Wide variation in function level assessment after stroke in Denmark

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ABSTRACT
INSTRUCTION: The aim of this study was to examine the use of standardised instruments to describe functioning in stroke patients in the transition from hospital to home-based rehabilitation.

METHODS: Questionnaires were sent to 26 hospitals discharging patients with stroke and 52 primary care health services treating stroke patients at home, within an area with a population of three million. Questionnaires were targeted at healthcare professionals who typically take part in home-based stroke rehabilitation asking: *Which instruments, outcome measures or tests are commonly used to describe functioning in persons with stroke?* Instruments routinely used to assess functioning were reported.

RESULTS: 85% of the hospitals and 90% of the primary care services returned the questionnaire. 95% of the hospitals and 96% of the primary care services used standardised instruments. Hospitals reported 81 standardised instruments and primary care services reported 60 standardised instruments. A total of 89 standardised instruments were reported. No instrument was used in every hospital or primary care service.

CONCLUSIONS: The vast majority of services use standardised instruments, but there is absolutely no consensus on which instruments to use. There is a strong need for recommendations on which instruments should be used in stroke rehabilitation in the transition from hospital-based to home-based rehabilitation.

FUNDING: This study was supported by a grant from the Management Forum for Collaboration between Aarhus University and the Central Denmark Region, Denmark. None of the authors have any personal financial interests in the work undertaken or the findings reported.

TRIAL REGISTRATION: not relevant.

In recent years, acute stroke treatment and rehabilitation have improved considerably: the duration of in-hospital stays has been reduced dramatically, and there is a growing emphasis on home-based rehabilitation [1]. The challenge is to start home-based rehabilitation at the right time and at the right level when the patient’s environment and the rehabilitation team both change. Having a routine in place for outcome monitoring by means of relevant instruments is a way of ensuring coordination, communication and continuity during the transition.

Assessing the patient’s recovery after stroke at an individual level is important, but selecting the right instruments is a difficult process [2] and ensuring routine use of standardised instruments in clinical practice can be challenging [3]. Several studies on standardised instruments in stroke exist, but none have specifically considered the transition from hospital to home-based care, and recommendations from clinical guidelines are vague [4, 5]. A standard set of patient-centred outcome measures after stroke suggests that a minimum set of functioning data should be collected at discharge, either from clinical data or via provider reporting [6]. However, the standard set does not suggest specific instruments. Simply asking the patient might be an option, but as cognition is affected during the first days after stroke in up to 70% of patients [7], the use of patient-reported instruments at discharge is fraught with difficulty.

Recognising that no single instrument can fully encompass functioning in patients with stroke, we expect that a small battery of standardised instruments will be necessary to describe functioning. The WHO International Classification of Functioning, Disability and Health (ICF) is a framework for health and disability [8]. Instruments to describe functioning can be categorised on an ICF continuum ranging from instruments of body function to instruments focusing on participation. The further one moves along this continuum, the longer it may take to reach a measurement endpoint from stroke onset. In other words, participation within a social context may take longer to stabilise than the impaired body function [9]. It has been recommended that a systematic assessment of participation should be completed 90 days after stroke onset [6].

In the initial assessment and treatment of stroke, emphasis is placed on body functions and anatomy as the initial treatment aims at stabilising the patient and reducing brain damage [4, 10]. At discharge, it is recommended to assess the following areas of importance as a minimum: mobility, feeding, toileting, dressing and ability to communicate [6]. The minimum set focuses on activities that are meaningful to the patient’s daily life [11] and should ideally describe the develop-
ment of functioning throughout the patient’s course of rehabilitation. Due to the shorter hospital stays in stroke rehabilitation, there is greater emphasis on post-acute care and rehabilitation. Post-acute care or rehabilitation facilities vary from country to country, but the same minimum set of outcome measures could be used everywhere.

Rehabilitation may become unnecessarily complicated if healthcare professionals use different instruments to describe functioning during the acute phase compared to post-acute rehabilitation. The use of relevant instruments in the transition is important, but knowledge about what instruments are actually used is lacking [12]. Thus, the aim of this study was to examine the use of standardised instruments to describe functioning used in clinical practice at hospitals and in home-based rehabilitation.

METHODS
Two separate sectors are responsible for rehabilitation in Denmark: The regional sector is responsible for hospital services and inpatient rehabilitation. Acute stroke care and inpatient rehabilitation are closely related in Danish stroke units [13]. Inpatient rehabilitation commences immediately after the end of acute treatment and is based on a multidisciplinary assessment made no later than 48 h after admission. The second sector, the local authority sector, comprises 98 municipalities responsible for primary healthcare treatment and rehabilitation after discharge from hospital. Here, rehabilitation commences as soon as possible, often on the day after the patient is discharged and no later than seven days after discharge. It continues for weeks or months depending on the patient’s needs.

