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How patients view their contribution as partners in the enhancement of patient safety in clinical care

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Abstract

Despite the call from the World Health Organization for more active involvement from patients in the prevention of health care-related risks, there is still insufficient evidence about how patients can be more proactive in the safety of their own care. This study helps understand the perspective of patients as partners regarding their roles, as well as their relatively untapped potential in detecting and limiting adverse events (AEs) for patient safety. 17 patients-as-partners were interviewed on five themes: 1) Behavior of patients/relatives for avoiding AEs; 2) Competencies sought in patients/relatives to play an active role in patient safety; 3) Factors limiting or facilitating the role of patients in the safety of their own care; 4) The Partnership in Care approach as a way of limiting the occurrence of AEs. Patients-as-partners revealed several key behaviours that helped patients avoid AEs: proactivity; communication; trust; vigilance; reporting and flagging; being accompanied by relatives, being accompanied by health professionals. Furthermore, several competencies helped as well: being curious, observant, responsible, able to trust, respectful, and diplomatic. Finally, factors facilitating and limiting patient engagement in safety included personal characteristics, information, interpersonal relations, and organisational aspects. Through the Partnership in Care approach, patients-as-partners develop behaviours and competencies which are yet to be directly applied to improve patient safety. However, obstacles remain: the engagement and official training of patients-as-partners and their appropriate roles in safety, including the identification of AEs; and finally, the redefinition of AEs so as to include the patients' point of view and experiences.

Keywords

Patient engagement, patient safety, patient partnership, patient experience, adverse events, clinical care, quality of care, qualitative methods

Introduction

For over a decade, it has been recognized that patient engagement (PE) at clinical and organizational levels can help improve outcomes and reduce the burden on health services¹⁻⁶. Nowadays, engaging patients in their health and care is a key component for achieving higher quality and safety in health care^{7,8}. Moreover, patients who actively participate in health care decision-making turn out to have better health outcomes and more positive care experiences^{2,6,9}. Also, they contribute to improvements in quality and patient safety^{9,15} and help control health care costs^{6,16}.

In 2017, the “Patient for Patient Safety” program of the World Health Organization (WHO) called for more active involvement from patients in the prevention of health care-related risks¹⁷. Recently, a few systematic and literature reviews were published about PE and patient safety. However, these reviews reach the same conclusion: how, and with how much evidence, can patients be more

proactive in the safety of their own care^{15,18}? Furthermore, the authors highlight a lack of clear definitions of patient and family engagement in patient safety. Also lacking is evidence regarding the kind of patients who might feel comfortable engaging with providers, as well as the contexts¹⁸ and the type of methods that would encourage patients to report adverse events (AEs)¹⁹. In their study, Leape et al. (2014) consider AEs as unwanted events for the patient - or staff - which occurs during the delivery of care, as part of the prevention, diagnosis, treatment or rehabilitation, whether the event is due or not to the exposure to a health product, or any other malfunction. There are two types of undesirable events: avoidable and serious. Avoidable ones can be described as those that would not have occurred if care - or the environment in which care is being delivered - were compliant with regulations in place. Whereas serious undesirable events are those that are responsible for death, immediate threat to life, hospitalisation extension, incapacitation or disability²⁰.

It is at this juncture that our research aims at better understanding how patients, who are aware of the notion of partnership in care, act to limit AEs. In fact, a new rational model based on the partnership between patients and healthcare professionals (HCPs) has been developed at the University of Montreal (UofM) ²¹. This Patient Partnership Model is based on the recognition of the patient's experiential knowledge gained from living with a disease. This knowledge is not only related to symptoms and reactions to treatment, but also to the use of services in the health system, which makes it complementary to scientific knowledge from HCPs.

To support these major changes in healthcare practices and health organizations, the next generation of HCPs are being prepared to work within the context of collaborative practices and to contribute to the deployment of partnerships in clinical institutions. Accordingly, since 2011, the UofM has integrated patients as co-facilitators in training courses, aiming for the progressive development of inter-professional collaboration skills and care partnership for students from 13 undergraduate programs in various health-related professions and psychosocial sciences. Each year, around 3,000 future HCPs are trained by patients acting as partners, also known patients-as-partners ²¹.

Hence, it is from the vantage point of patients-as-partners that our research has been conducted by posing the following questions:

1. How do patients-as-partners get involved in their care and how do they go about reducing AEs?
2. How does patients-as-partners training influence the perception of patients regarding their roles in health care safety?
3. What are the factors that can facilitate or inhibit the engagement of patients in care safety from the point of view of patients-as-partners?

Methodology

Study design and recruitment of participants

A qualitative approach was chosen to better grasp patient perspectives regarding their roles in health care safety. A convenience sample of patients-as-partners was interviewed between February and May 2016. To ensure the relevance of collected data with regards to our research questions, the following inclusion criteria have been defined: 1) Participating or having participated in courses on "Collaboration in Health Science" at the UofM; 2) Living with at least one chronic illness ; 3) Having experienced one or several AEs with their own care or that of a relative (near misses, incidents, accidents or both) during the last five years; 4) Being older than 18 years of age; 5) Being available for a 30 to 45-minute phone interview.

Potential participants were identified by the UofM Faculty Collaboration and Patient Partnership Unit (CPPU). The CPPU provided a list of 33 potential participants. Following the above-mentioned inclusion criteria, 17 patients-as-partners were selected and agreed to be interviewed. The remaining 16 patients were not included in the study because they reported not having experienced any AEs.

All potential candidates were initially contacted by email to inform them about the project. Then, patients were contacted by telephone to confirm their interest, undergo screening for eligibility, and schedule an interview. A consent form (signed by the patient and returned to the researcher by email) was used to formalize participation and the authorisation to record calls.

