

From paper to informatics: the Post Soft Care-App, an easy-to-use and fast tool to help therapists identify unmet needs in stroke patients

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Summary

Even after rehabilitation, post stroke patients remain disabled. The Post Stroke Checklist (PSC) was developed to highlight unmet needs of community-dwelling stroke patients. The present study set out to validate Post Soft Care-App, designed to administer the PSC using smartphones and tablets, in order to monitor unmet needs in chronic patients. Fifty-three patients and fifteen physiotherapists were enrolled. The therapists ad-

ministered the PSC to patients using the app, and then completed a structured questionnaire on its usability and utility.

The Post Soft Care-App highlighted the following unmet needs: increased spasticity (56.6%), reduced independence in activities of daily living (47.2%), reduced mobility (45.3%), absence of secondary prevention (45.3%). Therapists positively evaluated Post Soft Care-App as useful, practical, quick to complete (96.2%), and effective in helping improve communication with patients (75.5%).

The Post Soft Care-App can be considered a valid assessment tool for helping therapists to monitor functional outcomes in chronic patients.

KEY WORDS: long-term outcomes, neuropsychology, patient care, quality of life, rehabilitation, stroke.

Introduction

The World Health Organization (WHO) defines stroke as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin" (WHO MONICA Project Investigators, 1998). In developing countries, 10-12% of deaths are caused by stroke and its consequences. In 2011, the WHO estimated that stroke mortality rates are sensitive to geographic location and that stroke incidence can vary widely between different countries (World Health Organization, 2011).

Strokes are caused by partial or total lack of blood supply to the brain, and many different outcomes are possible. However, stroke is often highly disabling. Patients may have physical and/or cognitive impairments even a year after the acute event (Čengić et al., 2011), when many other complications can occur.

As reported by the Italian National Institute of Health, about 200,000 people in Italy have experienced stroke (80% of the cases being a first episode and the remaining 20% recurrences) (SPREAD, 2017). Stroke is the third most common cause of death in Italy, followed by cardiovascular disease and neoplasms. It is the first cause of disability. In Italy, stroke survivors, who live with varying degrees of disability, currently number around 913,000 (SPREAD, 2017). It has been reported that a third of patients presents a high degree of disability one year after the acute event, to the point that they can be defined totally dependent in activities of daily living (SPREAD, 2017).

In a detailed Italian study (Paolucci et al., 2008), at discharge from neurorehabilitation units only 4.58% of stroke patients could climb the stairs independently, 8.7% could walk outdoors, 14.41% could walk indoors, 27.46% needed support from a walking aid, and 44.85% were still confined to a wheelchair. Another complication found to persist at one year after stroke is pain: the prevalence of some types of stroke-related pain, such as spasticity-related pain, even increases in the chronic stage (Paolucci et al., 2016). Other reported complications are incontinence, fatigue and cognitive disability, all factors that negatively impact on personal independence, daily activities and quality of life (Wondergem et al., 2017).

Stroke patients require long-term care, which should continue even after they have been discharged from neurorehabilitation hospitals. Despite the chronic absence of standardized follow-up care processes, several guidelines recommend serial assessment of follow-up symptoms (Ward et al., 2014; Paolucci et al., 2015). In 2013, the Global Stroke Community Advisory Panel developed the Post Stroke Checklist (PSC) (Philp et al., 2013), a tool aiming to help clinicians standardize the process of identifying long-term problems and make appropriate treatment referrals. Ward et al. (2014) validated the PSC in a sample of 42 patients in the UK and 100 patients in Singapore. In that study, in which researchers used a paper-and-pencil version the PSC, it was reported that the PSC was evaluated as an easy-to-use tool that is sensitive for identifying patients' needs after discharge.

An Italian version of the PSC has previously been proposed (Paolucci et al., 2015) and tested (Iosa et al., 2018). It was found to help general practitioners understand the needs of chronic stroke patients, and thus decide whether to refer them for more specialized exams or consultations with neurological, neuropsychological or rehabilitation professionals.

The increasingly widespread use of portable devices, such as smartphones and tablets, and mobile app technologies is opening up new scenarios for the care of stroke patients. This is illustrated by the increasing development of mobile/tablet-based therapies supporting continuous rehabilitation of patients at home (Pugliese et al., 2018). These tools could also be used for patient assessment and monitoring (Barrett et al., 2017). As highlighted several years ago in a review of the seven most promising technologies for the future of stroke rehabilitation (Iosa et al., 2012), apps, being easy to download and use, are changing our way of life, and offer potential benefits in the healthcare and rehabilitation fields, too.

