People Reported Behavioural Functions and Needs in Neurologically-Based Disabilities: Role of Leisure

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Abstract

Leisure involvement has many components from volunteering, sport, arts and crafts, civic engagement, to tourism. Individuals may acquire a disability as they age or suffer from a disease. How does the person’s ability level influence their engagement in volunteering, sport, arts and crafts, civic engagement, to tourism? How does the person’s ability level influence their family and their engagement in volunteering, sport, arts and crafts, civic engagement, to tourism? The International Classification of Function (2001) provides insight into the complexity of a person’s abilities within the person’s lived experience. Individuals with a neurological condition have differing levels of abilities that may influence their possibility of travelling and their use of leisure time. Based on the literature reviewed and focus groups with people with neurological conditions and their family members, the researchers developed and validated a questionnaire for this study which was comprised of the following sections: I) personal factors; II) behavioural functions rated as: fully independent, partially dependent, or fully dependent from another person; and III) ability to travel. Two hundred and eleven (211) ambulatory persons with neurological-based disability were included in the survey. More than 70%, were assessed at low level of disability by clinicians, but reported dependence in one or more behavioural functions. Discordance between patient and clinician was present in each of the four conditions (multiple sclerosis, Parkinson, peripheral neuropathies and stroke) examined. It appears from the findings of this study that clinical scales do not predict patients’ abilities and their needs to engage in their physical and social environments (tourism). Our questionnaire to verify if it was possible to obtain answers and information that would help understand and find solutions to the real life difficulties of questionnaire respondents: for the purposes of this survey we included, as a model, patients with neurological disabilities. The high response to our survey shows that participation in recreational, leisure, and sport activities is an important factor for people with disabilities, and the results show that our questionnaire is a good tool to identify disability and needs so that new strategies to promote leisure involvement can be assessed for their effectiveness.

Keywords

Leisure, People with disabilities, Needs, Behavioural functions
Patient Reported Behavioural Functions and Needs in Neurologically-Based Disabilities: Role of Leisure

According to the International Classification of Functioning, Disability and Health (ICF) (2001), disability refers to difficulties in human functioning arising from the interaction of personal health conditions with the individual, institutional and social environments. Hence, the approach to disability requires social action and is a responsibility of society. Article 30 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) specifies participation in cultural life, recreation, leisure activities and sport as an explicit right for persons with disabilities. This includes also the right to travel freely, accessibility of the means of transportation and destinations, and the right to full participation in society. Participation contributes also to empowerment, allowing people to achieve increasing control of various aspects of their lives and participate in the community with dignity. The article will be discussed according to the following: leisure, chronic neurological disorders and conditions, methods, results and discussion.

Leisure

The literature supports a protective role of active leisure participation on the risk of neurological diseases. Systematic reviews (Stern and Munn, 2010) and primary studies, both randomised trials (Ritchie et al., 2010) and controlled cohort studies (Scarmeas et al., 2009; Fratiglioni et al., 2004) indicate that an active lifestyle or actively participating in cognitive leisure activities during mid- or late life are beneficial in preventing the risk of Alzheimer's disease and other dementias; the higher level of engagement the stronger protection (Paillard-Borg et al., 2009). Other studies suggest that a broad spectrum of activities containing mental, social and physical components seems to be more beneficial than to be engaged in only one type of activity (Karp et al., 2006; Schleien et al., 2009; Hakim et al., 2000; McIntosh-Michaelis et al., 1991). Men and women who were physically active were significantly less likely to have a stroke compared to those who were inactive (Karp et al., 2006; Bickel et al., 2012). The literature recommends that efforts to increase mental, physical and social activities in both the work place and in leisure time should be encouraged for the person (Schleien, et al., 2009; Hakim et al., 2000).