Data collection

Interview questions (appendix 1, interview guide) were structured around five main topics related to our research questions. The first topic was the identification of risk situations directly encountered by patients or by their relatives. Identifying these risk situations leads to the second topic, which is understanding the roles of patients or their relatives in the avoidance of AEs. For the third topic, in a complementary perspective, attention was paid to competencies sought in patients (and relatives) to play an active role in patient safety. Factors that limit or facilitate that role constitute the fourth theme, while the fifth one explores the partnership approach in care as a way of limiting the occurrence of AEs.

Each telephone interview lasted approximately 40 minutes. Interview questions were sent in advance to provide patients with sufficient time to reflect. To protect privacy, interviewers avoided the use of names during interviews. Recorded calls were transcribed and interviewees were assigned fictitious names.

Data analysis

In compliance with criteria for methodological rigour in qualitative research ^{22, 23}, two techniques were used for coding: primary open coding followed by thematic and selective coding. The thematic coding was mainly based on themes developed in our interview guide and was performed by all research teams. Initially, three team members independently coded three transcripts, developed codes and themes, then met to discuss and reach consensus on the relevant codes and themes to maintain. Three additional transcripts were independently coded using the established codes and themes, and then compared to assess reliability. At the end of the process, an analysis grid was developed by the team. Subsequently, all transcripts were coded by two researchers using QDA Miner.

Ethical considerations

This study was approved by the University of Montreal Health Sciences Research Ethics Committee (certificate #14-127-CERES-D).

Results

The characteristics of the 17 interviewees are summarized in Table 1. Several patients dealt with safety issues during their care: two patients decided to file complaints to the organisation or to the HCP; two wanted to file a complaint but finally decided against it due to a lack of awareness and the procedure being too complicated; eight discussed the event with the HCP involved in the event; four have lost trust and switched HCPs after the AE. Moreover, no patients were involved in the feedback/evaluation or follow-up actions after the AEs to prevent them from happening again.

The interview results were presented in terms of the five themes covered during the interviews: 1) Risk situations encountered by the patients or their relatives; 2) Behaviour of patients and relatives to avoid AEs; 3) Quality or competence sought in patients to play an active role in care safety; 4) Factors facilitating or limiting patient participation; 5) The Partnership in Care approach as a way of limiting the occurrence of AEs.

1. AEs encountered by patients or their relatives

Among the 17 interviewed patients, 32 events related to safety issues occurred during the last five years: 27 of these events were experienced by the patients themselves and five by their relatives; 13 were accidents; 11 were incidents and eight were near misses, among which seven were avoided by patients and one by a HCP.

Out of all AEs, 88 per cent occurred in a hospital setting while 12 per cent in an ambulatory setting; 54 per cent were related to medication; 17 per cent to infection acquired in health care settings; 26 per cent related to diagnostic errors; and two per cent were classified as “others” or “near misses” (*A summary of encountered– near misses is presented in Table 2*).

Connecting patient partnership and patient safety

Initially, it was not obvious for interviewed patients to clearly identify their role in patient safety. Despite being familiar with the concept of patient partnership, the Partnership in Care training does not explicitly confront the role of patients as partners in safety. Thus, many of the participating patients did not see the connection between patient partnership and patient safety. For patients, their engagement revolved around quality / improvement of services (e.g. be included in their personal intervention plan, discussing about treatment or being involved in a quality improvement committee). In addition, one of the patients, Edward, summarizes: “*The partnership is also used to*

empower, inform and equip patients and their families with regard to their responsibilities and rights in health”. Though accurate, the potential connection or application to patient safety is not apparent. In fact, it was during the interviews that seven patients realized the importance of integrating the patient safety aspect within the partnership approach (*see table 3 for more verbatim*). Here is what some patients said about the partnership in care training in relation to patient safety:

“[...] what prevents patients from being involved in the safety of their care is that there is nothing that is done to get them to 1: know, 2: understand, 3: implement, [...]. How can a patient become a partner if he or she does not even know what it is, what are the concerns or should be his concerns about his state of health; especially when it is in a particular pathology case? So, if the patient is not even aware of the advantage of participating more, we go nowhere. First, the patient must know.” - William

“I think the partnership in care, if the healthcare professionals really speak to each other and listen to the patient, that there is a link [...] it is really an ideal model that must evolve over time. Patient safety education is required. How do you do it? Maybe by word of mouth?” - Allison

Patients realized that the abilities they developed while being in partnership with their healthcare professional could be put to contribution to help reduce AEs, and that the Partnership in Care approach would benefit from being extended to current and future patients and health professionals. Patients, as much as healthcare professionals, will have to be trained together for better interdisciplinary work in patient safety. Here are some examples of what patients mentioned in relation to the scalability of the partnership in care training and the interdisciplinary work:

“[...] the healthcare partnership program would have to be extended to a wider scale ... to patients and health professionals, both the future and senior. [...] It seems that our body is dissected into sections: then if you have a bad toe, you have to see this, then if you get hurt, you got to see some else, then another, then another, [...] instead of taking an overall view of your problem [...].” - Kathy

“I just did the classes with the students [...] to make these future professionals aware of the safety aspect. [...] it is important to not just change these future professionals but also patients need to be aware of the safety aspect. [...] it is a team thing” - Maggy.

