Identifying Unmet Rehabilitation Needs in Patients After Stroke With a Graphic Rehab-Compass™

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Background: Unmet rehabilitation needs are common among stroke survivors. We aimed to evaluate whether a comprehensive graphic "Rehab-Compass," a novel combination of structured patient-reported outcome measures, was feasible and useful in facilitating a capture of patients' rehabilitation needs in clinical practice. *Methods:* A new graphic overview of broad unmet rehabilitation needs covers deficits in functioning, daily activity, participation, and quality of life. It was constructed by using 5 patient-oriented, well-validated, and reliable existing instruments with converted data into a 0 (worst outcome) to 100 (best outcome) scale but unchanged in terms of variable properties. Satisfaction of the Rehab-Compass™ was studied by a qualitative interview of 9 patients with stroke and 3 clinicians. Practical feasibility and capacity of the instrument were evaluated in a cross-sectional study with 48 patients at 5-month follow-ups after subarachnoid hemorrhage. *Results:* The Rehab-Compass™ identified and graphically visualized a panoramic view of the multidimensional needs over time which was completed before clinical consultation. The Rehab-Compass™ appeared to be feasible and time-efficient in clinical use. The interviews of both patients and clinicians showed high satisfaction when using the Rehab-Compass™ graph. In the studied stroke patients, the Rehab-Compass™ identified memory and processing information, fatigue, mood, and pain after subarachnoid hemorrhage as the most common problems. *Conclusions:* The graphic Rehab-Compass™ seems to be a feasible, useful, and time-saving tool for identification of unmet rehabilitation needs among stroke survivors in clinical practice. Further research is needed to make the Rehab-Compass™ more concise and evaluate the instrument among different stroke subgroups.

Abbreviations: SAH, Subarachnoid Hemorrhage; aSAH, aneurysmal Subarachnoid Hemorrhage; ADL, Activities of Daily Life; SIS, Stroke Impact Scale; HAD, Hospital Anxiety and Depression Scale; FSS, Fatigue Severity Scale; mRSq, modified Rankin Scale questionnaire; MoCA, Montreal Cognitive Assessment; EQ-5D, EuroQol Five Dimensions questionnaire; ICF, International Classification of Functioning, disability, and health; FIM+FAM, Functional Independence/Assessment Measurement; PSC, Post Stroke Checklist; ICHOM, International Consortium for Health Outcomes Measurement; IQR, Interquartile range, TM, Trademark

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Introduction

Stroke is a leading cause of disability among adults worldwide. A growing aged population, in conjunction with a decreased acute stroke mortality have resulted in an increasing number of stroke survivors with various long-term impairments, for example, fatigue, cognitive and affective dysfunction, pain, restricted communicative abilities, immobility, as well as restrictions in social participation, and quality of life[1,2]. Many stroke survivors are living with multidimensional impairments with heavy burden on the family and the society[3]. Subarachnoid hemorrhage (SAH) accounts for one-third of all cerebral hemorrhages and 5% of stroke. The mean age of onset for SAH is almost 20 years younger compared to that for stroke in general, which leads to substantial restrictions in health-related quality of life among many SAH survivors[4]. However, long-term care after SAH as well as stroke is still underdeveloped. One of the challenges in long-term care is monitoring and addressing the comprehensive and dynamic postacute rehabilitation needs over time[5,6]

The full impact of stroke is often realized by patients and their next-of-kins at home after being discharged from hospital or by the early supported discharge team. Stroke survivors often face multidimensional impacts not only on various functions as mentioned above but also on restrictions in social participation and dissatisfaction with quality of life[1,2,7,8]. This makes it difficult to obtain a holistic view of patients' unmet rehabilitation needs, especially under the time-pressed consultations which are common today. The unmet rehabilitation needs could be either a need that has been detected but not been fulfilled or a need has not been detected previously. Some functional outcome measurements used by rehabilitation professionals for long-term care may underestimate dependence and may lead to different prioritizing between rehabilitation professionals and patients[5]. Thus, patient-reported outcome measurements prior to consultation may be an attractive option in long-term care after stroke.

There are many well-validated and reliable instruments used to assess the various stroke impact spectra over time, such as the Stroke Impact Scale (SIS)[9], modified Rankin Scale[10], the Greater Manchester Stroke Assessment Tool[11], Functional Independence/Assessment Measurement (FIM+FAM)[12], EuroQoL-5 Dimensions (EQ-5D)[13], the Post Stroke Checklist[7,14] and the International Consortium for Health Outcomes Measurement[15]. However, some of them provide only part of a comprehensive overview of the multiple poststroke effects[10,12,13], whereas others have not been used for all subtypes of stroke, for example, SAH[11,15]. Some of them have difficulty capturing dynamic profiles of stroke impact during long-term follow-ups due to their dichotomous construction[7]. Others lack a comparative database due to derivation from expert consensus[7,15]. Moreover, many assessments use different scales, which results not only in problems with comparisons of various outcomes, but also difficulties for clinicians to capture the most need-to-treat symptoms during consultation.

To overcome these problems and to highlight patients' actual diverse rehabilitation needs over time, we constructed a graphic Rehab-Compass™ in the current study to visualize patients' rehabilitation needs. In contrast to abolishing the "old" evidence-based assessments in the recent new instruments[14,15], we tried to construct a new pragmatic "Rehab-Compass" comprising 5 well-validated and reliable extant instruments as building blocks. When choosing the patient-centered questionnaires, the most common and well-validated instruments were prioritized. The rationale was using the minimum number of assessments to cover board poststroke affects[7], that is, diverse deficits in functioning, daily activity, participation, and quality of life according to the concept of International Classification of Functioning, disability, and health (ICF). Meanwhile, we attempted to cover both autonomy (the patient's ability to be independent) and functional dimension (the patient's ability to compensate and performa specific activities) when choosing the questionnaires[16]. Since it is common issue that an improvement in functional recovery may not be detected by a global outcome measures and vice versa, 5 patient-centered outcome measures were chosen for the construction of Rehab-Compass. Special attention was also paid to those hidden conditions after stroke with different severities, such as cognition and neuropsychiatric functions (anxiety, depression, and fatigue)[8] as well as incontinence and sexual dysfunction[17]. The aim of the study was to evaluate whether a comprehensive graphic “Rehab-Compass,” a novel combination of structured patient-reported outcome measures, was feasible and useful in facilitating a capture of patients' rehabilitation needs in clinical practice.

Methods

Ethics

Ethical approval was obtained from the regional Ethical Review Board in Umeå, Sweden with D-nr 2013/366-31 (for baseline data only) and 2015/144-31.

Development of the Rehab-Compass™

The Rehab-Compass™ was constructed to provide a content-wise comprehensive and graphically “panoramic”