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Bringing patient advisors to the bedside: a promising avenue for improving partnership between patients and their care team

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Cover Page Footnote

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Abstract

This paper presents an innovative model of care, which brings patients who have already been through a similar experience of illness (*patient advisors*) directly to the bedside of patients, where they are viewed as full-fledged members of the clinical team. As part of a pilot project, three patient advisors were recruited and met with patients who had sustained a traumatic amputation and were admitted to the only center of expertise in replantation of the upper limb in Canada. Several individual interviews and focus groups with patients and patient advisors have revealed very promising results. Indeed, patients have expressed tremendous appreciation for their meetings and interactions with patient advisors. They have stated feeling less isolated, having a better morale and increased hopefulness regarding the outcome of the care pathway. Patient advisors also felt a positive impact of their involvement. A larger study needs to be conducted to determine the impact of this model of care on patient adherence to treatment and on members of the health care team.

Keywords

Patient partnership, peer support, patient advisors, communication, quality of care, model of care

Acknowledgement

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Introduction

Peer volunteers have successfully been involved in a variety of settings for a few decades now¹. The benefits of having peer volunteers serving as educators for large-scale community-based health promotion efforts are now widely recognized². Group peer support programs designed for individuals living with an illness have also been largely developed, especially for patients living with cancer³ and other chronic diseases⁴. Such programs have generally proven beneficial for patients and for peer volunteers, alike¹.

Nevertheless, not all patients are willing and/or able to engage in peer support workshops for which they have to sign in and that are scheduled at a given time and place. Individualized and more flexible forms of peer support have also been experimented⁵. For instance, studies have been conducted on the use of one-to-one peer support offered during their hospitalization to patients who suffered a burn injury⁶. One-to-one peer support is also widely present in the field of mental health, where individuals who have progressed in their recovery can undertake a substantial training program to be employed as *peer support specialists*⁷. Studies have linked this approach to positive impacts on service users and their satisfaction regarding the care that they have received, on peer support

specialists themselves, as well as on the practices of other members of the care team⁸. The resources required to train and to pay peer support specialists, however, is an important limitation for the transfer of this model to other settings.

A promising avenue to overcome this challenge lies in the development of a new model of intervention that allows one-to-one peer support to be fully integrated in the care delivered to patients but without positing peers as paid professionals. This article describes such a model, bringing patients who have already been through a given illness experience (*patient advisors*) directly to the bedside of patients, where they are viewed as full-fledged members of the clinical team. Patient advisors are recruited and trained by care teams in order to meet with patients on a voluntary basis to share their own experience.

In addition, an important characteristic of this model is that patient advisors are considered as actively helping in the creation of a partnership between patients and members of their care team. Because patient advisors have already lived through a similar experience they are indeed uniquely positioned to serve as a bridge between patients and healthcare professionals and to ensure that patients are engaged to their satisfaction in their own care. The model described in this article is, as such, directly in line with the current emphasis put on patient engagement as a promising and innovative approach to improving the quality of care in a healthcare environment where resources are limited⁹. Important considerations to take into account when implementing this approach on a larger scale will be highlighted on the basis of qualitative (interviews and focus groups) and quantitative (survey) data collected during the pilot phase of the project (July 2014-June 2015).

Experimenting with a new model of patient partnership: patient advisors at the bedside

The *Centre d'expertise en réimplantation et revascularisation microchirurgicale d'urgence* (CEVARMU) du *Centre hospitalier de l'Université de Montréal* (CHUM) is currently testing this model of care¹⁰. The CEVARMU is the only center of expertise in replantation of the upper limb in Canada. Its specific mandate is to optimize all medical, surgical and rehabilitation care pre-, peri- and post-surgery for all persons over fourteen years of age in Quebec who have suffered a traumatic amputation of the upper limb. Members of the team include plastic surgeons specialized in microsurgery of the hand, occupational therapists with expertise in rehabilitation post plastic surgery of the hand, nurses, psychologists and social workers. Approximately 150 patients are admitted annually to the CEVARMU, 80% are men and 44% are between 35 and 54 year of age. Patients remain in acute care for an average of five days post-surgery. Interdisciplinary rehabilitation begins at the

first postoperative day and is offered for a duration of approximately one year at a rate of 25 hours per week.