2. Behaviour of patients and relatives to manage and avoid AEs

While several patients could not clearly identify their role in patient safety, they eventually took notice, during interviews, of their ability to help reduce AEs (which directly contributes to patient safety). In doing so, patients highlighted several behaviors which allowed them to avoid AEs: being proactive, allowing patients to better communicate, trusting, being vigilant, being accompanied

Table 1. Patient Characteristics

Patient	Sex	Disease	Self-experience or Relatives' experience	Nature of experienced AEs
Jack	M	Type 2 diabetes	Self	Incident: Failure to administer treatment for several days (two days) in a rehabilitation clinic.
				Accident: Diagnostic error from the doctor and administration of the wrong treatment (did not diagnose diabetic foot, beginning of gangrene and applied balm and heat on a diabetic foot) -Led to the hospitalization of the patient 48 hours later, then to the amputation of his foot.
				Near Miss: Additional insulin doses and snacks without the knowledge of healthcare professionals. - Not a real incident because the nurses / doctors have respected the doses recommended by the protocols.
Mary	F	Cancer, Muscular Dystrophy Oculopharyngeal (MDOP)	Self and relatives	Accident: "Error" that led to a temporary disability of the patient's child.
				Incident: Consults a first time for pain in a finger. An x-ray is prescribed. The doctor finds nothing special and sends her back home. - Back in the hospital two days later, dealing with persistent pain. Ask to see another doctor who diagnosed a fracture.
Maggy	F	Myeloid leukemia	Self	Accident: Nosocomial infection (during hospital stay) after a transfer to another unit. - Delay in the grafting process.
Allison	F	Breast cancer	Self and relatives	Incident: Knee operation delayed due to non-transmission of test results.
				Accident: Pressure ulcer.
				Incident: Withdrawal of the wrong drug treatment just before its administration. - Injection of a "bad" treatment avoided by the patient who recognized the treatment thanks to the color of the bottle.
Jennifer	F	Cervical chronic pain, myofascial syndrome		Accident: Chronic pain + MRI hospitalization for two months + myofascial syndrome.
				Accident: Hyperlaxia following treatment with magnesium.
Laury	F	Multiple sclerosis and otosclerosis ossicles	Self	Incident: Absence of local anesthesia. Delay for the distribution of analgesics in postoperative /ear surgery intervention.
Stephanie	F	Breast cancer	Self and relatives	Near miss (relatives): Surgical intervention was reported because the patient needed a particular device (fiber optic) for intubation.
				Accident: Overdose.
Georges	M	Cystic fibrosis, diabetes	Self	Near miss: Patient identifies a treatment that is not intended for him (antibiotics destined for another person).
				Incident: Hyperalgesia of a disconnected epidural. Health care team did not take that into account. It happened in a context of transfer between institutions.

(Table 1 continued next page)

Table 1. Patient Characteristics (Continued)

Patient	Sex	Disease	Self-experience or Relatives' experience	Nature of experienced AEs
Betty	F	Breast cancer	Self and relatives	Accident (relative): Long-term hospitalized patient - felt ill after discharge. - a request for re-admission was refused – and the patient died.
				Incident: 2 nd surgery because narrow margins in the context of cancer – the patient received radiotherapy afterwards – it was very painful.
				Near miss: Joint follow-up by two hospitals – An oral chemotherapy was prescribed at the same time a surgery was scheduled.
				Near miss: Hospitalized patient – an anxiolytic was not delivered by the hospital. -The patient became very anxious.
				Incident: Delayed diagnosis of cancer.
				Accident: Delayed diagnosis. - After a consultation in the emergency room, a consultation for neuro program was only given 48h after. The prescribed antivirals led to sequels and facial paralysis. Therapeutic abstention was then proposed.
Kathy	F	Lupus	Self	Incident: Failure of a care protocol (blood coagulation test) prior to puncture of the kidneys. The incident was without consequence.
				Accident: Omission of drug (cortisone). -Led to longer hospital stay because of kidney failure + staphylococcus.
Howard	M	Type 2 diabetes and Parkinson	Self and relatives	Accident: Spine surgery - mouth drain in post-operation - 2 nd emergency operation.
Virginia	F	Type 1 diabetes and leukemia	Self	Incident: Fall of an elderly person - Immediate care was given and was being judged adequate (x-ray was completed, etc.)
Flora	F	Thyroid cancer and breast cancer	Self	Incident: Request for transfer to another hospital with her medical file - she is provided with a copy of someone else's file, the patient decided not to change hospital right away.
				Incident: Oncologic surgery - the doctor alone decides that the patient will not need care at home after a post-operation. - Patient was in pain and anxious in post-operation.
				Near miss: Consulted with the wrong psychologist
Patricia	F	Fibromyalgia, colorectal inflammatory disease, psoriasis	Self and relatives	Near miss: Chirurgical intervention context - allergy to antibiotic was not noted on file. However, the allergy verification was done by IDE in pre-op.
Edward	M	Thyroid cancer	Self	Accident: Diagnostic error (appendicitis diagnosed as miscarriage), with consequence (emergency surgery during pregnancy).
William	M	Malignant disease, lymphoma	Self and relatives	Accident: Nosocomial infection following cardiac surgery. - Stayed six weeks in hospital instead of six days.