The hospital draws up a rehabilitation plan describing the level of rehabilitation including a description of the patient’s functioning. The doctor is responsible for the rehabilitation plan which serves as a referral to home-based rehabilitation. As in most other countries, no standardised/specific requirements apply to this description of functioning. The regional and local authority sectors both use multidisciplinary teams [14] to provide rehabilitation. No doctors are involved in local authority sector rehabilitation.

All rehabilitation services in Denmark are tax-funded and free of charge for patients. Otherwise, they closely resemble the rehabilitation efforts in other Western countries [12, 15]. Thus, establishing efficient cross-sectoral communication is crucial.

Questionnaire design
An email survey design was chosen. All hospitals discharging patients with stroke and all primary care health services in three of the five administrative regions in Denmark were contacted. The study area covers a total population of three million (55% of the entire Danish population). An email was sent to the heads of the rehabilitation services. Each email included five questionnaires: three mono-disciplinary questionnaires for nurses, physiotherapists and occupational therapists; one questionnaire for the team treating stroke patients (i.e. reporting inter-professional instruments); and one questionnaire for “other health professionals”, including, e.g., speech therapists, nursing assistants and neuropsychologists. The email noted that the instruments relevant to the survey were those used by healthcare professionals evaluating patients with stroke in the post-acute phase of rehabilitation. Each questionnaire had just one open-ended question: “Which instruments, outcome measures or tests are commonly used to describe functioning in persons with stroke?” Furthermore, the person responsible for filling in the questionnaire was asked to fill in his or her name. The questionnaires emphasised that only instruments that were used routinely to assess functioning should be reported. “Routine” was defined as being used at least every second week. If no instruments were used, this was to be stated.

Procedure
In May 2013, emails were sent to the heads of 26 hospitals and 52 primary care health services. A covering letter explained the purpose of the study and invited the heads to distribute the questionnaires among their staff for completion. Non-responders were reminded of the survey in another email within four weeks. This procedure was repeated after two weeks and followed by a telephone call.
Data analysis
The instruments reported were divided into “standardised” and “others”. A standardised instrument was defined as a published instrument that offers uniform and consistent test administration, preferably instruments for which the reliability and validity are known. Instruments modified by the responders or homemade instruments were defined as “others”. Data were entered into an Excel database and subjected to descriptive analysis. Instruments used in more than a third of the hospitals or primary healthcare services were listed. Data on the use of instruments were registered and listed by professions.

Ethics
The Central Denmark Region Committees on Biomedical Research Ethics was notified of the project (280/2015).

Trial registration: not relevant.

RESULTS
Of the 26 hospitals and 52 primary healthcare services contacted, 69 (88%) returned the questionnaire. Results are shown in Figure 1. A total of 21 (95%) of the responding hospitals and 45 (96%) of the responding primary healthcare services used standardised instruments.

The hospitals reported using 61 standardised and 45 other instruments. The primary healthcare services reported using 60 standardised and 53 other instruments. In total, 89 standardised instruments and more than 80 other instruments were used to describe functioning in stroke patients.

None of the reported instruments were used in all hospitals or all primary healthcare services. A majority of the standardised instruments were used in just one or two places; 30 (50%) of the standardised instruments were used in just one or two hospitals, and 36 (59%) were used in just one or two primary healthcare services.

Seventeen standardised instruments were used in more than a third of the hospitals or a third of the primary care services (see Table 1).

The various healthcare professionals reported diverse use of standardised instruments: occupational therapists at hospitals were the most frequent users, while nurses reported the least frequent use of standardised instruments (see Table 2).

Use of interprofessional instruments was reported in 42% of the hospitals and 45% of the primary care services.