Chronic Neurological Disorders and Conditions

They affect functioning, limit activities and restrict participation. Disability and cognitive impairment may cause young persons with multiple sclerosis loss of employment and withdrawal from social and leisure activities (Hakim et al., 2000; McIntosh-Michaelis et al., 1991; Stroud et al., 2009). Persons with neurologically-based disabilities encounter many difficulties in leisure engagement and their participation is still considerably limited because attitudinal and environmental barriers hinder their full and effective participation on an equal basis with others. (Rains, 2009). For many neurological persons participation in leisure activities remains an unmet need.

Purpose

The purpose of the research was to produce a practical tool for persons with neurologically-based disabilities to help them reviewing their disabilities and symptoms and direct them through the process of making decisions on leisure activities. The intent of the study was to focus on the abilities of the person rather than the condition (Cornelio, 2009).
In the first phase of the project we evaluated associations between clinically measured functions, self-reported performance and needs in physical and social environment for ambulatory persons with a chronic neurological disease.

Methods

The research developed through three stages. The study used a mixed methodology, quantitative and qualitative. Participants were engaged in focus groups to examine how the environment impacted upon their leisure and participants responded to a survey developed from the literature related to the environment, activities for daily living, why people travelled and how they used their leisure time.

In the first stage we conducted three focus groups (FG) to explore with patients and family members how the environment impacts on their leisure, that is, to describe their restrictions in behavioural functions and their needs. FG are a qualitative study design suitable for an inductive research question and for generating theoretical propositions (Carter & Henderson, 2005). As a method, they facilitate data to be gathered from interactions between people, thereby enabling people to express and respond to various viewpoints. Their benefits are that they are an efficient way to gather in-depth data on people’s experiences and views. The basis of our sampling was purposive and voluntary, i.e. methods used when you seek a diversity of opinion but need to consider feasibility and hard-to-reach groups (Carter & Henderson, 2005). The first two FG included three people with multiple sclerosis (MS) (2 women, 1 male); two people with Parkinson disease (PD) (1 woman and 1 man); and two people with post-stroke (1 woman and 1 man). The participants were of different disability levels. The third FG included six family members of people with MS (1 woman and 1 man), PD (2 women), post-stroke (1 woman and 1 man). We administered a short questionnaire to collect basic demographic information. FG were facilitated by a Research officer, taped with permission and transcribed. Permission to follow-up with individual participants was sought at the meetings, in case individuals wish to participate to the second stage of the project. The FG generated the themes of people restrictions in behavioural functions and their needs reported as relevant to better self-care and leisure activities. These themes were used to generate a series of items in the first version of the questionnaire that was examined with people who were involved in the FG.

In the second stage, we used the questionnaire with 60 persons with chronic neurological diseases. A trained interviewer interviewed 60 outpatients (22 MS, 25 PD, 13 post-stroke) at two different neurological facilities in Italy (22 patients), the second neurological facility (19 patients) and a rehabilitation facility (19 patients). The findings of the interviews guided the construction of the final version of the questionnaire.

The questionnaire includes five sections: sections A, B included personal details, clinical information and person’ needs for travelling; section C gathered the following behavioural functions defined as the interaction between the person and the environment: sight (1 item), hearing (1 item), balance (1 item), mobility (11 items), feeding (5 items), dressing (1 item), washing (3 items), use of bladder catheter (1 item), use of transport (6 items), relationship with others (4 items), memory (2 items). Each item is scored according to its state in the previous month before interview, as: (i) ability, no use of aids, and no need of help from others; (ii) ability with adjustments, slow, or requires aids or devices or environmental modifications, but without need of help from others; (III) inability, needs a person who helps even if only to supervise; section D includes items regarding frequency and reasons for use of the internet; section E collected reasons for travelling, availability and use of leisure time.
In the third stage of the project, we conducted a survey with 211 outpatients cared at the Besta Institute who were eligible according to our predefined criteria and who agreed to participate. Eligibility criteria were: age 18-75 years, a diagnosis of MS, PD or Parkinsonism, post-stroke, peripheral neuropathies (PN), Charcot-Marie-Tooth disease, polineuropathies, Friedreich ataxia, chronic inflammatory demyelinating polyneuropathy (CIDP), in a stable phase of the disease. All patients gave written informed consent. Exclusion criteria were: hospitalized patients, dementia or psychiatric disturbances. The following medical scales were used by the neurologists to score patient’s clinical disability the Expanded Disability Status Scale (EDSS, Kurtzke, 1983) for MS, the Unified Parkinson’s Disease Rating Scale (UPDRS, Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003) for PD, the Rankin scale for PN and post-stroke.

