

The Partnership Co-Design Lab: Co-constructing a Patient Advisor Programme to increase adherence to rehabilitation after upper extremity replantation

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SUMMARY

At the Centre of Expertise in Reimplantation and Emergency Microsurgical Revascularisation (CEVARMU) of the University of Montreal Hospital Centre (CHUM), a team noted a significant difference in the rates of adherence to rehabilitation interventions between patients followed at the CEVARMU and those transferred to other rehabilitation facilities. The team surmised that the higher rates of adherence to rehabilitation protocols at the CEVARMU could be explained partly by the implementation of a five-phase Patient Advisor Programme created with patient input through the Partnership Co-Design Lab.

Key Words

Patient partnership; peer support; patient advisors; co-design; partnership co-design lab

ABSTRACT

Background

The Centre of Expertise in Reimplantation and Emergency Microsurgical Revascularisation (CEVARMU) noted a significant difference in rates of

adherence to rehabilitation interventions between patients followed at the CEVARMU and those transferred to other rehabilitation facilities.

Aims

To increase the rate of adherence to rehabilitation interventions, the CEVARMU has initiated an innovative project to create a new intervention model. This new model involves Patient Advisors (Pas) in the development of a peer support programme.

Method

The project consists of five phases: 1) identification of needs through common understanding; 2) design of the idea through a vision and scriptwriting; 3) co-design and evaluation of a pilot project; 4) co-design and evaluation in “real life” through pragmatic trials. The last phase is embedded in the other four: 5) improvement, change management, sustainability and partnership to create and assess the peer support programme.

Conclusion

The Partnership Co-Design Lab (PCDL) allowed the creation of a peer support programme and 25 patients benefited from Patient Advisor support.

BACKGROUND

After traumatic upper extremity amputations, postoperative adherence to rehabilitation protocols is one of the main determinants of a functionally successful replantation.^{1,2} Functional long-term outcomes demonstrate that compliant and motivated patients seem to fare better than their counterparts. However, all patients cope differently with trauma, and various factors ultimately affect their adherence to treatment plans after hospital discharge. These factors can include: their social support environment; socioeconomic background; level

of education; and psychosocial health at the time of injury. Therefore, it is necessary to emphasise the laborious postoperative process of informed consent at the time of surgery. Unfortunately, it takes place during a race against ischemia. At this crucial time, surgeons may find it difficult to predict which patients will be compliant.

In 2010, the University of Montreal Hospital Centre (CHUM) was designated as the Centre of Expertise in Reimplantation and Emergency Microsurgical Revascularisation (CEVARMU) by the Quebec government.³ In 2013, the CEVARMU team noted a significant difference in rates of adherence to rehabilitation intervention protocols between patients followed at the CEVARMU and those transferred to other rehabilitation facilities throughout the province (85 per cent vs. 35 per cent). Non-adherence to rehabilitation protocol has serious physical, psychological, and social implications and may jeopardise the replantation surgery.

The CEVARMU team assumed that this gap in rates of adherence to rehabilitation protocols could be explained partly by the isolation of patients followed outside the CEVARMU—sometimes in remote regions of Quebec, where highly specialised care of this nature is scarce or even absent. In response, the CEVARMU team has initiated an innovative project aimed at creating a new model of intervention; namely, to involve Patient Advisors (PAs) in the development of care partnerships. Previously published data, focused on qualitative aspects of care, have reported promising results in terms of patient appreciation, a better understanding of treatment plans, and an increased hope regarding functional outcomes.^{4,5} The project, funded by the Canadian Foundation for Healthcare Improvement (CFHI) as part of its Partnering with Patients and Families Collaborative, was based on three main principles: the patient-partnership paradigm, the Living Lab concept, and the co-design method. In this paper, we present the method that we developed, the Partnership Co-Design Lab, which helps us introduce PAs at the bedside.