Table 2: Near misses

Near miss	“If they do not do this intubation and if something happens, my blood pressure goes down or something like that, they have to be able to wake me up and if there is no tube to put oxygen, I can die. It was really ... it was a death accident.” (Stephanie)
Near miss	“It happened once that ... it was not mine and I realized it because I recognize the color or pocket of the antibiotic or something like that. Then, by checking, it was for another patient on the same floor.” (Georges)
Near miss	I told him: “if you just give me that as a snack before going to bed, with what I have, I will probably do a hypoglycemia during the night. So, for 2 or 3 nights I called the nurse at 3:00 am, telling her I was lacking sugar. I was hypoglycemic. Then, she realized that I was right not because I wanted to be right but because I knew quite well that with the amount of insulin that the doctor gave me, plus the little I ate before going to bed, I was going to have a hypoglycemia. And it happened every time the nurse was following the chart. (Jack)
Near miss	I was able to recognize the color of my treatments’ bottle... if I hadn’t they were going to administer the wrong drug. (Allison)
Near miss	Joint follow-up by 2 hospitals - oral chemotherapy prescribed at the same time as a planned program. It was for chemo. But the other doctor had not been warned or whatever... There was no consultation between the two institutions. And it was to take the oral form chemo but she would have taken it without ... anyway, it was not the right thing to take and it was definitely not the right time. Had it not been for the vigilance we had, she would probably have had a lot more complications ... she would have had problems because that was not what she had to do. (Betty)
Near miss	There were plenty of little clues I could have spotted and she could have spotted some too, or even see that the name did not match ... there was no verification of identity. (Flora)
Near miss	The nurse who was present for the operation came back to validate with me how I felt etc. So, she tells me "no allergies", so there I talk to her. She says "oh! It was not on the record ". (Patricia)
Near miss (professional)	“I was a witness to the remark he made to the nurse: mademoiselle you should have advised me that the drain (...), it is not normal.” (Howard)

by relatives, reporting safety issues, and being accompanied by health professionals (see Table 4 for more verbatim).

Being proactive

All the patients-as-partners (n=17/17) mentioned how crucial it was to be proactive. As a summary, one of the patients (Howard) defined proactivity as “an ability to share, ask questions ... it is certain that the more the person is involved, the more likely [...] we avoid accidents, incidents.”

Communication

14 patients raised the essential role of good communication in both directions (from the patient to the professional and vice-versa) and the problem of not understanding medical terms. Here is an example of patient-to-professional communication as mentioned by Mary:

“The professional cannot guess how you feel, [...] react to such a drug. I am not embarrassed to say whether something is not right. I was glad I listened to myself. It is a matter of relationship: you have to take your place [...] a patient’s space.”

Another patient (Kathy) mentioned that HCPs must also be proactive in communicating and that communication characterizes human relations; therefore, they must demonstrate more compassion in that regard.

Trust

Most patients raised an important issue regarding trust (n=12/17), as recounted by Jennifer: a relationship is, at first, built on suspicion before being built on trust. Trust is not obvious between patients and HCPs. Although some individuals are more likely to easily trust others, patients test the confidence of HCPs by asking questions and being wary of how the relationship evolves. The HCP must value the patient as a true interlocutor.

That said, for some patients, confidence can be double-edged. For example, Maggy is not comfortable when professionals exhibit too much confidence and, therefore, potentially no openness to review certain at-risk behaviors:

“I felt confident when I felt that the staff around me was confident. I do not like people too confident and who have the innate truth. I like

(continued p. 43)

Table 3. Patients-as-partners mentioning the difficulty of making the link between the partnership approach and patient safety

Interviews	Verbatim
Allison	<i>To avoid the incidents, we talked a little about it in training, but it is certain that being a patient-as-partner helped. [...] it helped me be more aware of things. I think we need to talk more about it. Do we have to talk about it four times before we get to a result? Yes, I think the partnership in care, if the healthcare professionals really speak to each other and listen to the patient, that there is a link [...] it is really an ideal model that must evolve over time. Patient safety education is required. How do you do it? Maybe by word of mouth?</i>
Laury	<i>That is why I hesitated to participate at the beginning of the study, because [...] I find it difficult to establish a partnership of care when it is a safety issue in surgery.</i> <i>[...] it's clear that patients should be involved in think-tanks with professionals and managers. [...] it is in a continuum that one must think about the involvement of patients and not only at the level of the intervention, but also upstream to really think with patients. For example, in the context of chronic diseases and surgeries [...] we need to educate [people who have experiences] regarding the organization of care and care safety. [...] after an operation, it would be important to involve the patients to validate how it happened; there can be different ways to evaluate it. [...] maybe this exists but I have never been asked for this kind of feedback. [...] It seems important that patients be consulted throughout the reflection continuum on care safety and not just when they are receiving care.</i>
Stéphanie	<i>I hope that with the interviews [...] we will try to identify this type of patient [for patient safety] because it is difficult. But I believe in it.</i>
Georges	<i>We talked about a lot of collaboration in the first year [...] it is really basic there. 2nd year, we are really trying to determine the role and responsibility of each worker. We talked about collaborative leadership as well, that every worker needs to function well in a meeting. Then, the 3rd year [...], we put in place an interdisciplinary intervention plan, which made really more collaborative behaviors between them [...], so we talk a little less about security [...]. We work on teamwork, communication, and on leadership ... But there is a little bit less talk about safety and risk at the hospital level.</i>
Flora	<i>The partnership in care, as developed, can help to limit incidents and accidents if there really is patient involvement in safety and [...] awareness of caregivers, and I'm talking about all the people involved in this project. And if people really want to do something to improve care, it can work for sure.</i>
Patricia	<i>Yes. Patient safety could be taught, but I think it would have to be done more globally; [for a patient-as-partner] it would have to be done during the partnership in care course. Being a partner means being vigilant, caring, avoiding incidents and accidents. I think there's no one telling us that. It may sound stupid, but you learn from mistakes. I think it's something we learn as we go along.</i> <i>There is a difference between teaching and practicing it too. My incident experience and my patient-resource experience now allows me to be very vigilant on everything that is said and to be really attentive and to say "good, ok, that he just said that", "I did not understand", "no", or to make sure that I make the decision.</i> <i>Culture change will certainly help as well. Training new professionals in the care partnership.</i>
William	<i>[...] what prevents patients from being involved in the safety of their care is that there is nothing that is done to get them to 1: know, 2: understand, 3: implement, [...]. How can a patient become a partner if he or she does not even know what it is, what are the concerns or should be his concerns about his state of health; especially when it is in a particular pathology case? So, if the patient is not even aware of the advantage of participating more, we go nowhere. First, the patient must know.</i> <i>When training the future healthcare professionals, something is being done now, even if [...] it could get better. But still, could we find actual healthcare professionals that are willing to train in such activities?</i>