Data analysis

Each behavioural function (sight, hearing, balance, mobility, feeding, dressing, washing, use of bladder catheter, use of transport, relationship with others and memory) was scored as: “ability” when all its items were reported as “ability”; as “ability with adjustments” when even only one of its item was reported as “ability with adjustment”; and as “inability” when even only one of its items was reported as “inability”.

Each patient was considered “fully independent” when all the nine tested functions were scored as “ability”; “partially-dependent” when even only one of the nine functions was scored as “ability with adjustment”; or “fully dependent” when even only one of the functions was scored as “inability”.

A descriptive analysis of the patients’ clinical characteristics was conducted. The median score value of the medical scales was used to classify the patients in the “low disability” group including patients with EDSS 0-2.5 (MS), UPDRS 0-20 (PD) or Rankin 0-2 (PN and post-stroke), or in the medium-high disability group including patients with EDSS >2.5, UPDRS >20 or Rankin >2.

Results

Characteristics of the patients are reported in Table 1. 45% (95 of the 211 patients) reported full dependence in one or more functions and 49% (104) partially dependence. Full or partially dependence in mobility was reported respectively by 41% and 49% of the patients, in travelling by 31% and 37%, in feeding by 15% and 30%, in balance by 14% and 62%, in dressing by 13% and 60%, in washing by 12% and 56%, in sight and hearing by 0.5%.

Figure 1 presents disability scores measured by medical scales vs levels of dependence reported by persons: 71% of patients classified as “low disability” (EDSS 0-2.5; UPDRS 0-20; Rankin 0-2) by neurologist reported to be partially dependent and 17% fully dependent in one or more behavioural functions. A good correlation was found between disability scores measured by medical scale and person-reported level of dependence for persons with severe disability (EDSS>2.5; UPDRS >20; Rankin >2).

Similar results were found for all neurological conditions included in the study. For example, 57% and 37% respectively of persons with MS, judged of low disability (EDSS ≤2) by neurologist, reported to be partially dependent in walking and balance, 70% and 10% respectively of persons with PD reported to be partially or fully dependent in walking, but were judged with low disability by the UPDRS scale. Disagreement between medical scales and level of dependence as reported by persons was found in all behavioural functions included in the questionnaire.
With regards to aspects related to leisure time, 58% of persons in the study regularly used the Internet, 63% to find information about their disease, 93% for leisure time in general and 58% for study or work reasons. In response to the question ‘Reasons for travel or stay’, 63% declared that they travelled for health or wellness, 66% to visit new places and 37% for cultural purposes.

In the section about leisure time availability measured on a ‘Likert’ scale from 1 to 7, the average was 4.58±1.60, while leisure time satisfaction was 4.56±1.63. This data is partially in accordance with Powdthavee et al. (2009) who reported that disability had a negative impact on satisfactions with income, social life, and use of leisure time, but was positively associated with the levels of satisfaction with amount of leisure time.

If ‘leisure time availability’ score was less than 4, patient was asked: “What aspects should be satisfied to take full advantage of your leisure time?”. 24% of patients referred to architectural barriers, 20% to public transport, 38% declared that the presence of family or friends was helpful, 37.5% referred to the need for economic assistance in the form of discounts for rehabilitation treatments and/or free entrance to cultural sites while 31% requested more flexibility regarding their working hours.