METHOD

In developing the Partnership Co-Design Lab method, we decided to part from “The Montreal Model,” the patient-partnership model developed by and used at the University of Montréal,⁶⁻¹⁰ which recognised patients as

essential partners in all decisions affecting them. The PCDL method integrates the patient-partnership model, the Living Lab concept,¹¹ and the co-design method.¹²⁻¹⁷ The central principles used in the PCDL method include:

- Recognise the patients’ experiential knowledge as complementary to professional knowledge;
- Consider the patient as a full team member;
- Recognise decision-making and quality actions based on the professionals’ scientific and experiential knowledge and the patients’ experiential knowledge from living with the disease;
- Integrate all stakeholders who can be called out by the intervention from the beginning;
- Integrate research methods as feedback loops to improve continuously; and
- Adopt an incremental approach.

By integrating these principles, the five phases of the PCDL were identified: 1) Identification of needs 2) Co-design of the intervention; 3) Pilot project; 4) Evaluation in “real life”. The last phase is embedded in the other four and is called: 5) Improvement, Change Management, Sustainability and Partnership (Figure 1).

RESULTS

Among the 113 patients admitted to the CEVARMU in the first 10 months of 2013, 85 per cent adequately followed their treatment plan, compared to only 35 per cent among patients treated elsewhere. However, occupational therapists realised that patients who completed their rehabilitation at the CEVARMU had the opportunity to share what they lived and encourage fellow patients in re-adaptation rooms. Seeing the same patients three times a week motivated them to attend their occupational therapy sessions. In addition, new patients who arrived were systematically greeted by former patients who shared their experiences with them. Meeting former patients encouraged new patients to look to the future and foresee the progress they could achieve in the coming months. Informal discussions with patients validated these perceptions reported by occupational therapists, and even more so when it was mentioned that CEVARMU should evolve into a tertiary surgical care centre and relinquish rehabilitation to specialised structures spread across the province of Quebec. Therefore, this situation risked a significant loss of patients’ support at the CEVARMU. However, it has

been recognised that rehabilitation attendance is influenced by psychosocial conditions.¹⁸

Intervention Co-Design

Thanks to funds obtained through the Canadian Foundation for Healthcare Improvement (CFHI) in 2014, a working group based on the Living Labs model was created. This group was composed of: the Head of the plastic surgery unit (a plastic surgeon); the Coordinator of Occupational Therapists at the CEVARMU (a project manager formerly occupational therapist at the CEVARMU); two advisors in health promotion and therapeutic education; the directors of quality, multidisciplinary services and medical services of the institution (three decision-makers); a former patient and two researchers (one specialised in qualitative methodology and the other one in quantitative methodology, whom are also occupational therapists). Through this working group, the scope of expertise covered was: surgery, rehabilitation, health education, care partnerships, management, quantitative and qualitative research, and patient experience. In identifying the ideas to increase adherence to rehabilitation interventions based on the patient partnership principles, four focus groups were conducted: one with the CEVARMU clinical team; one with a sample of clinicians from three Physical Deficiencies and Rehabilitation Centres (CRDP); one with managers from the CEVARMU and CRDPs; and one with former patients interested in the project. All four focus groups proposed to introduce PAs at the bedside under the assumption that former patients can help new patients to: 1) enhance adherence to treatment; 2) decrease post-traumatic stress; 3) increase quality of care experience; and 4) decrease incidence on patients' perception of handicap.

In addition, questionnaires were sent to all professionals at the CEVARMU and the Consortium of rehabilitation centres to assess the needs of patients. Sixty-nine per cent of respondents expressed the need, qualified as a priority, to support and educate patients on the rehabilitation process, with PAs as an identified pathway. In addition, 80 per cent of professionals at the CEVARMU answered that they were ready to collaborate with PAs using the Agency for Healthcare Research and Quality (AHRQ) questionnaire.¹⁹ Finally, a questionnaire was sent to all former patients who were treated by the CEVARMU

during the last three years. Thirty-four per cent of respondents (33 per cent response rate) expressed the need to benefit from meetings led by patients living with a similar condition.

On this basis, the working group added three clinicians from rehabilitation centres and two additional former patients. To co-construct the intervention, the working group first established the care trajectory of patients treated at the CEVARMU and identified the time at which contact between a PA and a patient would be the most relevant: during hospitalisation, at one month and at four months post-surgery. The group also fixed a quantitative objective: to decrease by 15 per cent the perceptions of disability (Figure 2).