In 2016, the Italian Society of Neurological Rehabilitation (SIRN) started the Post Soft Care project (POSt STroke checklist SOFTware validation for primary CARE physicians), which was supported by an unconditional contribution from the company Allergan and received information technology support from Alfameg Italy. The project entailed the development of an app, which was given the same name as the project itself "Post Soft Care". The app is designed to administer the PSC and also a questionnaire on the utility and usability of the app. The Post Soft Care-App runs on devices, such as smartphones and tablets, with android operating systems.

The purpose of this study was to validate the Post Soft Care-App, which was administered by physiotherapists to a sample of chronic stroke patients with the aim of highlighting their unmet needs.

Materials and methods

The present paper conforms to the STROBE statement on cross-sectional studies (Von Elm et al., 2007). All experimental procedures were carried out in Italy. The project was coordinated by SIRN.

Participants

Fifty-three stroke patients were enrolled in this study on the basis of the following inclusion criteria: patients had to have experienced a cerebral infarction or intracerebral hemorrhage and been discharged from a neurorehabilitation hospital after the subacute phase of the stroke; at least 3 months had to have elapsed since the acute event. The patients, enrolled by the therapists, had to be receiving extensive rehabilitation treatment at home, in extensive rehabilitation units or in day hospital wards. Patients in intensive rehabilitation units were excluded.

Fifteen therapists participated in this study. They received specific training from a researcher involved in the study and instructions on correct administration of the Post Soft Care-App. The trained therapists administered the Italian version of the PSC (Paolucci et al., 2015) to the patients face to face using the Post Soft Care-App either on a tablet or smartphone, as they preferred (Iosa et al., 2018).

Post Soft Care-App

The PSC is an 11-item questionnaire that is administered to post-stroke patients by a clinical professional (Ward et al., 2014). The questions are dichotomous, requiring a yes/no answer on the basis of which referral/care recommendations may be given (Ward et al., 2014). The eleven domains covered by the PSC are: secondary prevention, independence in activities of daily living, mobility, spasticity, pain, continence, communication, mood, cognition, personal life after stroke, relationship with caregiver. This checklist is used to evaluate the health conditions of chronic stroke patients. As mentioned, for the present study, we used the Italian version of the instrument (Paolucci et al., 2015).

The questions are designed to highlight any changes that have occurred since the patient was discharged or since his/her last checkup. Therapists can download the Post Soft Care-App onto their own devices and then log in using their own profile. The therapists created an anonymous profile for each patient by entering clinical information such as: age, date of stroke, gender, presence of neglect and/or aphasia, type of stroke, and lesion site. They were instructed to put the questions to each patient directly or with the help of his/her caregiver. Data were collected and anonymously stored in a secure online database.

After completion of the PSC, patients and clinicians completed two different satisfaction questionnaires, in

each case providing answers on a numerical scale ranging from 0 (worst) to 10 (best).

Data and statistical analysis

The data were summarized using means \pm standard deviation (SD) or with median and first (Q1) and third (Q3) quartiles, or as positive answers expressed as a percentage of all the collected answers. Sample size was defined on the basis of samples involved in previous studies: the number of therapists ($n=15$) was the same as that in a previous study with Italian general practitioners (Iosa et al., 2018), whereas the minimum number of patients to enroll was set at 42, in line with the UK sample used in the first PSC validation study (Ward et al., 2014). Given that an ordinal scoring system was used, non-parametric Spearman's coefficient (R) was used to evaluate correlations between scores. Kruskal-Wallis analysis was used to test score differences between patients grouped by time since stroke: < 1 year, between 1 and 2 years, > 1 year. The alpha level of significance was set at 0.05 for all the analyses.

Results

Fifteen therapists (mean age 38.07 ± 11.65 years; 60% females) and 53 patients (mean age 65.76 ± 13.50 years, 64.15% males) were involved in the study. The interval between the acute event and the assessment performed using the PSC showed a wide range, from 3.3 months to 21 years (median 14.82, Q1: 10.43, Q3: 33.90 months). In most cases, the stroke type was ischemic (66.04%). A left lesion occurred in 52.83% of cases. Aphasia was detected in 39.62%, whereas unilateral spatial neglect was present in 3.77%. The majority (96%) of the patients answered the PSC questions themselves, while the remaining 4% answered with the help of caregivers or therapists.