Table 4. Adverse events encountered by oneself or by relatives: Examples of verbatim

Proactivity	Kathy	<i>"I realized, I documented, I had discussions with each physician, and I asked them to explain to me how it worked, what was the mechanism."</i>
	Howard	<i>"An ability to share, ask questions ... it is certain that the more the person is involved, the more likely [...] we avoid accidents, incidents."</i>
	Jack	<i>"[...] I have developed an intuition when I notice that they are not sure of themselves. I ask them questions to check if they have seen a diabetic foot, if they have treated cases like mine; so, I do not hesitate to ask them if they are sure of their claim, and if not, have someone else treat me."</i>
Communication	Mary	<i>"The professional cannot guess how you feel, [...] react to such a drug, I am not embarrassed to say whether something is not right. I was glad I listened to myself. It is a matter of relationship: you have to take your place [...] a patient's space."</i>
	Kathy	<i>"The professional must listen when the patient says that he is afraid, not just hear (...). For professionals, to listen means to communicate, to relate, to recognize the signs ... Those with whom I have had problems put on their professional hats but not their humanity."</i>
	Kathy	<i>"So, I saw my radiologist who was going to make the puncture in my kidney." And then, he said: - "Ok, but before we start, I must explain to you what is coming. [...] Have you received a sedative? Did they do the test?" He looks at my forearms: - "Have you not been tested?" - "No." - "There, it says in your file, you're at risk of clots, risk of bleeding" ... Then he starts giving me statistics."</i>
Trust	Jennifer	<i>"I'm always a little suspicious. With doctors it is different, but all those who take care of me... I am suspicious; but I now recognize when I go too far. I know my limits."</i>
	Betty	<i>"I tend to trust health professionals around me. I think it is a relationship [...]. I also collaborate in my care, but I am still going to ask questions, get informed on what I am going through. I will not take anything. I want to be informed first; I do not want to be treated as a child ... because it is a little common mentality on the part of doctors"</i>
	Georges	<i>"I have always trusted the medical professionals around me. But, first I know how to take care of me, I know how to properly take part in my care, then I trust."</i>
	Maggy	<i>"I felt confident when I felt that the staff around me was confident. I do not like people too confident and who have the innate truth. I like people who say: "maybe I'm wrong" and will seek answers elsewhere."</i>
Vigilance	Flora	<i>"Be very careful about what is said [...] and think "well, ok, that's what's being said "; "I did not understand "; or making sure that it's me who takes the decision ... I try to be as focused and on top of things. I try to understand ... I take notes, ask questions, try to better anticipate problems."</i>
	Betty	<i>"... But there is also curiosity; what I call the ability to ask the right questions and vigilance, which does not necessarily mean to monitor the care team, but to support it to avoid errors and encourage the patient to cooperate."</i>
	Patricia	<i>"The nurse [...] came to check how I was feeling. She said: "no allergies?", so I told her about my allergies. She said: "phen! It was not on record."</i>
Vigilance versus trust	Patricia	<i>"I trust when it comes to care, but worry when it comes to treatments and medication. Since, in the past, they almost killed me because they did not listen to what I was saying."</i>
	Georges	<i>"I'm not a patient who goes with everything and anything without asking questions. I'm able to take part... I know how to properly take part in my care, and then I trust."</i>
	Jack	<i>"We are very vigilant because we realize that the patient must do [his/her] part by being vigilant and so does the professional. We must help each other in order for care to be the best as possible."</i>

(Table 4 continued next page)

Table 4. Adverse events encountered by oneself or by relatives: Examples of verbatim (continued)

Reporting and flagging	Allison	<i>“My silence would perhaps cause a mistake with another patient. It is important to report incidents because it makes us think... and never, ever [...] have I blamed someone. We analyzed and questioned those involved.”</i>
	Allison	<i>“The complaint [...] must start with basics they do not tell us ... When you are sick, you feel so vulnerable. Hospitals do not facilitate the path that a patient must take to complain or denounce something.”</i>
	Betty	<i>“Patients, they will not file a complaint. Why? Because they are afraid of being categorized and told that we [as patients] whine. Others, it is because they lack the energy to do so, they are sick, they are diminished, and they are vulnerable. Once out of this nightmare, we do not want to complain anymore. We cannot get the results, too, which are still the well-known phenomenon of treating us like children.”</i>
	Patricia	<i>“I do not like the term service complaints. I am not saying to get rid of it, there is a very negative side to it. It is a very negative rating... in the complaints... the health professional has not done [his/ her] job, then the patient will get on his back by complaining.”</i>
Be accompanied by relatives	Stephanie	<i>“Having someone close accompanying us and who is vigilant [...] because a person who is sick [...] can be a bit stubborn. It depends on age and all that ... Maybe [he/ she] does not take all his medication. [the companion] must be able to be encouraged [him/ her], calmly, talk things over.”</i>
	Georges	<i>“I think we should involve relatives based on situations. As soon as care becomes a little more problematic, there must be a relative nearby... who may be able to take the information, to assist the sick.”</i>
	Laury	<i>“Being accompanied, it seems unavoidable to me. Having a relative with oneself who can ensure communication with caregivers when we, ourselves, are not able to do so.”</i>
	Betty	<i>“The role of relatives is very important to support the person, because often we feel that patients feel abandoned when they leave the hospital.... they are left to themselves.”</i>
Be accompanied by health professionals	Kathy	<i>“So, ... I see my radiologist who will make the puncture in my kidney. And then, he said: - “Ok, but before we start, I must explain to you what is coming. [...] Have you received a sedative? Did they do the test?” He looks at my forearms: - “Have you not been tested?” - “No.” - “There, it says in your file, you're at risk of clots, risk of bleeding...” Then he starts giving me statistics.”</i>

Vigilance

For patients, vigilance transpires through their ability to be involved throughout their care. Close to three-quarters of interviewed patients (n=12/17) were aware of the importance of always remaining alert to limit the occurrence of AEs. One of the preferred ways to achieve this is to prepare, inquire, be curious and ask questions without fear.