Post-surgery rehabilitation in jeopardy

In 2013, the CEVARMU team noted a significant difference in the rates of adherence to their rehabilitation intervention protocol between patients followed at the CEVARMU and those transferred to other rehabilitation facilities throughout the province (85% vs. 35%). Non-adherence to rehabilitation protocols has serious implications at multiple levels: physical, psychological as well as social and may jeopardize the replantation surgery. Assuming that this gap in rate of adherence to rehabilitation protocols could be explained at least partly by the isolation of patients followed outside the CEVARMU, sometimes in remote regions of the province where highly specialized care of this nature is scarce or even absent, the team of the CEVARMU has initiated an innovative project aimed at creating a new model of intervention based on the involvement of patient advisors in the development of care partnerships. The project, funded by the Canadian Foundation for Healthcare Improvement as part of its *Partnering with Patients and Families Collaborative*, involved the formalization of the modalities of recruitment, training and involvement of patient advisors within the care team.

Evaluation of the pilot phase

We conducted interviews and focus groups to ensure best conditions for implementation. Interviews were conducted with three patient advisors to assess their ability to offer quality support, their motivation to offer time and share their experience. We also conducted a focus group with these three advisors after at least three interactions with patients to identify with them: 1) the content of interactions, 2) the difficulties encountered, 3) their needs in support and supervision (probation period), 4) the need for the same patient advisor to accompany the same patient throughout the process, 5) the need for exchanges amongst patient advisors and 6), the contribution and the limits of realizing these interactions via video-conferencing.

The three persons in charge of project management were interviewed to highlight the facilitating and limiting factors related to the introduction of the patient advisors in the care continuum. A survey, adapted from the *Readiness to Partner With Patient and Family Advisors* tool¹¹, was used to evaluate care team members' readiness to partner with patient advisors. Fifteen care team members, within and outside of the CEVARMU, have responded to the survey.

Finally five patients out of the eighteen patients who had at least one interaction with a patient advisor during the pilot phase of the project, were interviewed by telephone to better understand their expectations, the content of their interactions with the patient advisor, the contribution

of the patient advisor in their care pathway and the difficulties encountered (particularly in relation to technology when interactions were conducted via video-conferencing) or their fears.

Patient advisors recruitment and training

At the beginning of the pilot phase of the project (July 2014), a patient advisor – who later became patient coach for other patient advisors – was recruited to conduct a first series of meetings with hospitalized and discharged patients to establish preliminary guidelines regarding procedures for recruitment and training of patient advisors. The optimal timing and content of the meetings with the patients were also further developed and tested during the first months of the pilot phase of the study. The components of the model are described below.

Recruitment of patient advisors is a key element to ensure the success of this model of care developed at the CEVARMU. Since the introduction of the intervention with the first patient advisor, two additional advisors were recruited (between October 2014 and February 2015). To ensure adequate fit of chosen individuals to the model, members of the care team were asked to identify, amongst their patients, those who corresponded to criteria that were established with the help of the experts from the *Direction Collaboration et Partenariat Patient (DCPP)*¹² of the Faculty of Medicine of the *Université de Montréal*. Selection criteria include:

- Good communication skills, ability to put others at ease and to understand nonverbal cues while communicating
- Good listening skills, attentiveness to details
- Willingness to share their own experience
- Control over one's own emotion and empathy
- Ability to work in team
- Availability and willingness to give their time to help others