DISCUSSION
Healthcare professionals are encouraged to use evidence-based practices in the pursuit of “best practices” for their patients. This includes the use of valid and reliable instruments in healthcare transitions, but no recommendations exist on which instruments to use. This survey of more than half of the Danish healthcare sector shows that the vast majority of services use standardised instruments for stroke rehabilitation, but also revealed that there is no consensus on the selection of instruments or the areas of importance, resulting in a considerable number of instruments being used.
Our results are comparable with a survey of UK rehabilitation centres where 86% reported use of outcome measures [16]. The UK survey targeted rehabilitation centres treating patients with a variety of diagnoses while we focused on stroke. Nevertheless, we found some of the same instruments. A 2009 study focusing on physiotherapists found that only 48% used standardised instruments [17]. As the study used a different selection approach, a different method and targeted a profession rather than an inter-professional team treating a group of patients with the same diagnosis, the results are not comparable to ours. Several studies focus on barriers to the routine use of standardised instruments [3, 18]. A review found four themes of importance for routine use in practice: 1) knowledge and perceived value of instruments; 2) support/priority for use of instruments; 3) practical considerations; and 4) patient considerations [18]. The areas found in the review corroborate the areas of importance found in an editorial on routine use of outcome monitoring in psychiatry [3]. These areas are significant for somatic conditions as well. There is a need for clear decisions on: Which instruments to include in routine outcome measurement and who should assess, and a there is a need for discussion on how different stakeholders can benefit from routine use of outcome measurement [3].

In the present study, we found a myriad of different instruments used by hospitals and in primary care; this might complicate communication along the patient’s path of rehabilitation. If functioning is to be described meaningfully to the patient, healthcare professionals on either side of a transition must focus on the same areas of importance, and they must use – or at least know – the same instruments.

Table 1 shows that all instruments used in more than one third of the health services target the activity domain in ICF, with some instruments targeting body functions and participation as well. This supports the idea that the activity domain should be dominant in routine assessment during the transition phase (especially in cases with brief periods of hospitalisation); assessment of activity should be supplemented by instruments assessing body function and participation.

In the UK and Australia, national sets of outcome measures (named UKROC and AROC) have been defined for stroke patients admitted for hospital-based rehabilitation [19], but these instruments seem more relevant for inpatient rehabilitation focusing on body functions. For use during transitions from hospital to home-based rehabilitation, the UKROC and AROC outcome measures must be expanded by a set of instruments covering all areas of importance (mobility, feeding, toileting, dressing and ability to communicate) [6]. There is a need for international consensus on such outcome measures used in stroke rehabilitation [20]. A shared set of relevant instruments could be used in research and clinical practice for benchmark evaluation [20].

The strength of this study is the high response rate. The discussion on routine outcome measurement in health services and the discussion on how to monitor change in functional status have surely contributed to the response rate [3, 16, 18].

A potential limitation might be that the questionnaires were emailed to the heads of the rehabilitation services, inviting them to redistribute questionnaires to the relevant healthcare professionals. The name and profession of the person responsible for responding were stated on the questionnaire, but we cannot know whether it was filled in by that one person alone or after consultation with their group. The number of instruments and the comments given on the questionnaires (comments not stated in this article) make it most likely that the designated healthcare professionals have answered after discussions in their groups.

The use of instruments varied greatly in scope: 3-26 at hospitals and 2-26 in primary healthcare services. Some may have over-reported, reporting all the instruments they know instead of just the ones routinely used, which may compromise the study results.

Four hospitals and five primary care services did not respond to the survey, and one hospital and two primary care services reported no systematic use of instruments. The non-responding hospitals were three small and one medium-sized hospital; the hospitals not using standardised instruments were medium-sized. The non-responding primary care services were five small and two medium-sized services; the primary care services not using standardised instruments were small. Non-responding and non-using hospitals and primary care services are evenly distributed geographically across the three regions of interest. Given that the non-responders and non-users are small or medium-sized rehabilitation services, we do not believe that their responses would significantly impact the result, but it might indicate that smaller rehabilitation services are less frequent users of routine outcome monitoring.

The survey targeted allied healthcare professionals, not medical doctors. Doctors have a key role in inpatient treatment and are part of the inpatient rehabilitation team and responsible for the rehabilitation plan, but doctors are not yet part of the rehabilitation team in home-based rehabilitation in the municipalities. We recognise the need for doctors’ professional knowledge and for their routine use of outcome measurement. If doctors had been included in the survey, this might have disclosed more instruments used at hospitals and changed our list of instruments used in more than a third of the health services.
These limitations might have influenced the survey, but we do not believe that they affect the main results: A very high number of instruments is being used and consensus is limited on the use of areas of importance.

CONCLUSIONS
This survey of more than half the Danish healthcare sector shows that the vast majority of services use standardised instruments. A very high number of instruments used in the description of functioning in stroke patients were found, and there is absolutely no consensus on the selection of instruments. There is a strong need for recommendations outlining which instruments should be used in stroke rehabilitation in the transition between hospital-based rehabilitation and home-based rehabilitation.

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ACCEPTED: 13 July 2018
CONFLICTS OF INTEREST: none. Disclosure forms provided by the authors are available with the full text of this article at Ugeskriftet.dk/dmj

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