Another way to remain alert was to be very attentive to one’s surroundings and interactions with HCPs. This is how *Patricia* avoided an event that could have triggered her allergies:

“The nurse [...] came to check how I was feeling. She said: “no allergies?”, so I told her about my allergies. She said: “pbeu! It was not on record.””

Vigilance versus Trust

Over a quarter of patients (n=5/17), like *Patricia*, became more vigilant because of previous experiences related to safety issues:

“I trust when it comes to care but worry when it comes to treatments and medication. Since, in the past, they almost killed me because they did not listen to what I was saying.”

Patients also demonstrate that confidence builds through vigilance. Trust can also be built by being involved, concerned about what is happening in one’s environment and being able to share it with care staff. However, vigilance goes both ways. According to Jack, in order to trust, both HCPs and patients must be vigilant and work as a team.

Reporting and flagging

Reporting AEs or at-risk situations is recognized as essential (n=6/17). However, reporting or flagging is not easy for patients, as many claimed that their vulnerability and fear of retaliation did not encourage them to act. In addition to being overly complex for some patient-as-partners, the reporting system can be difficult to understand and use. Moreover, health care institutions do not necessarily possess encouraging or facilitating measures that would allow patients and their relatives to easily contribute to reporting activities.

And finally, patients question the complaints system as it is based on blame culture rather than learning culture. For them, it is essential that an event is considered as a source of learning to ensure that other people do not suffer the same consequences.

“I do not like the term service complaints. I am not saying to get rid of it, there is a very negative side to it. It is a very negative rating... in the complaints... the health professional has not done [his/her] job, then the patient will get on his back by complaining.” (Patricia)

Being accompanied by relatives

As described in their testimonials, when patients undergo complex treatments in vulnerable situations (without the ability to be proactive, vigilant and to communicate), being accompanied by relatives becomes important. Therefore, 35 per cent of the patients (n=6/17) think that it is essential to have relatives by their side to ensure that their safety conditions are respected. Furthermore, the transition period between hospital and home is recognized as a critical time during which AEs may occur. The following quote captures how patients can value support by relatives during transition periods:

“The role of relatives is very important to support the person, because often we feel that patients feel abandoned when they leave the hospital... they are left to themselves.” (Betty)

Being accompanied by health professionals

Four patients mentioned that “accompaniment” can also be provided by professionals, especially in the case of an event or accident, to allow patients to better understand what has happened and feel support and empathy from HCPs.

3. Qualities or competencies sought in patients to play an active role in care safety

In addition to the above-mentioned behaviours, it is important for patient-as-partners to acquire six core competencies to play a proactive role in the safety of their care (see Table 5 for examples of verbatim).

- The first competency is to cultivate curiosity. Indeed, being curious makes it easier to ask questions, observe one’s environment and share one’s apprehensions.
- The second competency is to be more vigilant about (or to self-monitor) the impact that certain treatment decisions can have on oneself. This can help flesh out side effects from medications and share them with HCPs as soon as possible.
- The third competency is to be responsible. Thanks to their patient-as-partner journey, patients are more likely to be aware of the significance of their actions towards their own health. One patient, Kathy, perfectly illustrated this situation:

“I have always been in a dynamic where I am responsible. The HCP did not have to worry about whether or not I would change or stop my medication.” (Kathy)

Table 5. Quality or competence sought in patients to play an active role in care safety: Examples of verbatim

Table 5. Quality or competence sought in patients to play an active role in care safety: Examples of verbatim	
1. Being curious	<i>“I ask a lot of questions, I want to know what... to share my apprehensions”.</i> (William)
2. Being able to observe	<i>“When I have a new drug, I check my behavior and what happens. Then, I can report the results to the doctor.”</i> (Howard)
3. Being responsible	<i>“I have always been in a dynamic where I am responsible. The HCP did not have to worry about whether or not I would change or stop my medication. The doctors worry about that, they worry about the risks if your patient is not taking his medication, and they know the consequences”.</i> (Kathy)
4. Being able to trust	<i>“In general, I trust the doctors and I really trust their knowledge. I would be scared if I was to question them all the time, “harass” them. You have to balance things.”</i> (Confident - Flora)
5. Being respectful	<i>“I talked to the doctor and was not afraid to tell her my opinion while remaining polite.”</i> (Jack)
6. Being diplomatic	<i>“It takes listening, empathy, a good dose of diplomacy. We also need to be careful of how we ask things.”</i> (Betty)