A recruitment team composed of a patient coach and a patient partnership advisor at the CHUM then approaches these patients. Following a phone interview, a second in-person interview is held to further assess the skills and the preparedness of the patients to fulfill a role as patient advisors. Selected patients are invited to a 3-hour group training session led by the recruitment team and an expert from the DCPP. This training has three aims: 1) to provide general information on the CHUM and on the CEVARMU's mandate, 2) raise their knowledge of the theoretical foundations of patient partnership and 3), clarify the role of patient advisors, which is centered on four main elements:

1. To accompany and support patients in their experience of illness, in respect of the confidentiality rules that apply

2. To help facilitate communication and creation of a partnership between patients and their care team, notably in regards to the elaboration and evolution of the care plan
3. To share their experiential knowledge of the illness in order to contribute to patients' empowerment and feeling of self-efficacy
4. To respect the limits of their role by acknowledging and respecting the complementarity of their expertise of life with an illness and the clinical expertise of the care team.

A patient coach or a staff member of the CEVARMU accompanies new patient advisors to their first few meetings with a patient. A patient coach provides an ongoing support for advisors for the duration of their involvement on an as-needed basis.

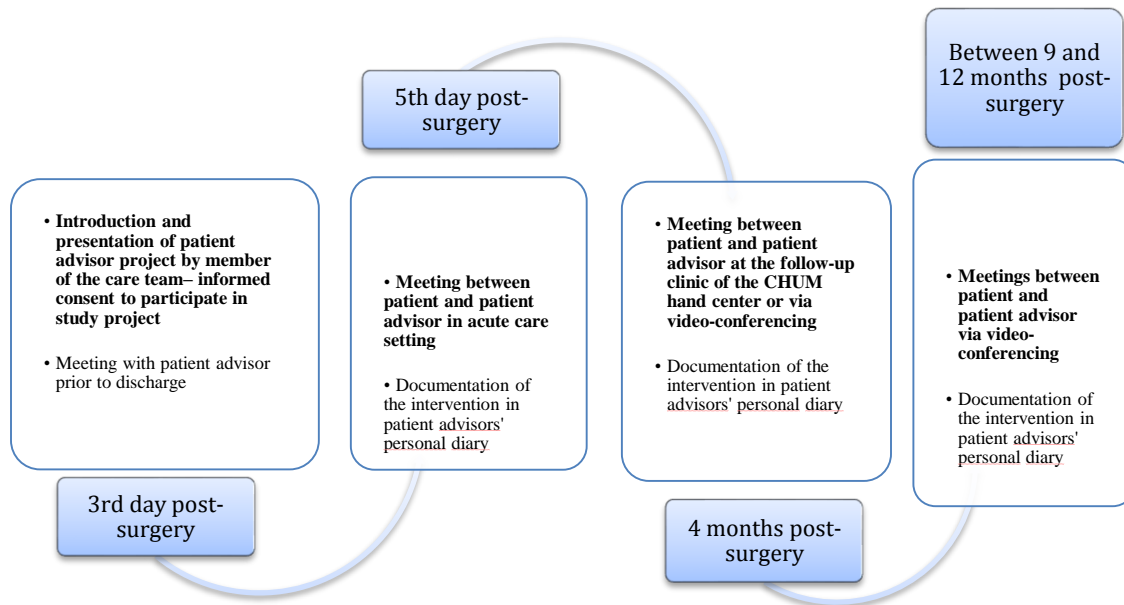
Integration of patient advisors in the trajectory of care

The pilot phase of the project has led to the formalization of the modalities under which patient advisors are invited to interact with patients (see figure 1).

