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Nathalie Clavel
Ursula Aho-Glele
Noemie Ferré
Paloma Fernandez-McAuley

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

Marie-Pascale Pomey, Université de Montréal, marie-pascale.pomey@umontreal.ca
Nathalie Clavel, Université de Montréal, nathalie.clavel@umontreal.ca
Ursulla Aho-Glele, Université de Montréal, ursulla.aho-glele@umontreal.ca
Noémie Ferré, CHU de Nice, ferre.n@chu-nice.fr
Paloma Fernandez-McAuley, McGill University, paloma.fernandez-mcauley@gmail.com

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 services 1, 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 risks 17. 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 contexts 18 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 disability 20.
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 too, you have to see this, then if you get hurt, you go 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...
How patients view their contribution as partners in the enhancement of patient safety in clinical care, Pomey et al.

Table 1. Patient Characteristics

<table>
<thead>
<tr>
<th>Patient</th>
<th>Sex</th>
<th>Disease</th>
<th>Self-experience or Relatives’ experience</th>
<th>Nature of experienced AEs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jack</td>
<td>M</td>
<td>Type 2 diabetes</td>
<td>Self</td>
<td>Incident: Failure to administer treatment for several days (two days) in a rehabilitation clinic.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>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)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Led to the hospitalization of the patient 48 hours later, then to the amputation of his foot.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Near Miss: Additional insulin doses and snacks without the knowledge of healthcare professionals.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Not a real incident because the nurses / doctors have respected the doses recommended by the protocols.</td>
</tr>
<tr>
<td>Mary</td>
<td>F</td>
<td>Cancer, Muscular Dystrophy Oculopharyngeal (MDOP)</td>
<td>Self and relatives</td>
<td>Accident: &quot;Error&quot; that led to a temporary disability of the patient’s child.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Back in the hospital two days later, dealing with persistent pain. Ask to see another doctor who diagnosed a fracture.</td>
</tr>
<tr>
<td>Maggy</td>
<td>F</td>
<td>Myeloid leukemia</td>
<td>Self</td>
<td>Accident: Nosocomial infection (during hospital stay) after a transfer to another unit.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Delay in the grafting process.</td>
</tr>
<tr>
<td>Allison</td>
<td>F</td>
<td>Breast cancer</td>
<td>Self and relatives</td>
<td>Incident: Knee operation delayed due to non-transmission of test results.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Accident: Pressure ulcer.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Incident: Withdrawal of the wrong drug treatment just before its administration.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Injection of a &quot;bad&quot; treatment avoided by the patient who recognized the treatment thanks to the color of the bottle.</td>
</tr>
<tr>
<td>Jennifer</td>
<td>F</td>
<td>Cervical chronic pain, myofascial syndrome</td>
<td>Self</td>
<td>Accident: Chronic pain + MRI hospitalization for two months + myofascial syndrome.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Accident: Hyperlaxis following treatment with magnesium.</td>
</tr>
<tr>
<td>Stephanie</td>
<td>F</td>
<td>Breast cancer</td>
<td>Self and relatives</td>
<td>Near miss (relatives): Surgical intervention was reported because the patient needed a particular device (fiber optic) for intubation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Incident: Overdose.</td>
</tr>
<tr>
<td>Georges</td>
<td>M</td>
<td>Cystic fibrosis, diabetes</td>
<td>Self</td>
<td>Near miss: Patient identifies a treatment that is not intended for him (antibiotics destined for another person).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Incident: Hyperalgesia of a disconnected epidural. Health care team did not take that into account. It happened in a context of transfer between institutions.</td>
</tr>
</tbody>
</table>