To better understand the nature of the interaction between a PA and a patient, the group decided to place a patient in a situation with another patient and record the interaction. The first intervention was performed between a PA and a patient refusing his rehabilitative treatment in a remote rehabilitation centre of the CEVARMU. The project manager interacted remotely with the PA through a video conferencing system (REACT system) which filmed the interaction. During the interaction, the PA told his story and showed his hand. The remote patient was lying with his face downwards at the beginning. Gradually, he tried to make eye contact with the PA and his body language showed interest in what the PA was saying. He started asking him about treatment and, by the end of the interview, the patient admitted he was very depressed but that, thanks to this exchange, he was ready to try the treatments again.

Subsequently, three other interventions were carried out by the same PA with other patients. All of these interactions were recorded and analysed, which allowed the team to highlight seven themes addressed by the PA: 1) context of the accident; 2) emotions/psychological reactions (eg, guilt, shame, grieving); 3) family and entourage (eg, relationships, children); 4) care episode (eg, pain management)/hospital stay (eg, next steps); 5) social perception of the accident (eg, isolation); 6) return to daily life (eg, tying shoe laces, eating, moving)/work (ie, when and how); and 7) financial issues (eg, coverage).

The evaluation showed that patients stated feeling less isolated, increased morale, and hopefulness regarding the

outcome of their care pathway. Furthermore, PAs felt positive about the impact of their involvement, helping patients open up about their feelings regarding the injury. PAs also felt that they can support the healthcare team by simplifying and making the entire process and information conveyed in more “user friendly” ways for patients undergoing stressful and emotional times. Finally, their experience makes sense because it can be used to help other patients. As for the team, the role of the PA was not clear. In response, team members were invited to attend a training session in order to become more familiar with the role of PAs within teams.

Pilot project

In light of the encouraging results achieved with a PA, the decision was made to recruit two other patients. This led to structuring the intervention and to conduct a pilot project. Patients were first recruited according to specific criteria (Table 1).

Table 1: Specific criteria to recruit patients

Patient recruitment criteria
<ul style="list-style-type: none"> • Ability to express themselves clearly and simply • Display a generally constructive attitude during their interventions with the healthcare system • Experience living with illness or rehabilitation • Relevant experience with health care and services targeted by the project • Stable health status at the time of recruitment (not in a severe or crisis situation) • Ability to distance themselves from their own experience of living with illness and learning how to live with it • Ability to generalise their experience to other care contexts • Demonstrate a desire to help people and to contribute to an objective beyond their individual interests • Demonstrate patience, respecting others’ rhythms and processes in which they become involved • Interpersonal skills suitable for collaboration (listening, empathy, etc.) • Critical judgment, even with respect to teams in which they had experience as patients • Understand the vision and implications of a care and services partnership model • Availability and motivation to be involved for the duration of the project

After careful recruitment, they were enrolled in a comprehensive training programme provided by the Health Promotion Department in collaboration with the first PA. The training programme has three aims: 1) provide general information on the mandate of the centralised replantation care unit;¹⁷ 2) refine their knowledge about the theoretical foundations of patient partnerships; and 3) clarify their role when they interact with patients and within the healthcare team. The PAs were recognised as volunteers at the CEVARMU.

During the first postoperative week, the treating surgeon or occupational therapist proposed to patients with difficulties (ie, psychological suffering, difficulties in their rehabilitation treatment, etc.) the possibility to discuss with PAs. The PA then visited the hospitalised patient, leading to their first interaction. Tailored to the patient’s needs, the PA could intervene during the rehabilitation process in person, by telephone, or by video-conference at two other times (eight weeks and four months after surgery). Intervention notes are also taken, orally and in writing, with a team member to make sure that the patient received all necessary treatment and care and did not need further support.

Between July 2015 to January 2016, eight patients were able to benefit from the experiential knowledge of PAs. In total, 20 interventions were completed during hospitalisation at the CHUM: six to eight weeks after discharge; and four months following replantation. The average duration of interactions was 35 minutes.