It was established that the first week of hospitalization was a good time for a first meeting between the patient advisor and the patient. On the 3rd day of their hospitalization following their surgery, the coordinator of the project or another care team member working at the CEVARMU offers patients and their families the possibility to meet with a patient advisor. Those who express an interest in meeting with an advisor are asked to sign a consent form and a meeting is arranged on the 5th day of their hospitalization. This meeting allows for the 'diffusion' of the anguish and fear, the shock and any other strong emotions or issues related to the accident and the treatment that will follow. It also gives hope regarding the function of the hand even if deficits are present. It is usually relatively brief (15-30 minutes) as it is considered still too early in the rehabilitation process for patients to have specific questions regarding their care pathway. The encounter typically begins by patient advisors introducing themselves and sharing the story of their own accident and rehabilitation process. They then ask patients to describe how their injury happened as well as any significant events surrounding the time of the injury. Patient advisors then explain to patients what are the milestones of the rehabilitation process that they are about to undertake and offer other meetings on an as-needed basis. Globally, themes that have been identified in the pilot phase as being important to touch upon during this encounter are: feelings about their accident, problems that may have arisen following their injury (insomnia, nightmares, lack of control over their life, etc.), worries regarding their work and financial situation and the management of social life following the accident.

While it is possible for patients to solicit a discussion with a patient advisor at any time during their rehabilitation

Figure 1. Modalities under which patient advisors are invited to interact with patients



trajectory, the pilot phase of the project has helped determine two specific moments in this trajectory when the opportunity to meet with a patient advisor should be systematically offered to every patient, regardless of the fact that they have already had such an encounter or not. The first of these moments is three to four months following the surgery. This has been identified as a key point in the rehabilitation process as it is a time when patients should start regaining their autonomy and resuming their life roles. It is also a time when they realize the full impact of their injury on their lives.

We realize that there are some things that we had not thought we would have difficult doing for the rest of our lives, habits will be changed, maybe our hobbies. In short, there is a more "thoughtful" awareness than at the time of the accident of what it implies and all that raises new questions.... (Patient advisor 1, free translation)

Another important time to plan a meeting is between nine and twelve months after the surgery. An encounter at this point in time may 'force' a discussion the patient may not have felt the need to have before this point but may help the patient express emerging feelings about the perception of their level of disability, post-traumatic shock, return to activities of daily living and updating their life projects. Also, twelve months is generally close to the end of the rehabilitation process.

Rehabilitation was the center of their life for a very long time and they are now returning to a normal life with in a 'definitive' way (we may have reached a plateau and are still living with functional limitations, etc.) I think some patients may need to express some things or ask questions on how we lived that time etc... (Patient advisor 1, free translation)

These post-discharge meetings usually last longer (30-45 minutes) as patients have had time to experience different situations that they may wish to share with patient advisors. These time points correspond to regular visits established for follow-up visits at the CEVARMU as part of the regular care pathway but as most of the CEVARMU patients live outside of the Montreal region, videoconferencing tools can be used to facilitate access to one of the patient advisors that are currently part of the project. It is envisioned that organizations outside of Montreal could eventually recruit and train their own patient advisors to increase the opportunity for in-person meetings.

At any stage during the rehabilitation process, patient advisors are assigned to patients mainly on the basis of their availability, as it would be impossible to ensure a fit based on other (socio-demographic, type of injury, etc.) criteria due to the small number of advisors that have been recruited and trained so far. Patient advisors document all encounters in a standardized form. Formal debriefing

sessions are also arranged, by phone or in person, between patient advisors and the coordinator of the project. A summary of each session is included in the patient's medical chart. The actual use of these summaries and of the forms filled out by patient advisors to improve care in real time has not been documented. It is believed, however, that the implementation of a more systematic mechanism for feedback to the clinical team of the CEVARMU – yet to be designed – would yield additional benefits for patients and care team members alike. This would allow for healthcare professionals to learn more about the social situation of their patients, to improve their partnership with them and to make adjustments to the care plan as required. Interestingly, informal feedback mechanisms seem to be gradually emerging between patient advisors and the team on the unit on which CEVARMU patients are hospitalized. In addition, any information shared by a patient that is believed by the patient advisor to be critical for the wellbeing and/or safety of the patient is immediately shared with the clinical team.