Table 6. Factors facilitating or limiting patient participation in safety

	Facilitating factors	Limiting factors
Patients	<ul style="list-style-type: none"> • Support • Involvement of relatives • Trust • Patient qualities (found above) 	<ul style="list-style-type: none"> • Poor knowledge of procedures • Fear of the consequences • Vulnerability due to illness and other characteristics (age, education, disability, etc.) • Lack of interest • Ignorance of their rights
Professionals	<ul style="list-style-type: none"> • Expertise • Empathy • Open Communication • Humility • Respect • Considerate care • Adherence to partnership 	<ul style="list-style-type: none"> • Non-recognition of errors • Lack of questioning • Not listening to patients
Organization	<ul style="list-style-type: none"> • Health Professional PIVOT • Care partnerships • Committees • City-Hospital Collaboration • Training for Professional 	<ul style="list-style-type: none"> • Lack of time • Lack of coordination • Unsafe Hospital environment • Organizational pressures <ul style="list-style-type: none"> ○ work overload ○ lack of money ○ staff turnover • Ignorance of health systems • Blame culture
Society	<ul style="list-style-type: none"> • Accountability • Transparency 	<ul style="list-style-type: none"> • Lack of accountability and responsibility • Lack of transparency

- The fourth competency is trust. Trust is emphasized as a skill to acquire and it requires a certain amount of subtlety and time to build.
- The fifth competency is to be respectful. Speaking about emotional issues is not always easy, which is why it is important to take a step back and voice concerns in a respectful way. And finally, also related to being respectful, patients mentioned the importance of being diplomatic.

4. Factors facilitating or limiting patient engagement

While behaviours and competencies enabled patients-as-partners to better engage in the safety of their care, their engagement was also affected by other factors found at multiple levels (*patients, professionals, organizations and society; all summarized in Table 6*).

At the patient level, facilitating factors such as support and involvement of relatives, trust and all the other factors on quality and competence are mentioned in Table 5. Limiting factors include: poor knowledge of procedures, fear of consequences, vulnerability due to illness and other

characteristics (age, education, disability, etc.), lack of interest, and ignorance of patient rights.

At the professional level, facilitating factors are: expertise, empathy, open communication, humility, respect, considerate care, and adhering to partnership; while limiting factors are: non-recognition of errors, lack of questioning, and not listening to patients.

At the organisational level, facilitating factors include: health professional care partnerships (or nurse navigator), committees, city-hospital collaboration, and training for professionals; whereas factors limiting engagement are: lack of time, lack of coordination, unsafe hospital environments, organizational pressure, work overload, lack of money, staff turnover, ignorance of health systems, and blame culture.

And finally, social factors such as the lack of transparency and accountability also came across as limits to patient engagement in safety.

5. The Partnership in Care approach as a way of limiting the occurrence of AEs

Knowing that behaviours, competencies and various factors affect the intensity of engagement of patients, how can all these elements be introduced and imparted to potential patients-as-partners? The Partnership in Care approach offers some initial building blocks.

All patients-as-partners involved in the study were part of patient partnership activities at the UofM, and it is worth underlining how these activities appear to have led them to change their behaviors or acquire new skills.

First, prior to their involvement with the UofM, patients-as-partners considered themselves as more passive, not daring enough to say “no” and being assertive. After enrolling, they claimed to have become more aware of their initial vulnerabilities and ability to offer treatment alternatives based on their experience, as well as encourage those around them to be proactive in their care.

Furthermore, they managed to recognize how the Partnership in Care approach could contribute to safety. Greater awareness is achievable by being proactive, working with professionals to avoid AEs and ensuring that professionals share the same desire. Patients-as-partners also mentioned proactivity as a central element to increase knowledge about one's illness, one's treatment, and the organization of care. The partnership approach fosters the development of better communication skills, particularly regarding one's expectations and risk situations (potential and actual). It also reinforces the notion of shared responsibility amongst each other. And finally, it allows patients to better understand the supporting role of relatives.

6. Limits and Discussion

This study has two main limits. The first one is the over-representation of women compared to men and the fact that the sample size does not cover all situations faced by patients and all behaviors and competencies to be developed by patients. The second limit is the uncertainty of whether the 16 other patients, who were not included in the study, have experienced an AE or not. Nonetheless, even though the patients were facing different situations, we reached data saturation after the 15th interview since there were no new shared ideas.

However, the main contribution of this research is to offer an analysis of how trained patients, who also teach the Partnership in Care approach, view their roles in patient safety (even if their training does not focus specifically on patient safety). The aim was to test the potential of the Partnership in Care approach as a promising way to improve patient safety. Although, at the beginning, for

many patients-as-partners, the connections between their patient partnership training and patient safety was not evident, they all managed to identify applicable AEs within their experiences and explore potential avenues for greater implication in patient safety. Even if patients-as-partners recognize safety issues and the importance of patient engagement in their own care, they do not make an immediate connection between the partnership approach training and patient safety applications. This indicates that the patient's role in safety is not obvious and need to be made more explicit, for example, during the patient-as-partner training programmes.

As suggested by the literature, significant emphasis is placed on the patients' ability to communicate with HCPs and the necessity of being confident to reduce risk situations^{18,24}. More recent literature supports the weightiness of patient proactivity, which is enabled by the recognition of patients' experiential knowledge and ability to share their learnings gained during care episodes^{19,24}. Moreover, proactivity by relatives has also been recognized for enhancing vigilance and limiting potentially dangerous situations, particularly in instances where patients are incapacitated by their condition. The role of relatives is increasingly noticed thanks to, for example, the “Better Together” campaign by the BC Patient Safety & Quality Council, which encourages relatives to stay in healthcare institutions around the clock (24 hours)²⁷. Such proactivity is in line with other objectives found in initiatives from around the world, in which patients and their relatives can declare at-risk situations and AEs¹⁹.

On the other hand, the literature also identifies a certain number of inhibitors, which could potentially discourage patients from engaging in care safety. Those include: levels of education and literacy²⁵, language barriers²⁶, or low levels of satisfaction^{9,14,24,25}. Patients part of our research also shed light on other elements such as curiosity, responsibility, as well as the ability to be respectful and diplomatic (as in expressing concerns with tact), which is not always evident to accomplish in at-risk situations.