An analysis was conducted to compare the eight patients to other patients being treated at the same time at the CEVARMU (n=43). By comparing their handicap recovery scores (Disability of the Arm Shoulder and Hand score, ie, DASH score), the team noticed that scores improved by 13 per cent following a meeting with a PA, which means that the perceptions of disability decreased by 13 per cent. Moreover, the perception of pain decreased by 45 per cent among patients within the six-to-eight-weeks and four-to-six-months post-surgery groups, compared to patients who did not have PA support.²⁰

As for the PAs, they felt useful by answering questions from patients, sharing unique knowledge that no other member of the team can provide. They felt that they were supporting and appeasing patients. A difference is often

notable between the beginning and end of the meeting: the patient is more physically, and probably mentally, relaxed.

The interviews with plastic surgeons and occupational therapists showed that the intervention of PAs: 1) improve patient education; 2) open discussions about practice variations among surgeons; 3) encourage patient observance in rehabilitation treatment; and 4) help fluidify the service continuum for better transition and improved remote practices of occupational therapists.

Currently, seven PAs have been hired and, in 2017, roughly 25 patients were recruited at the CEVARMU by treating surgeons or occupational therapists, all of whom were able to benefit from PA support. The recruited patients are followed for one year, and the same outcome measures are used for patients who do not benefit from PA support (eg, quality of life, disability, pain, etc.).

Evaluation in “real life”

In order to provide the CEVARMU and the Consortium of rehabilitation centres with evidence-based medical practice, a pragmatic clinical trial will begin in 2018 to assess the effectiveness of the Patient Advisors Programme for victims of traumatic amputation. In total, 130 patients will be allocated to two groups. Patients in the control group (65 patients) will be subjected to the current standard of care only. Patients in the interventional group (65 patients) will be subjected to the current standard of care plus the Patient Advisors Programme. As in one of our other studies,²¹ we are planning to conduct this study with one of the PAs who recruits patients for two-and-a-half days per week.

Randomisation will be stratified according to the presence/absence of invalidity insurance. Meetings with the PA will take place systematically during hospitalisation, as well as at six weeks and at four months following replantation surgery. The DASH questionnaire will assess the impact of trauma on the perception of disability. Secondary measures of functional disability and pain will also be performed. For all measurements, data will be collected at eight weeks and at six months after surgery, as well as during the rehabilitation leave.

Improvement, Change Management, Sustainability and Partnership

At each of the five previous phases, we put in place an evaluation system to make retroactive adjustments and improve practices during each phase. We also trained the entire healthcare team in patient partnership, and currently lead the introduction of PAs as a change management project.²² For the sustainability of the Patient Advisors Programme, the fact that all stakeholders have been included from the outset has allowed us to rely on our first research results to maintain the programme.

DISCUSSION

The development of the PCDL allowed the team to not only co-design the Patient Advisors Programme idea with patients, but also develop a prototype intervention and a pragmatic randomised trial. Another characteristic of this method is to engage all stakeholders from the beginning, including decision-makers, which ensures the constancy of resources throughout the programme.

However, for the clinical team, the arrival of PAs at the bedside is not easy to understand at first. A change management strategy must be put in place simultaneously to help the clinical team better understand the complementarity of PA interventions relative to theirs.

The first results we obtained are very promising. With regard to patients, this affects not only their physical health, but also their psychological and social health. For PAs, this allows them to make sense of their experience by helping others through their ordeal. However, it is also important to track the psychological impact that the interventions may also have on the patients. And finally, for the healthcare team, this methodology helped them to understand better the concept of care partnership and how it can be embodied at the clinical level; and to better take into account the needs of patients throughout their care path, from the CEVARMU to rehabilitation centres, and to reflect on their practices.

CONCLUSION

In conclusion, the development of the Partnership Co-Design Lab allowed the creation of a space to co-design with patients an intervention based on patient partnership at the clinical level. The introduction of Patient Advisors into the healthcare team is very promising. We are currently introducing them in other programmes for patients with chronic diseases (eg,

cancer²³) and young patients who must transfer from paediatric medicine to adult medicine for their care (eg, heart congenital disorder²⁴) using the PCDL method.

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PEER REVIEW

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CONFLICTS OF INTEREST

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ETHICS COMMITTEE APPROVAL

Research Centre of the University of Montreal Hospital Centre (CR-CHUM) Ethics Committee, certificate naganano:CE 12.242

Figure 1: The Partnership Co-Design Lab



Figure 2: Assumption of the Patient Advisor Impact