Some promising results

Appreciation of patients and impact on their experience of care

According to our data, patient advisors can reformulate and strengthen the credibility of the professional interventions, making it easier for patients to understand the nature and reason for these interventions. This, in turn, helps to promote a sense of self-efficacy for patients and may increase adherence to the prescribed treatment and rehabilitation plans.

Encounters with patient advisors also help to break the isolation of patients and help them de-dramatize their situation. The occurrence of a traumatic amputation is often accompanied by a sense of shame that can cause people to withdraw from their social environment and isolate themselves. One patient expressed: *'We see that we are not the only ones to go through it. Not to be ashamed of disability and accept to get help and ask for help.'* (Patient 1, free translation). Another said: *'I found that I was not alone and even if there will be less sensitivity in my fingers as long as they function, that's what is good.'* (Patient 2, free translation) They may also present with an inability to recognize and tap into their own personal strengths and resources to get through the medical and rehabilitation processes that follow the surgery. Patients expressed the sentiment of increased morale:

'We saw that it came from his heart to talk to me, it was the truth, he was happy to meet me... I saw the light at the end of the tunnel, it helped me to feel better and I decided to fight like that's the result I see before me.' (Patient 4, free translation)

'Following the meeting my morale rose to 50%.' (Patient 5, free translation)

Meeting and discoursing with a person who has lived through a similar experience provides patients with a certain complementary 'hands-on' expertise: living through a traumatic experience as well as a dramatic change in body image that has the potential to greatly impact on personal and social interactions. One patient expressed his feelings as *'seeing a functional hand, especially psychologically, to see a repairable hand and that works well for me was very important during this period'*. (Patient 3, free translation)

Patient advisors also provide hope to patients by embodying the result of the rehabilitation process. The visualization of a functional hand after replantation and rehabilitation is a proof of success that contributes to empowering the patients to regain control over their lives and their own treatment plan. Here is an example of a quote from a patient:

'I now see how he (patient advisor) has regained mobility and strength of his fingers and his hand, which helped me gain confidence in myself. I also talked about my accident and it was the same kind of accident as mine with the same pattern.' (Patient 4, free translation)

Meeting and discoursing with a patient advisor may also increase patient adherence to their prescribed treatment plans: *'I was encouraged to start the occupational therapy. I saw a concrete result, a well repaired hand which helped me to visualize my hand and imagine how it will be after treatments.'* (Patient 3, free translation). *'The meeting brought me a lot, especially moral support because my morale was low and at the end of the meeting my morale became 100%.'* (Patient 4, free translation).

Motivations of patient advisors and perception of their role

The first motivation stated for becoming an advisor was giving back to others and supporting patients that are living through similar traumatic experience: *'I strongly believe in giving back. I have an experience of life before the accident, so if I can [it is important] to give back to someone.'* (Patient advisor 3, free translation); *'If it can allow other people like me to go through it and continue to have a normal life, to resume work and all that, I think it would be ... something.'* (Patient advisor 2, free translation)

Another motivation to partake in this endeavor was to remain occupied while they were off work: *'Also, it occupies the time ... I knew I had six months I had nothing to do, so I told myself to be able to [help]. It's just that.'* (Patient advisor 3, free translation)

In general, patient advisors felt they play four major roles. The first one is to listen. They feel they can bring the patients to open up about their feelings regarding the injury. Second, patient advisors also feel they can support the health care team by simplifying and making the entire process and the information conveyed during a very

stressful and emotional time ‘user friendly’ for the patients. A third important role stated by patient advisors is breaking the patients’ loneliness and lastly, they feel they are giving them hope and increasing their motivation regarding the rehabilitation process.

A challenge: care team members’ involvement

While patients and patient advisors have globally answered very positively to the project, some difficulties have been encountered in getting care team members to actively participate in the implementation of the model. Care team members have a key role to play, as they are responsible for offering their patients the possibility of meeting with a patient advisor. The low number of referrals that were made by team members other than the coordinator of the project during the first months of pilot phase suggests that there was a resistance on the part of members of the care team to effectively involve patient advisors in their practice.