In most cases (81%), the PSC was completed in less than five minutes, and 89% of patients judged the questions easy to understand. The needs identified by questionnaire were considered important by 81% of patients, and around 72% of them declared that the checklist covered all their possible needs.

Table I shows the proportions of stroke patients with unmet needs identified in each of the PSC domains. In this Italian sample, the unmet needs highlighted by the Post Soft Care-App were mainly problems related to spasticity (56.60%), activities of daily living (47.17%), the absence of secondary prevention (45.28%), and mobility issues (45.28%).

The level of satisfaction of the therapists using the PSC was 7.4 ± 1.2 with regard to the overall assessment, 7.3 ± 1.2 in terms of the instrument's ability to help them identify patients' needs, and 7.1 ± 1.6 in terms of its ability to help them offer patients appropriate recommendations.

Similarly, the satisfaction of the patients was 6.9 ± 1.7 with regard to the overall assessment, 6.8 ± 1.8 in terms of its ability to identify their needs; and 6.3 ± 2.1 in relation to their acceptance of the referral/healthcare recommendations offered. Figure 1 shows the relationship between the utility of the Post Soft Care-App in identi-

Table I - Proportions of stroke patients with unmet needs identified in the eleven Post Stroke Checklist domains.

PSC item	Patients (n=53)
1. Absence of secondary prevention	45.28%
2. Activities of daily living	47.17%
3. Mobility	45.28%
4. Spasticity	56.60%
5. Pain	28.30%
6. Continence	30.19%
7. Communication	33.96%
8. Mood	41.51%
9. Cognition	43.40%
10. Life after stroke, sex	22.64%
11. Carer relationship	32.08%

fying patients' unmet needs, the patients' own levels of satisfaction (above, $R=0.868$, $p < 0.001$), and their acceptance of recommendations given (below, $R=0.357$, $p=0.009$). This latter correlation was poor. After dividing the patients by the time since the acute event, significantly higher acceptance ($p=0.012$) was observed in chronic patients whose time since onset was > 2 years ($n=16$), compared with those with a shorter disease duration: < 1 year ($n=17$) or between 1 and 2 years ($n=20$). No differences were found between these three groups in terms of overall satisfaction ($p=0.306$) or satisfaction with the identification of their needs ($p=0.259$).

Table II shows the therapists' answers to the questionnaire on the usability and the utility of the PSC administered using the app. In most cases, the usability and the utility of the PSC, assessed for each single patient, were judged positively. The therapists considered the Post Soft Care-App to be informative (100%) as well as useful, practical and quick to complete (for each, 96.23%).

In 75.45% of cases, the PSC was judged to have helped the therapists to improve their communication with patients, and in 81.13% to have highlighted at least one unmet need.

Discussion

The PSC was developed by the Global Stroke Community Advisory Panel in order to provide a simple and standardized method to help patients, medical practitioners and physiotherapists identify long-term problems of patients with stroke (Philp et al., 2013). Clinical aspects related to 11 domains including activities of daily living, spasticity, motor control and pain have previously been described in order to encourage greater attention to the prevention and care of patients who have experienced a stroke, in line with a developmental model of care which brings together primary and secondary care (Allen et al., 2002). In fact, stroke