With regards to factors inhibiting or encouraging patient participation, this study also reveals areas of improvement (as identified by patients-as-partners): a reporting mechanism integrating follow-through by HCPs¹⁹, lack of knowledge of care pathways, the fear of consequences, ignorance of patient rights²⁵. Patients-as-partners also identified the importance of making HCPs more aware of listening and recognizing their mistakes^{24,25} and to apologize^{24,25}. From an organisational perspective, the lack of time, work overload and blame culture could also stand in the way of increased patient engagement²⁵. In addition, the results of the research highlighted the importance of HCPs training. Not only for future HCPs but also for current ones. In fact, many renowned organisations released guides and training programs for

patient engagement in patient safety²⁹⁻³¹, as well as case studies to improve patient experience in reducing AEs³² and to help the HCPs in their practice to better integrate the patients' experience for patient safety. These organisations are also working on continued education on this matter. It would be relevant to encourage interdisciplinary training that includes patients as team members and where patients teach side by side with HCPs on how to engage patients in patient safety.

Findings of this study underscore that patients who are aware of the partnership approach perceive their care in a more proactive manner and realize that they possess useful knowledge applicable to care safety with regards to their disease, treatment and the organisation of care. They also develop communication abilities and the realization of shared responsibility in safety alongside other HCPs. Thus, thanks to patient partnerships, it is possible to envision a transition from a blame-oriented culture to a shared-risk and learning culture, in which patients are included in safety teams not only for their own safety, but that of HCPs as well.

Conclusion and Recommendations

The Partnership in Care approach is an important foundation for promoting the safety of care. However, to date, it still does not incorporate how patient-as-partners, can be engaged in the prevention of AEs, thus patient safety. The Partnership in Care approach recognizes not only the experiential and technical knowledge of patients, but also their knowledge of the organization of services¹². The recognition of patients and their relatives as full members of the care team grants them the right and responsibility to identify any situation that may impact their safety and integrity. This approach, if applied to the context of patient safety, would acknowledge the consequential impact of acts committed towards patients and, therefore, develop a shared responsibility between patients and HCPs. This shared responsibility will complement vigilance that professionals may lack (due to blind spots, fatigue, or other unexpected circumstances) and avoid a blame culture.

Furthermore, based on the notion of partnership and results from this study, a set of recommendations emerge for academic institutions and healthcare decision-makers. Indeed, more formal patient engagement relies primarily on the training of HCPs, whether at initial stages or in continued education. It is essential, as supported by the Montreal Model²¹, for patients to be present or included in courses pertaining to safety, first to share their experiences, but most importantly, bestow their contributions upon future HCPs to help reduce risk. Therefore, the Partnership in Care approach should integrate a missing safety component in order to engage and influence relatives/carers (along with patients and staff) not only in

quality improvement but also in patient safety, which would further support the reduction of AEs.

Moreover, through teaching patient rights and responsibilities, patients-as-partners could be leveraged to awaken the abilities of other patients in terms of partnership with HCPs. Thinking more broadly, training could be provided to all staff, relatives, patients, and carers at the point of entry or at pre-admission according to the care in question. The closer the training is to practice, the more effective it can be²⁸. We now need to think about how this could realistically be done.

Besides the importance of integrating a safety component in the Partnership in Care training, academic institutions and healthcare decision-makers could involve patients, carers and their relatives in shared decision-making, committees, work-groups and improved the overall health literacy of their patients^{29,33}.

Finally, for safety purposes, though it remains crucial for health professionals to report close calls, incidents or accidents, the current procedures only capture the definition of safety as perceived by HCPs. In fact, the patients' definition of safety is usually disregarded. Our research indicates that feelings of insecurity with regards to the relationship of care, or vis-à-vis the environment (e.g. emergency rooms), or the prescription of new medication and allergies, or waiting times, are considered as AEs for patients. Such key information would allow the health system to not only capture AEs from a broader perspective (namely from the actual users of care and services), but also enhance the feedback loop of the complaints system by making it more proactive, inclusive and constructive toward better communication to patients about actions undertaken as a result of their complaint. In other words, the very definition of AEs needs to be revised and made more inclusive as to incorporate the perspective of patients.

In conclusion, Chinese philosopher Confucius once said: "Tell me, and I will forget. Show me, and I may remember. Involve me and I will understand." Patients need to be involved in health care safety, which could be improved by implementing a safety component in the Partnership in care approach.

Appendix

Interview guide

1. Can you tell us about your care experience or your relative's care experience? How long have you been sick and what types of care have you or your relative received?
2. Have you experienced an incident, an accident or a near miss related to your care, your treatment or your medication? How did you manage the situation? How

did your healthcare professionals or clinical team react to the situation?

3. How do you define your behaviors regarding the risks associated with your care, treatment and medication? Are you rather confident or rather distrustful with healthcare professionals about their capacities to prevent or manage a potential incident or accident?
4. What lessons have you learned about the roles of patients and relatives to avoid or manage incidents or accidents during a care episode at hospital or during recovery (when returning to home)?
5. Have you already avoided incidents or accidents? What was your role in avoiding the situation? Has being a patient-as-partner helped you? If yes, why?
6. How can the partnership approach in care, as it is taught at University of Montreal, help limit incidents and accidents related to care?
7. From your perspective, what are the necessary qualities and competencies for patients or their relatives in order to limit or prevent care incidents or accidents? What are the qualities or competencies important for healthcare professionals?
8. From your perspective, what factors facilitate or inhibit patients to be engaged in care safety? (examples: care and services operations, roles or behaviors of healthcare professionals, patient characteristics, etc.)

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