Discussion and Conclusion

We used a questionnaire to verify if it was possible to obtain answers and information that would help understand and find solutions to the real life, the lived experience of the respondents. For the purposes of our survey we included, as a model, patients with neurological disabilities.

In this study we decided to consider self-management in all necessary outdoor activities whether going to the theatre, spending a few days at a hotel or resort, or travelling. This was not an external evaluation of the architectonic barriers that prevent full enjoyment of leisure time, but the personal view of a persons’ needs (not what he/she knows but rather than which he/she does not know how to do alone) related to the neurological disability. We compared the personal view with the medical evaluation of disability.

From the data the most noticeable outcome which emerged was the lack of correlation between the actual participants’ needs and the medical scales used to determine the level of disability and which contain items important to motor disability. In the group of patients classified as ‘low disability’, 34% of the interviewed persons stated that they always needed a companion to face the difficulties outside the home, and all others, except 11%, needed mobile aids. For this reason, a number of them, who were classified on the medical scale as ‘mildly disabled’ and therefore considered by doctors to be ‘autonomous’, declared serious problems for mobility and management of needs outside the home, and that they could only pass time outside the home with assistance. In our sample, whether stroke victims or those with peripheral nervous system pathologies, the disability medical measure did not correspond to what was reported by respondents. On the first level of the Rankin Scale (0-2= mild) amongst stroke victims no one declared to be autonomous in walking and 35% referred to the need for assistance; among subjects with peripheral nervous system diseases, 15% have lost mobile autonomy and all other needed aids. Also to wash oneself was an item that did not correspond to the disability valuation on the medical scales: the same level of ‘low disability’ on the Rankin Scale corresponded to the need for aids for all interviewed stroke victims, and the lack of autonomous subjects. In peripheral nervous system diseases, probably for different compromised functional skills, the discordance was less serious even if evident. All of this demonstrates that the scales generally used by clinicians to measure behavioural functions are not useful to assess human functions in a social environment.

Our results indicated that the necessary activities for complete outdoor autonomy were impaired or lost in this group of patients who were able to walk and whom clinicians considered to have a low
disability. Mobility was lost in 41% for walking > 100 mt, 46.5% walking on uneven surfaces, 34% climbing high stairs, and 73% for short sprints. All these are activities necessary to take public transport, cross the street at traffic lights, attend cultural events and travelling. A lower percentage of persons failed in feeding oneself (cutting food, bringing food to the mouth 15%), washing and dressing oneself (12% & 13%). Some of these activities are not adequately specified in the clinical disability scales but for a complete analysis of people needs this information is essential. Ability to manage self-medication and in general remember daily commitments should also be considered when reviewing people needs: in our group the proportion of patients having difficulties with these abilities were 21.5% and 29% respectively.

Doctors should encourage persons with disabilities in determining and meeting the challenges they face in physical and social environment, and help them to review their disabilities and symptoms. Persons understand their own needs better than anyone else and therefore they should be encouraged both to define their needs and act upon them.

**Conclusion**

Leisure involvement has many components from volunteering, sport, arts and crafts, civic engagement, to tourism (Stumbo & Peterson, 2009). Historically studies viewed the individual as the person who selected and engaged in an opportunity and measured their experience individually. Scholars have found that we are interdependent on others when engaging in opportunities (Bullock & Mahon, 2010; Schleien, 2009). A person’s pattern of involvement in opportunities changes across the life course. Individuals add and drop opportunities based upon the presence or absence of a partner, presence or absence of children (age of children) and presence or absence of care giving (Harvey & Singleton, 1989, 2009; Singleton & Harvey, 1995). The Internal Classification of Function (WHO, 2001) illustrates the complexity of the interactions between the environmental factors, personal factors, body function and structure and the health condition.

