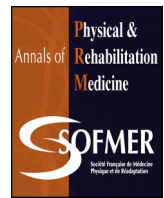




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Original article

Participant and service provider perceptions of an outpatient rehabilitation program for people with acquired brain injury

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ARTICLE INFO

Article history:

Received 23 September 2016

Accepted 26 March 2017

Keywords:

SWOT analysis
Rehabilitation
Service delivery
Quality
Outcome
Measurement

ABSTRACT

Background: A holistic, intensive and interdisciplinary rehabilitation program for people with acquired brain injury (ABI) was developed at the Pitié-Salpêtrière Hospital, France (5 days/week for 7 weeks). This program, recently demonstrated effective, aimed to optimize the ability of people with ABI to perform activities and improve their participation by using individual and group interventions involving ecologically valid activities inside (e.g., in the gym and kitchen) and outside the hospital. However, the perception of the quality of the program by participants and service providers has not yet been reported. **Objectives:** This study had 3 objectives: (1) report the perception of participants (adults with ABI) in terms of service quality of the program, (2) report the strengths, weaknesses, opportunities, and threats (SWOT analysis) of the program as perceived by service providers, and (3) triangulate findings to draw conclusions about the program's quality and provide recommendations for quality improvement.

Methods: We used a mixed-methods design with a validated questionnaire (Perception of Quality of Rehabilitation Services [PQRS-Montreal]) and interviews (structured around a SWOT analysis) involving program participants and service providers.

Results: We included 33 program participants (mean age 43.6 years) and 12 service providers (mean years with program 7.6 years). In general, study participants showed a convergence of opinion about the high quality of the program, particularly regarding the team and its participant-focused approach. Specific aspects of the program were viewed more negatively by both participants and service providers (i.e., addressing sexuality, family involvement and return to work/volunteer work/school).

Conclusion: Participant and service provider perceptions of the rehabilitation program under study were generally positive. A reliable and valid questionnaire and interviews helped identify aspects of the program that worked well and those that could be targeted for future quality improvement.

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1. Introduction

Acquired brain injury (ABI), including traumatic brain injury (TBI) and stroke, can be very disabling, with severe consequences to individuals, their families and society in general. Stroke is the

second cause of mortality in the world [1] and 16.7 million people experience strokes each year [2]. In France, like in Canada, stroke is the third leading cause of death [3,4]. Each year, 150,000 people are hospitalized for a TBI in France [5] and 13,000 more in the province of Quebec, Canada [6]. People with ABI may experience major difficulties in managing and organizing simple activities of daily living (e.g., dressing) and many people remain dependent when performing activities in their home or community (e.g., grocery shopping, meal preparation, managing the household and budget,

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<http://dx.doi.org/10.1016/j.rehab.2017.03.010>

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using public transport) [7–9]. These difficulties lead to activity limitations and participation restrictions, which justifies the need for adapted and specific rehabilitation programs to meet the complex needs of people with ABI.

The Physical Medicine Rehabilitation (PMR) Department of the Pitié-Salpêtrière Hospital (Paris, France) developed a specific, holistic, intensive and multidisciplinary rehabilitation program [10,11] to respond to clinicians who observed that ABI patients did not participate in community life after their hospitalization. The program is similar to others described in the United States (e.g., Toglia [12]; Bertens et al. [13]; Noe et al. [14]) incorporating cognitive and behavioral approaches aimed at improving neuropsychological and psychosocial functioning (e.g., emotional regulation, self-evaluation). However, the PMR program seems to differ from outpatient programs described in Canada, where patients typically attend therapy 2 to 3 times per week and have access to occupational therapists (OTs), physical therapists (PTs), speech-language pathologists (SLPs), social workers (SWs), physiatrists, and neuropsychology and neuropsychiatry clinicians [15].

The PMR program re-trains the patient in activities in the natural environment to resume activities of everyday life. It includes activities such as cooking, sports and leisure activities (e.g., swimming pool, ping-pong), outings (e.g., public transport, orientation in the city), newspaper, communication, speaking groups, and relaxation [10]. Also in contrast to other programs, participants do all the activities of the program and the therapist adapts each activity to the needs of the participant. For example, if a participant has planning difficulties, the focus will be on organizing the cooking activity, for example.