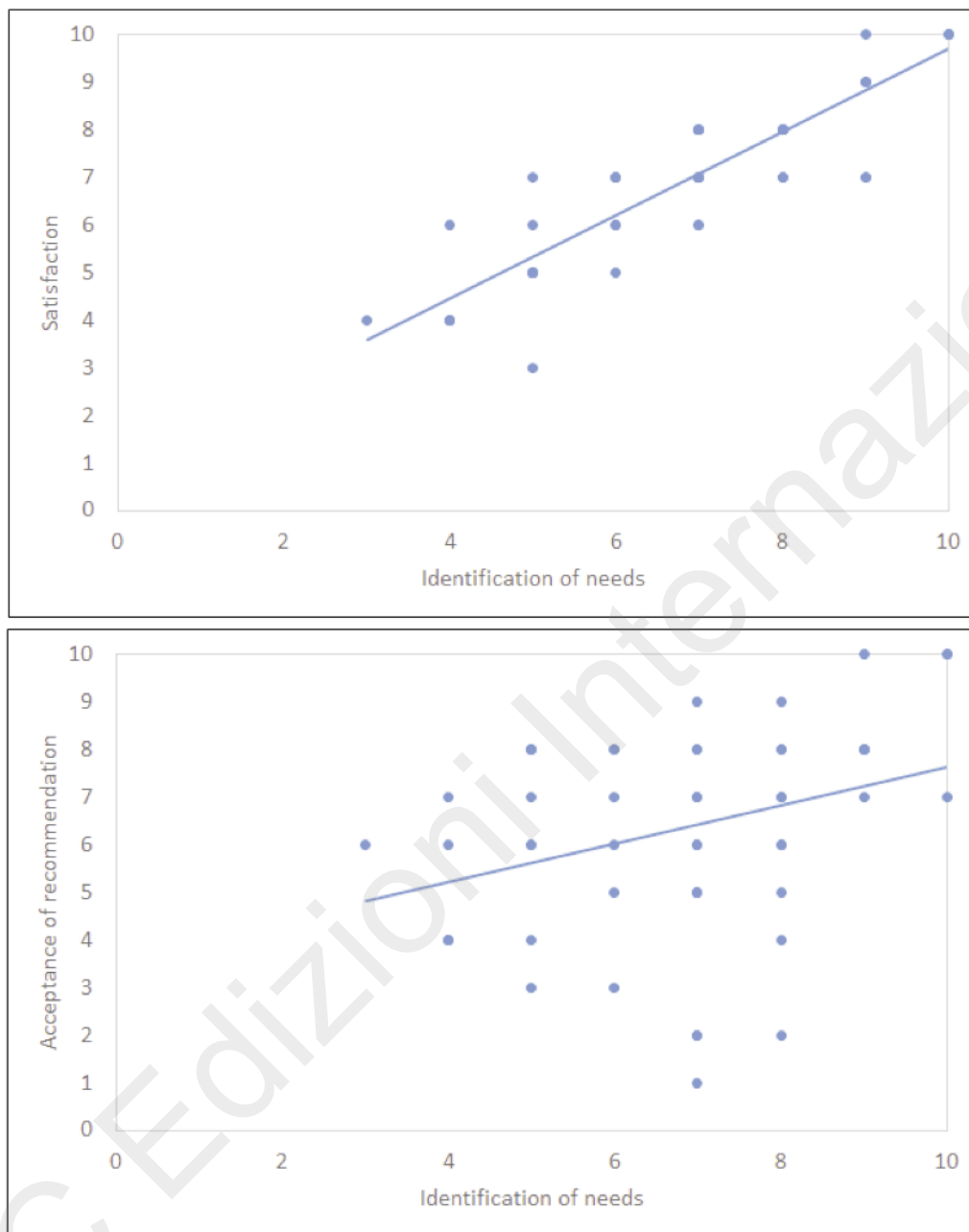


Figure 1 - Correlations between identification of needs and levels of satisfaction (top) and acceptance of recommendation (bottom) with relevant regression lines.

has been defined as a chronic disease with acute events (O'Neill et al., 2008).

An *ad hoc* Italian panel coordinated by the Italian Society of Neurological Rehabilitation developed the Italian version of the PSC (Paolucci et al., 2015). In the present study, we propose the administration of this Italian version by means of a special app installed on a tablet/smartphone.

In accordance with previous data on the use of the Italian version of the PSC (Paolucci et al., 2015; Iosa et al., 2018) the present study showed, overall, positive feedback on this tool. The identified needs are similar to those emerging in these previous studies. Furthermore,

the present results showed some advantages of the Post Soft Care-App, which was found to make the PSC faster and easier to administer.

In the aforementioned Italian study by Iosa et al. (2018), the most frequently reported worsening concerned mobility (53.1% as opposed to 45.28% in the present sample), whereas in the present study the most frequently reported unmet need concerned spasticity (56.60%). Spasticity is a severe problem that may have contributed to the impaired activities of daily living reported by 47.17% of our patients (Table I); spasticity is related to functional recovery in the first year after stroke, as recently reported in the literature (Shin et al., 2018).

Table II - Therapists' assessments of the usability and utility of the app version of the Post Stroke Checklist.

