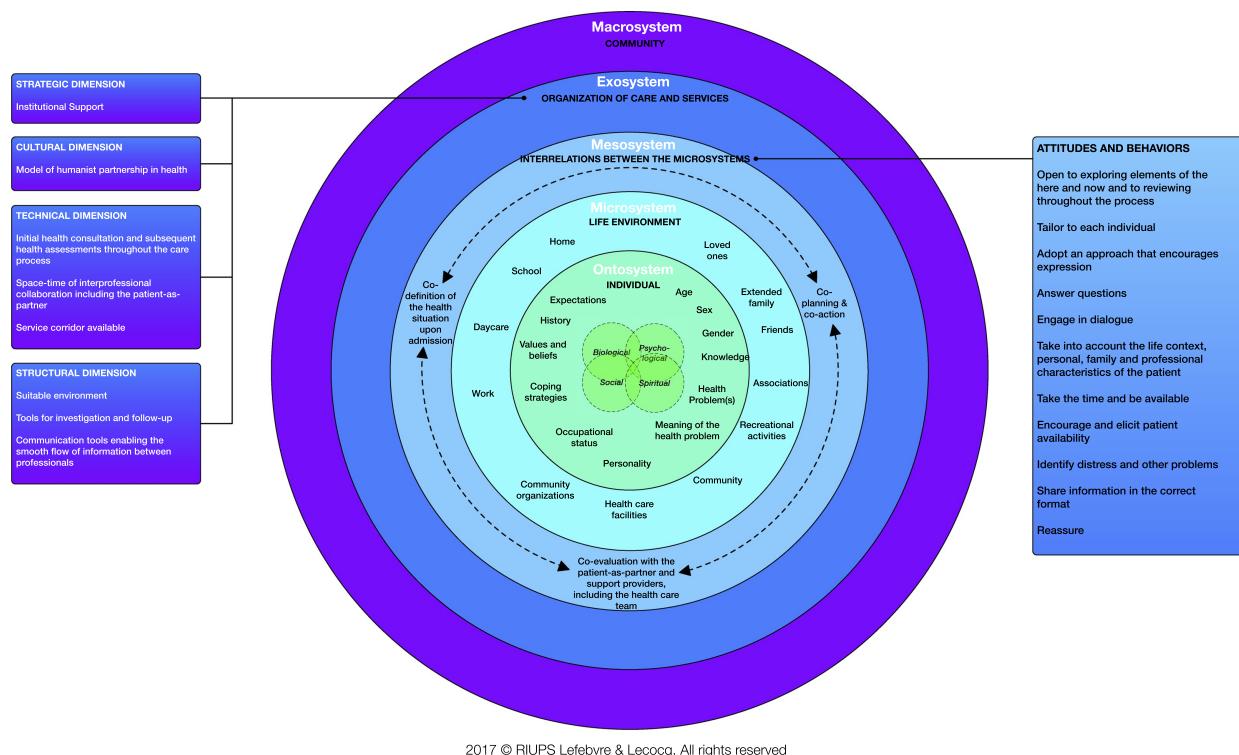
model of engagement of patients as partners in research. This work is inspired by research conducted by the *Comité sur les pratiques collaboratives et la formation interprofessionnelle* of the *Réseau universitaire intégré de santé de l'Université de Montréal* (RIUS) on the competencies observed in or expected of patient partners in clinical and care contexts (*Comité sur les pratiques collaboratives et sur la formation interprofessionnelle* (CPCFI), 2013). The model in development is built along four axes: roles and responsibilities, teamwork, ethics of patients as partners in research, and collaborative leadership.

The model will be progressively developed alongside future RIUPS projects, and as experimentation of the collaboration with patients as partners in research in clinical settings and the scientific literature evolve. It is based on a concept of collaborative support (Fig. 1) that consists of discussing with patients considered as partners the information required to find the necessary support during their care process at every transition and make informed decisions, not only related to their health situation but also to events in their personal and professional lives (Meleis, Sawyer, Im, et al., 2000). Collaborative support presupposes that the professional will be available to patient partners to guide them synchronously, specifically in the direction they desire and at their own pace (Lecocq & Lefebvre, 2017). Professionals must recognize the health care experience and life and care plans of patient partners in their physical and social environments, as they perceive them. Furthermore, professionals must consider patient partners as part of a system of meaningful relationships they entertain with their family and their environment as well as with their community in

order to promote patient partner wellness and the quality of the relationships they maintain in their environment.

Collaborative support involves identifying, with patient partners, the elements of the experience that are problematic, their impact on the various spheres of their life, and the strategies to implement. It takes into account patients' unique characteristics, their physical, social, economic and cultural environment, and the available means and resources to help them regain a healthy identity-integrity, transformed, thanks to the new experience. In their position as mediators, professionals initiate collaborative support with the patient by linking the biomedical, administrative and psychosocial spheres (Fig. 2). Whether this refers to administrative, medically-delegated, or independent actions, professionals commit to ensuring, in their role as institutional mediators, that all the members of the care team co-construct with the patient partners an integrative care trajectory that takes into account their aspirations and priorities (Nadot, Busset, & Gross, 2013). Through dialogue, they encourage the mutual search for meaning, the relationship between patient and professional that features two people discussing, as equals, a situation which necessitates their respective competence. Professionals adapt throughout the support process, which is continuously redefined and adjusted, according to the situation, through dialogue and consideration (Lecocq & Lefebvre, 2017; Paul, 2012).