The medical model of disability does not address the leisure needs of the person (how best to enjoy leisure time, travel, etc.) and may have a negative influence on the person’s planning of leisure time such as travelling (Packer, Mckercher, & Yau, 2007). According to Packer et al. (2007) having limited information about tourist destinations makes difficult the planning and participation in leisure time due to possible eventual major or minor risks. Packer’s survey found that the preferred information source for safe travel and stay was other persons with disability, however various other strategies to confirm the source were used. The need to travel and actively enjoy with satisfaction leisure time is conditioned not only by the degree of persons’ disability but also the level of awareness about their functional limits and that on behalf of their families or caregiver (Packer et al, 2007).

Enhancing the possibility of enjoying leisure time is a dynamic process, not only facing physical barriers but also creating a relationship with the tourism sector and collaborating with the medical world to change attitudes towards persons with disability particularly in information provision. This process should allow persons with disability to take responsibility for themselves, stimulating a more proactive attitude towards discovering their own needs. All of this suggests that with a common effort it is possible to move towards Inclusion of persons with various abilities into Leisure and Tourism.
References


Table 1. Characteristics of 211 patients with neurologically-based disability

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>MS N. 81</th>
<th>PD N. 52</th>
<th>PN N. 42</th>
<th>post-Stroke N. 36</th>
<th>Total N. 211</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender - n. patients (%)</td>
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<tr>
<td>Women</td>
<td>45 (56)</td>
<td>24 (46)</td>
<td>16 (38)</td>
<td>10 (28)</td>
<td>94 (45)</td>
</tr>
<tr>
<td>Men</td>
<td>36 (44)</td>
<td>28 (54)</td>
<td>26 (62)</td>
<td>26 (72)</td>
<td>117 (55)</td>
</tr>
<tr>
<td>Age (yrs.) median (min-max)</td>
<td>41 18-65</td>
<td>63.5 42-75</td>
<td>46.5 22-75</td>
<td>64 35-74</td>
<td>52 18-75</td>
</tr>
<tr>
<td>Education (yrs.) median (min-max)</td>
<td>13 5-22</td>
<td>11.5 3-18</td>
<td>11.5 2-18</td>
<td>8 5-17</td>
<td>13 2-22</td>
</tr>
<tr>
<td>Disease duration (yrs.) median (min-max)</td>
<td>8 0.6-42</td>
<td>4 0.6-22</td>
<td>5 0.6-43</td>
<td>2 0.6-13</td>
<td>4 0.6-43</td>
</tr>
<tr>
<td>Disability score median (min-max)</td>
<td>2.5* 1-8.5</td>
<td>20† 5-87</td>
<td>2‡ 1-4</td>
<td>2‡ 1-4</td>
<td>-</td>
</tr>
<tr>
<td>With copathologies - n. persons (%)</td>
<td>29 (36)</td>
<td>31 (60)</td>
<td>26 (62)</td>
<td>24 (67)</td>
<td>110 (52)</td>
</tr>
</tbody>
</table>

MS=multiple sclerosis. PD=Parkinson disease. PN=peripheral neuropathies.
* Expanded Disability Status Scale (EDSS). † Unified Parkinson’s Disease Rating Scale (UPDRS).
‡ Rankin Scale
Fig. 1. Disability scores measured by medical scales vs levels of dependence reported by patients.

**Medical Scales vs Patient-Reported Behavioural Functioning**

<table>
<thead>
<tr>
<th>Medical scale: disability degree</th>
<th>I (n. 104)</th>
<th>II (n. 105)</th>
</tr>
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<tbody>
<tr>
<td>100%</td>
<td></td>
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<tr>
<td>90%</td>
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<td>80%</td>
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<td>20%</td>
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<td>10%</td>
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<tr>
<td>0%</td>
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Patient’s questionnaire behavioral functions:
- **Fully independent**
- **Partially dependent**
- **Fully dependent**

Degree: (I) EDSS 0-2.5, UPDRS 0-20, Rankin 0-2
(II) EDSS>2.5, UPDRS >20, Rankin >2

p<0.001