A possible explanation for this situation is that members of the care teams were not involved in the project from its very beginning, i.e. in the design of the model and in the recruitment of the first patient advisor. The design and planning of the project were indeed done by one team member of the CEVARMU, in collaboration with external advisors but without the involvement of other care team members. Their limited involvement in the early phase of the project may also explain care team members’ ambiguity as to the role that patient advisors were to play and, thus, their reluctance to offer their patients meetings with a patient advisor. The results of the survey on care team members’ readiness to partner with patients and patient advisors that were collected between May 4th and May 18th 2015 indeed suggest a lack of consensus as to the usefulness of patient advisors’ involvement in the care of patients (see figure 2). Informal discussions in which care team members expressed concerns that patient advisors

would provide patients with advice that contradicts that of the care team or would comment negatively on the team’s work are in line with the results of the survey. Finally, the results of the survey also highlight a high level of uncertainty as to the professional and legal implications, for team members, to collaborate with patient advisors (see figure 2).

In response to these results, strategies were put in place in order to clarify the role of patient advisors to the care team members. For instance, some care team members were invited to attend a training session given to newly recruited patient advisors in order to become more familiar with the role of patient advisors within the team. This had very a positive impact on their willingness to collaborate with patient advisors and a gradual acceptance and involvement of care team members in the patient advisor model has been observed. This strategy will be retained.

Conclusion

A pilot study to examine the impact of a new partnership model integrating patient advisors directly in the trajectory of care, implemented in an acute care hospital for persons who have suffered a traumatic amputation of the upper limb has shown a positive impact on patients as well as on patient advisors themselves.

We believe this model could be easily transferred and adapted to other patient populations and care settings. Adaptations to the processes involved in the implementation of such a model would have to take into consideration the particulars of the targeted health condition and the setting into which it is to be implemented. A pilot phase during which both quantitative and qualitative data obtained through interviews with all parties involved helps in identifying

Figure 2 . Extracts from the results of the survey on care team members’ readiness to partner with patients and patients advisors.

Percentage of care team members surveyed who:	
Did not believe that patient advisors can look beyond their own experience to suggest ideas and solutions that are useful for other patients	37.5%
Did not believe that the participation of patient advisors in the planning and in decision-making about a patient’ care plan can be useful	31.25%
Considered that patient advisors had an impact on their work load	37.5%
Were unsure about their professional responsibilities towards patient advisors	87.5%
Were unsure about legal issues raised by the active implication of patient advisors within the organization:	75 %
Did not consider that the CEVARMU facilitated the integration of patient advisors in their everyday work	37.5%

important aspects to take into consideration and may help adjust the process along the way.

Of utmost importance is the standardization and quality of the recruitment and training processes of patient advisors. They must be carefully chosen to ensure an adequate fit to the model and to the patient population. As well, the training provided must be clear on patient advisors' role and co-taught by patient advisors and staff members with considerable experience of this model. This is crucial not only for providing patients with optimum care but also to ensure a positive impact on patient advisors and members of the health care team.

Also, our experience has highlighted the importance of taking into consideration the acceptance and approval of all care team members for this model of care. We believe the 'buy-in' of care team members is a sine qua non condition for the success of the implementation process. Particular efforts must be put in place to involve them in the early stages of the project to ensure a common vision of the role of patient advisors and of their contribution to the care of patients. This requires a clear commitment and sustained support from the coordinators of the project.

The true effectiveness of this model to increase patient adherence to their proposed treatment and rehabilitation plans needs to be further assessed through a larger study. To this end, a randomized controlled trial will soon be undertaken at the CEVARMU in which newly admitted patients will be randomly assigned to receive standard care alone or standard care supplemented with a patient advisor according to developed model. The results of this proposed study will allow us to determine whether the inclusion of a patient advisor in the care process is effective to produce a better return of upper extremity function and better adherence to the rehabilitation program for patients admitted to CEVARMU.

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