Professional competence in action during collaborative support requires the adoption of certain attitudes, including availability, presence, openness, and attention to others: "Being there" and communicating to others that "I am here". These attitudes are translated through behaviors



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Fig. 2. Nurturing organizational context

that involve interacting, responding, soliciting, and stimulating a constant re-examination in relation to the patient's current care situation. In sum, collaborative support aims to “*move with the patients towards...*” by adapting to each patient's situation (Paul, 2012). It is founded on a process that prioritizes interactions as equals between partners to “move towards together”. Professionals encourage the autonomy of individuals by relying on their resources and using an empathetic, human approach. Collaborative support sets in motion a process of negotiation with patients as partners, of understanding, of interactive deliberation, and of the development of shared meaning [10, page 17].

5. Discussion

Implementation theories emphasize the transformative role of patients in the context of the application of changes to clinical practices. Everything related to the involvement of patients or to efforts made to meet their needs/concerns must be viewed as fundamental factors to ensure the successful implementation of a clinical innovation (Damschroder, Aron, Keith, et al., 2009). The collaborative project highlights this, seeing as the contribution of patient partners has very clearly added value to the project. As partners in research, the patients were both a significant source of motivation and mobilization for nurse leaders, their teams, and researchers. Their participation provided input on hospital discharge planning and care transitions in oncology and led to a new outlook on the care situation. These findings are reflected in the scientific literature, as studies show the influence of patients' participation in research on the objective, methodology or orientation (Lavoie-Tremblay, O'Connor, MacGibbon, & Fréchette, 2016; South et al., 2016; Woolf et al., 2016). During the RIUPS collaborative project, the participation of patients as partners in research led to reorienting research questions for the benefit of patient partners and their loved ones. It also gave rise to new proposals for improving hospital discharge planning and care transitions in oncology that better reflect the actual needs of patients and underline the human aspects of care throughout the process (Bickell, Neuman, Fei, Franco, & Joseph, 2012). According to the needs expressed by the patient partners, an important challenge lies in being able to respond, in a timely manner, to the needs

expressed and to ensure quality care and service delivery, which would require a de compartmentalization of settings and service providers and a better coordination between them (Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS), 2007).

In line with the RIUPS project, several initiatives were launched internationally (USA, United Kingdom, France) in order to encourage the self-determination of patients as partners in their care. Training programs were implemented to equip patient partners suffering from chronic pain or other health conditions so they could develop self-management capabilities. Other programs aimed to integrate peer helpers into the care teams in clinical settings (Pomey et al., 2015). Since 2011, activities have been implemented in Quebec at the urging of the *Direction collaboration et partenariat patient* of Université de Montréal's Faculty of Medicine (*Direction collaboration et partenariat patient* (DCPP), n.d.). Among other things, these initiatives have enlisted patient partners to support other patients, to share their experience in academic contexts, or act as partners in research (*Comité sur les pratiques collaboratives et sur la formation interprofessionnelle* (CPCFI), 2013). Through all of these initiatives, key aspects influencing the self-determination of patient partners were identified, namely the importance for patients of having a measure of control over their treatment and care (e.g., having a say in their treatment, having the option of refusing a treatment, being able to contact a professional when necessary, having a firm grasp on their treatments, side effects, etc.); the ability to influence the organization and delivery of care according to their needs and concerns; and the self-management of their care (*Comité sur les pratiques collaboratives et sur la formation interprofessionnelle* (CPCFI), 2013; Pomey et al., 2015; Johnsen et al., 2017). Off-mentioned was the importance of patients being able to engage in dialogue with health professionals, ask questions, and influence the moment of the transfer of information and of contact with them (Brouard et al., 2014; Johnsen et al., 2017; Ledema & Angell, 2015; Woolf et al., 2016). However, these studies provide little insight into how patients manage to gain autonomy. The use of the tool to support patient partners during the oncology care process will lead to, within the framework of a future research project, the understanding of

the way in which patients manage to arrive at self-determination in different aspects of their care throughout the process, and enlighten professionals and administrators of health care facilities on the concerns of patients, to help them assume greater responsibility for their care (Johnsen et al., 2017; Lavoie-Tremblay et al., 2016). It will help pursue the development of a model to engage patients in their care in line with other studies that are beginning to take shape (Johnsen et al., 2017; Pomey et al., 2015; South et al., 2016).

6. Conclusion

The partnership between patients, professionals, and the health care team where patients are partners in their life plan aims to support patients in their bid to gain autonomy. From the beginning of the relationship and throughout its development, the support approach encourages patients to express themselves and relate their experiences since self-expression is the first condition for them to become involved in their care. It puts great importance on establishing a significant relationship with patients considered as partners to take into account the singularity of their choices, their life plan, and the shared responsibility of their care situation. This relationship is developed through communication and reflection and requires recognizing all aspects of the patient's experiences. It involves active listening, which presupposes being attentive, but mainly interacting, answering, eliciting, and encouraging questions associated with the current situation. The support process is part of an active teaching method that goes beyond the simple transfer of knowledge. Professionals implement an educational relationship with patients to encourage them to collaborate and invest in their treatments in the most favorable conditions. Through this understanding of patient partners in their entirety, professionals provide the support needed in order for them to carry out their plans throughout the care experience. This is achieved in the context of nurturing health care organizations, focused on personalized care and with enough flexibility to make changes in light of the concerns expressed by the patients and their loved ones as part of a patient partnership approach.

Declaration of Competing Interest

I declare, together with the other co-authors and collaborators of this manuscript, that we are not subject to any conflict of interest.

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