Active Patient Engagement: Long Overdue in Rehabilitation Research

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Patients can make a valuable contribution to developing and improving clinical care. Current foundations and strategies, including the Canadian Foundation for Healthcare Improvement and Canada’s Strategy for Patient-Oriented Research, focus on ways to engage patients in the development of health services, and a body of literature reports on engaging patients in decision making and policies to promote care delivered across acute-care settings. In comparison, patient engagement in research has received little attention.

Patients’ place in research has evolved from a passive role, in which they represent data points, to an active role that involves contributing to the research process. According to the Canadian Institutes of Health Research (CIHR), the term patient engagement refers to the meaningful collaboration of patients in the conduct of research, and patient engagement is now a requirement of any application for funding. The CIHR recommends integrating the patient perspective into every step of the research process, from conceptualizing a research idea and developing protocols through to translating the research findings into clinical practice.

Lessons on involving patients in research can be learned from other countries. In the United Kingdom, the government-funded INVOLVE program supports active patient engagement in health research across the country, but how patients have contributed to the research process is usually described only briefly in published research papers, if at all, and therefore the full impact of their involvement is seldom fully understood. Studies must routinely provide detailed information about the method of engaging patients in research and the impact of such engagement on outcomes and continuing research inquiry.

Very few published rehabilitation studies have included patients in the research process, except as participants. In the United States, the National Institute on Disability and Rehabilitation has recognized the importance of involving people with disabilities in rehabilitation research; several studies have explored the experience of living with a disability and people with disabilities have been included in program development—yet patient involvement in testing rehabilitation interventions is still rare, which may contribute to the current challenges of developing, translating, disseminating, and sustaining evidence-based rehabilitation interventions in clinical practice.

WHY PATIENT ENGAGEMENT IS IMPORTANT

Actively involving patients in research confers benefits to the patient, to the researcher, and to the public and wider community. At the patient level, studies that involve service users in selecting research topics result in the development of research protocols grounded in the day-to-day reality of patients’ experiences, meaning that research questions are more relevant to the needs of the population. For example, Morgan and colleagues recruited people with stroke as co-researchers in a study to assess public knowledge of stroke; this co-researcher role included identifying and directing the aims of the study. Patients reap personal benefits from engaging in research, including enhanced feelings of empowerment from contributing something valuable to the health and research community and improved disease management from developing greater disease-specific knowledge and coping strategies.

Actively involving patients can facilitate the research process at several stages, including development, recruitment, intervention, and analysis. Involving patients during the development of the research protocol can identify outcome measures that are important to them. Service users can also provide pragmatic criticism on the content of information sheets, thus assisting in the process of obtaining informed consent. Patient engagement has been shown to enhance participant recruitment and attrition; for example, Carroll and colleagues involved patients in delivering a community-based intervention consisting of one home visit plus telephone calls, which was successful in promoting attendance to cardiac rehabilitation. Patients’ insight can also increase the chances of developing and delivering an intervention that is feasible; in one study, for example, service users improved the timing of delivering therapeutic massage for people with Parkinson disease. Finally, patients can enhance the depth of qualitative analysis by adding insight to interpretations.

It has been suggested that patient engagement can strengthen the relationship between the community and

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researchers, thus making research findings easier to implement into the clinical service. More broadly, patient engagement builds communication with the community, which may then improve public understanding of science and research.

**HOW ARE PATIENTS ENGAGED IN RESEARCH?**

According to a systematic review of 142 studies, convenience sampling is the strategy most often used to identify patients for active engagement in research. Some of the reviewed studies recruited patient volunteers through advertisements, including posters and hospitals’ Web sites; social media platforms such as Facebook, Instagram, and Twitter may offer alternative options. Interestingly, recruitment via word of mouth from peers or clinicians does not appear to be a strategy commonly described in the literature, but it may present opportunities. For this method to be successful, health care professionals must be educated on patient engagement and aware of what the role entails, so that they can offer accurate information to patients. A combination of different methods maybe the best approach to recruit a diverse sample of patient representatives.

An active approach to patient engagement involves patients’ serving on a research board or advisory council throughout the study period; patients acting in this capacity are often called patient advisors or patient experts. A patient advisor may attend research meetings, help to develop ideas for future research, review study proposals and grant applications, and assist in translating and implementing research findings. Implementation activities may include writing articles for local newspapers and magazines, in addition to scientific journals, and presenting at local events, clinical team meetings, and research conferences.

Patient engagement can be a substantial commitment, and it is important that patients be aware of the role requirements from the outset. These can be presented in the form of a contract that both patient and researchers sign. Some institutions pay patients to contribute to research, although the amount of such remuneration varies.

It is important to ensure that patients receive adequate training in research methodologies. When appropriate training has not been provided, meetings can be dominated by patients’ personal stories about their experiences, rather than suggestions for improvements to the study design. However, the amount of training offered is worth considering, as the lines can become blurred between acting as a lay advisor and becoming a trained researcher. In fact, patients’ role may be time limited, as, over time, patients become professionals themselves.

**THE CHALLENGES OF PATIENT ENGAGEMENT**

Some patients engaged in the research process describe feeling overburdened, frustrated, and marginalized. It is important to be realistic in our expectations of patients; offering training in research methodologies can reduce their feelings of frustration by improving their ability to contribute. Feelings of being dismissed and marginalized may stem from patients’ perceptions of how researchers view their contribution. There have been concerns that patient engagement in research is tokenistic. Furthermore, community priorities have been shown to influence the scientific rigour of studies, which may explain why researchers resist input from patients. We hope that such views, on the part of both researchers and patients, will dissipate as the method and impact of patient engagement are reported more frequently in published studies.

**CONCLUSION**

Patient engagement in rehabilitation research offers significant benefits to patients, to researchers, and to the community. A diverse group of patient representatives can be recruited through the use of multiple methods, and these individuals should be actively involved throughout the research process. The role requirements of patient engagement must be clearly defined, and training must be offered, in order for patients to make a meaningful contribution. Applications for research funding need to include the cost of patient engagement. Involving patients in rehabilitation research is not without its challenges, but by valuing the contribution of patients, we can significantly enhance the quality of rehabilitation research, ensuring that we conduct relevant, feasible research whose findings can be more easily transferred to the clinical service.

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La participation active des patients : un aspect de la recherche sur la réadaptation qui s’impose depuis longtemps

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Les patients font une contribution précieuse à l’élaboration et à l’amélioration des soins cliniques. Les formations et stratégies actuelles, y compris la Fondation canadienne pour l’amélioration des services de santé et la Stratégie de recherche axée sur le patient du Canada, sont centrées sur les moyens de faire participer les patients au développement des services de santé. Par ailleurs, quantité de publications rendent compte des efforts visant à faire participer les patients à la prise de décisions et aux politiques pour la promotion des soins dispensés dans les milieux de soins actifs.1 Par comparaison, la participation des patients à la recherche n’a reçu que peu d’attention.2 L’apport des patients à la recherche a évolué, passant d’un rôle passif, dans lequel ils représentent des points de données, à un rôle actif, qui suppose leur contribution au processus de recherche. Selon les Instituts de recherche en santé du Canada (IRSC), l’expression

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