(Table 1 continued next page)
<table>
<thead>
<tr>
<th>Patient</th>
<th>Sex</th>
<th>Disease</th>
<th>Self-experience or Relatives' experience</th>
<th>Nature of experienced AEs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betty</td>
<td>F</td>
<td>Breast cancer</td>
<td>Self and relatives</td>
<td>Accident (relative): Long-term hospitalized patient - felt ill after discharge. - a request for re-admission was refused – and the patient died. Incident: 2nd surgery because narrow margins in the context of cancer – the patient received radiotherapy afterwards – it was very painful. Near miss: Hospitalized patient – an anxiolytic was not delivered by the hospital. -The patient became very anxious. Incident: Delayed diagnosis of cancer.</td>
</tr>
<tr>
<td>Kathy</td>
<td>F</td>
<td>Lupus</td>
<td>Self</td>
<td>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.</td>
</tr>
<tr>
<td>Howard</td>
<td>M</td>
<td>Type 2 diabetes and Parkinson</td>
<td>Self and relatives</td>
<td>Accident: Spine surgery - mouth drain in post-operation - 2nd emergency operation.</td>
</tr>
<tr>
<td>Virginia</td>
<td>F</td>
<td>Type 1 diabetes and leukemia</td>
<td>Self</td>
<td>Incident: Fall of an elderly person - Immediate care was given and was being judged adequate (x-ray was completed, etc.)</td>
</tr>
<tr>
<td>Flora</td>
<td>F</td>
<td>Thyroid cancer and breast cancer</td>
<td>Self</td>
<td>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.</td>
</tr>
<tr>
<td>Patricia</td>
<td>F</td>
<td>Fibromyalgia, colorectal inflammatory disease, psoriasis</td>
<td>Self and relatives</td>
<td>Near miss: Chirurgical intervention context - allergy to antibiotic was not noted on file. However, the allergy verification was done by IDE in pre-op.</td>
</tr>
<tr>
<td>Edward</td>
<td>M</td>
<td>Thyroid cancer</td>
<td>Self</td>
<td>Accident: Diagnostic error (appendicitis diagnosed as miscarriage), with consequence (emergency surgery during pregnancy.</td>
</tr>
<tr>
<td>William</td>
<td>M</td>
<td>Malignant disease, lymphoma</td>
<td>Self and relatives</td>
<td>Accident: Nosocomial infection following cardiac surgery. - Stayed six weeks in hospital instead of six days.</td>
</tr>
</tbody>
</table>
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 relationships: 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 open ness 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

<table>
<thead>
<tr>
<th>Interviews</th>
<th>Verbatim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allison</td>
<td>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?</td>
</tr>
<tr>
<td>Laury</td>
<td>That is why I hesitated to participate at the beginning of the study, because […] I find it difficult to establish a partnership in care when it is a safety issue in surgery. […] 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.</td>
</tr>
<tr>
<td>Stéphanie</td>
<td>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.</td>
</tr>
<tr>
<td>Georges</td>
<td>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.</td>
</tr>
<tr>
<td>Flora</td>
<td>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.</td>
</tr>
<tr>
<td>Patricia</td>
<td>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. 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 is just said that”, “I did not understand”, “no”, or to make sure that I make the decision. Culture change will certainly help as well. Training new professionals in the care partnership.</td>
</tr>
<tr>
<td>William</td>
<td>[…] 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.</td>
</tr>
<tr>
<td></td>
<td>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?</td>
</tr>
</tbody>
</table>
Table 4. Adverse events encountered by oneself or by relatives: Examples of verbatim

| Table 4 continued next page |
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: "phew! 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:

“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 your patient (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>
<thead>
<tr>
<th>Quality or Competency</th>
<th>Example Verbatim</th>
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<tbody>
<tr>
<td>1. Being curious</td>
<td>“I ask a lot of questions, I want to know what… to share my apprehension!” (William)</td>
</tr>
<tr>
<td>2. Being able to observe</td>
<td>“When I have a new drug, I check my behavior and what happens. Then, I can report the results to the doctor.” (Howard)</td>
</tr>
<tr>
<td>3. Being responsible</td>
<td>“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”. (Kathy)</td>
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<tr>
<td>4. Being able to trust</td>
<td>“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.” (Confident - Flora)</td>
</tr>
<tr>
<td>5. Being respectful</td>
<td>“I talked to the doctor and was not afraid to tell her opinion while remaining polite.” (Jack)</td>
</tr>
<tr>
<td>6. Being diplomatic</td>
<td>“It takes listening, empathy, a good dose of diplomacy. We also need to be careful of how we ask things.” (Betty)</td>
</tr>
</tbody>
</table>
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. 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. 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). 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 AEs.

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 literacy, language barriers, or low levels of satisfaction. 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 HCPs, lack of knowledge of care pathways, the fear of consequences, ignorance of patient rights. Patients-as-partners also identified the importance of making HCPs more aware of listening and recognizing their mistakes and to apologize. From an organisational perspective, the lack of time, work overload and blame culture could also stand in the way of increased patient engagement.

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 safety \cite{29,31}, as well as case studies to improve patient experience in reducing AEs \cite{32} 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 services \cite{12}. 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 Model \cite{33}, 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 be \cite{28}. 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 \cite{29,31}.

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 undertaking 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. Involveme 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.)

References


