Rehabilitation Research: Who Is Participating?

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Evidenced-based practice (EBP) is critical to advancing both the physiotherapy profession and physiotherapy outcomes.¹ EBP is facilitated by the results of well-controlled studies, the generalizability of which depends largely on wide recruitment and participation of people with the condition of interest. Recruitment of participants is acknowledged to be the most difficult aspect of research, and often determines the success or failure of a randomized controlled trial (RCT).² Despite its critical importance, however, very little is known about participation in rehabilitation research. A deeper understanding of who participates in physiotherapy research and of the factors that influence willingness to participate is critical both to achieving insight into how the results of a study apply to the general patient population and to designing future studies to maximize recruitment of appropriate participants.

The medical research community has already recognized the importance of understanding factors that influence willingness to participate in clinical trials, as shown by studies conducted on this very topic.^{3–5} These survey-based studies have revealed factors that influence a person's decision to participate in a medical study, such as a positive attitude toward human research and knowledge of the importance of clinical trials to advancing medical care.

In contrast, no study has directly investigated factors that influence the decision to participate in a physiotherapy study, or in rehabilitation research more generally, which may differ from those that influence participation in a medical RCT. The discrepancy may be attributable to the fact that rehabilitation studies are likely to require much more “active” involvement from participants than medical trials do. For example, consider two stroke RCTs, one investigating a medical intervention⁶ and the other a rehabilitation intervention.⁷ For the medical RCT, which investigated the efficacy of intra-arterial (IA) recombinant prourokinase (r-proUK), participation involved receiving the intervention (or placebo) and undergoing clinical and performance-based testing; angiograms were done within hours of administration of IA r-proUK, and CT scans at 24 hours and 7–10 days later.⁶ The

Rankin Scale, the National Institutes of Stroke Scale, and the Barthel Index were all administered at 7–10 days, 30 days, and 90 days after the intervention;⁶ thus, apart from the testing done while participants were still in hospital receiving medical care, the study required a total of only 3 testing days. Participation in the rehabilitation RCT investigating treadmill-based aerobic training post-stroke, on the other hand, was much more extensive:⁷ participants were required to attend 40-minute treadmill training sessions, working at a moderate pace, 3 days a week for 6 months, as well as to complete outcome testing at 3 time points that included peak exercise testing (VO₂ peak) and walking assessments (10 m walk and 6-minute walk test),⁷ for a total of 72 visits, and during all of these visits participants were performing aerobic exercise. The gait rehabilitation study arguably requires greater independence, mobility, and endurance on the part of participants to access the laboratory setting and tolerate prolonged data-collection sessions several times a week over a protracted period. It should also be acknowledged that the invasiveness of testing differed between these two studies, which may also have influenced the decision to participate; however, the impact of this factor may not be related to the functional level of potential participants. The crucial point here is that factors influencing the decision to participate likely differ between medical and rehabilitation studies, and these differences may be related to study design and to the exact nature of the participation required.

From these examples, we can see that while factors such as sensorimotor and gait impairments, mobility limitations, and limited ability to access and move around in the community may not affect participation in a medical research study, they may affect participation in a rehabilitation study. Therefore, rehabilitation research may be vulnerable to recruitment bias if higher-functioning individuals are more likely to participate. In describing the example studies mentioned here, I have considered only the influence of mobility and sensorimotor function; however, other factors such as communication and cognitive function are likely just as influential in determining research participation.

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Information on factors that influence research participation by people with the disabilities and conditions of interest to physiotherapist researchers would be invaluable to inform the design of future rehabilitation studies. Such factors could be broadly classified as (1) participant characteristics (e.g., impairments in gait, cognition, communication); and (2) study design characteristics (e.g., location of testing, time commitment, level of effort required). Participation by people with a wide range of impairments could be facilitated by designing studies to address such limiting factors. In addition, information about factors that influence research participation could inform physiotherapists seeking to apply evidence in their own clinical practice about the limitations of the applicability of study results. Future research needs to address this gap in knowledge related to participation in physiotherapy research to facilitate generalizable study results and advance EBP.

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La recherche en réadaptation : Qui y participe?

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La pratique factuelle joue un rôle crucial dans l'avancement à la fois de la profession et des résultats de la physiothérapie.¹ La pratique factuelle est facilitée par les résultats d'études bien contrôlées, dont le caractère généralisable dépend en grande partie du recrutement et de la participation généralisés des personnes qui ont le problème d'intérêt. On reconnaît que le recrutement de participants constitue l'aspect le plus difficile de la recherche et qu'il détermine souvent la réussite ou l'échec d'un essai contrôlé randomisé (ECR).² En dépit de son importance critique, toutefois, on connaît très peu de choses de la participation à la recherche en réadaptation. Il est crucial de comprendre davantage qui participe à la recherche en physiothérapie et les facteurs qui jouent sur la volonté de participer à la fois lorsqu'il s'agit de savoir comment les résultats d'une étude s'appliquent à la population des patients en général et de concevoir des études à venir afin de maximiser le recrutement de participants appropriés.

Les milieux de la recherche médicale ont déjà reconnu l'importance de comprendre les facteurs qui jouent sur la volonté de participer aux essais cliniques, comme le démontrent des études réalisées sur cette question même.^{3–5} Ces études fondées sur des sondages ont révélé des facteurs qui jouent sur la décision de participer à une étude en médecine : attitude positive à l'égard de la recherche sur les êtres humains et connaissance de l'importance des essais cliniques pour l'avancement des soins médicaux, notamment.

Par contre, aucune étude n'a porté directement sur les facteurs qui jouent sur la décision de participer à une étude en physiothérapie ou à des recherches en réadaptation, de façon plus générale. Ces facteurs peuvent différer de ceux qui jouent sur la participation à un ECR en médecine. L'écart peut être attribuable au fait qu'il est probable que les études sur la réadaptation exigent une participation beaucoup plus « active » que les essais en médecine. Prenons, par exemple, les ECR à

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