The rehabilitation program was recently investigated and found to be effective for participant activities and participation [11,16]. More specifically, using a single subject design ($n = 7$ people with ABI), the authors found an improvement between pre- and post-intervention phases in number of errors on the Cooking Task [17] for 6 participants: 4 participants showed significant improvement immediately after the program and at 3 and 6 months after program discharge. Six of 7 participants showed significant improvement on the Instrumental Activity of Daily Living-Profile (IADL) [18]; 3/7 participants showed improvements right after the program and 3 months later, and 4 showed improvements between after the program and 6 months later.

In addition to determining the program's effectiveness, we were interested in knowing participant and service provider perceptions about the quality of the program. We felt this information could help in decisions about how to maintain or modify specific aspects of care to better meet patient needs. Indeed, we need to evaluate, monitor and improve service delivery over time as part of continuous quality improvement of this rehabilitation program. Moreover, the recording of these perceptions could provide benchmarks for other rehabilitation programs in France and elsewhere.

Thus, the goals of this study were to (1) report the perception of participants with regard to service quality of the program, (2) report the strengths, weaknesses, opportunities, and threats of the program as perceived by the service providers, and (3) triangulate these findings to draw conclusions about the program's quality and provide recommendations for quality improvement.

2. Method

2.1. Setting

This study was conducted within the PMR Department of the Pitié-Salpêtrière Hospital. The 7-week intensive outpatient day program is offered to 4 individuals with ABI at a time. Participants attend the program weekdays from 9 am to 4 pm (i.e., 7 hours a day

because we consider meal time as a time for socialization), 5 days a week for 7 weeks (i.e., 245 hr), and every 8 weeks, a new session begins with new participants. The program aims to optimize the ability of individuals with ABI to carry out activities and improve their participation using individual and group interventions involving ecologically valid activities inside the hospital (e.g., in the gym and kitchen) and outside the hospital. In addition to individual care (e.g., OTs and PTs) typically provided in rehabilitation, the program offers specific group activities such as an expression group, a self-awareness group, a cooking activity and culture and leisure outings involving taking public transport and visiting public spaces such as a museum. The program is multidisciplinary and involves 14 program clinicians; however, the equivalent of 2.5 full time clinicians is required to run the program [10]. Clinicians' time spent with participants varies according to participants' needs and the skills of the therapists; 8 of the 14 clinicians are directly involved in the rehabilitation program and provide specific activities (1 clinical psychologist, 2 OTs, 1 PT, 1 SLP, 1 nurse, 1 attendant, and at least 1 physiatrist). The 6 other clinicians (e.g., neuropsychologist, SW) intervene, if needed, on specific problems (e.g., assessment of cognitive impairments, personal factors such as managing financial records). A neuropsychologist evaluates cognitive functions of potential participants before they enter the program to help identify the focus of interventions provided by the other disciplines. For example, the neuropsychologist might inform clinicians that a participant has acalculia (loss of ability to perform simple math calculations), so the OT could work with the participant to prepare a budget for the cooking activity, and the PT could ask the participant to count the points during a ping-pong game.

2.2. Design

A mixed-methods design [19] consisting of 3 components was used: (1) evaluating the perception of program participants by a transversal quantitative method and (2) evaluating the perception of service providers by a qualitative method. The third component consisted of triangulating these results to assess the global perception of the quality of the program.

2.3. Perception of participants

Participants were adults with ABI participating in the multidisciplinary rehabilitation program. They had to live at home for least 2 months before beginning the program and demonstrate difficulties managing multi-step IADL as assessed by OTs during their acute care stay or when they come in to be evaluated for admission to the program. Each participant had to have personal rehabilitation goals (self-established or established with clinicians) such as being able to move independently around Paris (taking the metro, navigating crowds etc.).

All study participants provided written informed consent and the study was approved by the hospital's ethics committee.

2.4. Procedure

To assess participant perceptions of the program, we used the Perception of Quality of Rehabilitation Services (PQRS-Montreal) [20], a 55-item questionnaire specifically developed and validated for use by French- and English-speaking adults with TBI. The PQRS-Montreal assesses the perception of 5 dimensions of care deemed to be important components of rehabilitation: ecological approach, client-centered approach, quality of service providers, continuity of care, and accessibility. Each response to the 55 items is scored on a 5-point scale, ranging from 1 (completely disagree) to 5 (completely agree). The scale has strong psychometric qualities;

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