Assessments		Yes	No
Assessment of usability	PSC took less than 5 minutes to complete	81.13%	18.87%
	PSC was easily understood by the patient	88.68%	11.32%
	Unmet need(s) important for the life of patient	81.13%	18.87%
	Patient answered without the help of caregiver	96.23%	3.77%
	Patient provided more information thanks to the PSC	75.47%	24.53%
	Patient reported other needs not covered by the PSC	28.30%	71.70%
Assessment of utility	Informative	100%	0%
	Useful	96.23%	3.77%
	Exhaustive	75.47%	24.53%
	Practical	96.23%	3.77%
	Easy to explain	88.68%	11.32%
	Unbiased	77.36%	22.64%
	Precise	94.34%	5.66%
	Helped with therapeutic decision making	90.57%	9.43%
	Simple	88.68%	11.32%
	Concise	92.45%	7.55%
	Improved communication with the patient	75.47%	24.53%
	Quick to complete	96.23%	3.77%

Another recent Italian study showed that pain after stroke is more frequent in the subacute and chronic phases than in the acute stage of stroke, and that it remains largely undertreated. The prevalence of pain has previously been found to be about 14% in the acute phase, 43% in the subacute phase, and 32% in the chronic phase of stroke (Paolucci et al., 2016). In particular, the prevalence of spasticity-related pain was higher in the chronic stage than in other stages of stroke. With respect to this previous study (Paolucci et al., 2016), in the present one, a slightly lower incidence of pain and a higher incidence of spasticity were found. Maybe these differences are due to differences in the samples enrolled in the two studies, in terms of time from the acute event and treatment options.

Unlike previous studies conducted on samples enrolled in Italy (Iosa et al., 2018), the UK and Singapore (Ward et al., 2014), our study analyzed in depth the patients' answers and showed that, despite their considerable satisfaction with the capacity of the PSC to identify unmet needs, the acceptability, to the patients, of the recommendations given was found to be variable, depending on the time since the acute event. The more chronic patients seemed to be more willing to accept the recommendation to see a specialist, and this may be related to a gradual acceptance of the chronic nature of their stroke-related deficits (Cooper et al., 2015). A similar conclusion has been drawn in relation to aphasia in a study whose title included a phrase often used by patients when offered care opportunities: "It's not really worth my while" (Lanyon et al., 2018).

The utility and usability of the Post Soft Care-App were assessed through direct questions put to patients and therapists. The data analysis showed that the PSC administered using the Post Soft Care-App is completed in less than five minutes and was easily understood by patients. According to inpatient evaluations, it was able to identify important needs for the patients' lives and prompted them, especially the more chronic ones, to provide more detailed information about their clinical problems.

Therapists judged the Post Soft Care-App to be informative, useful/ practical, precise in terms of its content, and quick to complete. Above all they considered it a valid tool capable of helping them with therapeutic decision making.

According to criteria set out by the Research Committee of the American Neuropsychiatric Association (Malloy et al., 1997), an optimal screening instrument should have a series of desirable features: a) it should take less than <15 min when administered by clinicians (at any stage of their training); b) it should include all major clinical domains of the examined pathology; c) it should provide a reliable measure, and allow testing over time. From this perspective, the Post Soft Care-App can be said to meet all the criteria to be considered a valid assessment tool with which therapists can monitor the needs of chronic stroke patients.

Our study is limited by the small size of the two groups (therapists and patients). In order to generalize its findings to Italian stroke patients, the study should be repeated on a larger scale, and include patients from different Italian regions. Our study enrolled chronic patients, not subacute ones, with the aim of identifying un-

met needs using an app. Further studies could compare the Post Soft Care-App with other tools that allow therapists to identify unmet needs in chronic stroke patients. Despite the positive feedback from both therapists and patients, Post Soft Care-App users may nevertheless encounter some limitations. Although the PSC is a specific tool and covers many of the clinical aspects of stroke, it may not take into account all the possible needs of stroke patients. For this reason, the app is suitable only for general monitoring and certainly cannot replace a proper clinical assessment. There are several advantages of using an app to administer a clinical tool, for example the convenience of being able to use the tool on a smartphone, and the possibility of storing all the information acquired in an online database. This is easier and quicker than the paper and pencil approach, and above all it encourages exchanges between the different professionals involved in the care of chronic stroke patients. It also facilitates the acquisition of big data. Technological devices are now quite frequently used in clinical and rehabilitation settings. Several studies have examined the use of new technologies for both diagnostic and rehabilitation purposes. In particular, a 2012 review looked at the single and combined use of these technologies in stroke patients (Iosa et al., 2012) and considered the role of familiarity with the use of these technologies in successful rehabilitation outcomes.

In today's high-tech society, the use of new technologies in the clinical setting can be seen as a response to the increasing pace of life, which is making it necessary to concentrate all the indispensable tools in a single device such as a smartphone.

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