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Pilot assessment of a comfort scale in stroke patients

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ABSTRACT

Introduction: Comfort/discomfort (C/D) is an important factor of quality of life (QoL). Brain damage is a major source of discomfort. We developed a questionnaire for assessing C/D in daily living situations and for identifying the main causes of any discomfort and presented its pilot assessment in a population of stroke patients.
Methods: The scale is a questionnaire of the patient or caregiver that addresses (i) comfort/discomfort in 15 situations of daily living (including getting dressed, washing, lying in bed and sitting in a chair) and (ii) the roles of physical difficulties, psychological problems and a poorly adapted environment. We analysed its metrological qualities in a group of 62 stroke patients.
Results: For the patients, the most uncomfortable activities were eating, dressing the lower body, urine and faeces elimination and walking, and the most significant factors of discomfort were motor impairments, fatigue, limb stiffness, joint pain, depression and anxiety. The reliability was fair for the overall score and for each C/D item and moderate for the impact of impairments on comfort/discomfort. We also found fair internal consistency and convergent validity against measures of functional status, QoL and burden of care. Sensitivity to change over a 6-week period was modest.
Conclusions: The scale can help to define difficulties in daily living situations and identify opportunities for intervention in stroke patients.

1. Introduction

Comfort is a state of physical well-being in which an individual is reasonably adapted to his/her immediate material environment. It may be felt through tactile, auditory, visual and olfactory afferences [1]. Comfort includes a psychological dimension that results from the perception of physical ease and freedom from pain and contributes to health-related quality of life (QoL) [2]. Patients with stroke and disability frequently suffer from discomfort caused by a non-optimal relationship between their body and the latter's surrounding material and human environment [1]. A variety of uncomfortable situations of daily living have been described [1,3]. They correspond to personal activities (ADLs), such as getting dressed, washing, lying in bed and receiving medical care. Improving patient comfort is an objective of care [4].

Although specific comfort scales have been developed (especially for patients suffering from severe difficulties at the end of life [5,6] and those admitted to intensive care units [7–9] or psychiatry units [10]), they mostly record the caregiver's perception. Comfort has also been investigated as a parameter in the patient's position in a chair or wheelchair [11–13] or in defining a patient's shoe preferences [14]. However, there is still a need for a generic scale adapted to patients with neurological disorders that (i) addresses comfort and discomfort in different ADLs, (ii) reflects the patient's point of view and (iii) investigates the reasons for discomfort.

We have developed a questionnaire (the Comfort Assessment Scale for Neurologic Patients (CAS-NP)) for assessing the levels of comfort/discomfort (C/D) experienced by neurologic patients during ADLs and determining the main discomfort factors. Here, we report on a pilot validation study in a population of stroke patients admitted to a rehabilitation ward.

2. Methods

2.1. Test design

A group of five specialists in neurology and physical medicine and rehabilitation participated in the building of the scale. In order to obtain at least fair content validity, they decided to follow the principles of the International Classification of Functioning, Disability and Health (ICF) [15]. The scale was built in two parts. First, comfort was considered in various ADLs [3]. Second, the scale identified the main C/D factors, which can variously be related to the patient's impairments or a poorly adapted environment. The scale focussed on the patient's point of view but also took account of the caregiver's perspective by using two parallel versions of the questionnaire. First, a list of items was suggested by four specialist physicians in neurology or physical medicine and rehabilitation. The questionnaire was presented to inpatients with stroke or traumatic brain injury and to their individual caregivers, and its items were progressively refined after receiving their feedback.

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The first part of the final questionnaire (see the Appendix A.) considered 12 ADLs: eating, washing the upper body, washing the lower body, dressing the upper body, dressing the lower body, urine elimination, faeces elimination, transfers, lying in bed, sitting in a chair, sleeping and nursing care. Three additional activities were included on an optional basis since they are not performed by all the patients but can be important in some cases: using a wheelchair, walking and sexual activity. For each activity, C/D was rated on a vertically orientated visual analogue scale (VAS) [16,17] ranging from 0 (the greatest possible discomfort) to 10 (the greatest possible comfort). For VAS levels, values between integers were recorded. In consideration to the fact that all the patients were confronted to the first 12 situations, an average score was calculated.

The second part of the questionnaire listed 20 possible discomfort factors, which covered both physical and mental impairments and a poorly adapted physical and human environment. The patient rated the degree of discomfort resulting from each factor on a VAS ranging from 0 (no related discomfort) to 10 (severe related discomfort) [18]. Each factor was potentially independent of the others and so we did not calculate a mean score for this part of the questionnaire.

At the end of the questionnaire, the patient's degree of cooperation was rated by the observer on a VAS ranging from 0 (no cooperation) to 10 (a high degree of cooperation).

2.2. Scale assessment

A pilot assessment of the scale was performed in a population of stroke patients admitted to the Neurological Rehabilitation Unit at Lille University Hospital. The main objectives were to estimate (i) intra- and inter-observer reproducibility, (ii) relationships between the patient's assessments and the caregiver's assessment, (iii) convergent validity with measures of personal independence and QoL and (iv) the scale's sensitivity to change over a 6-week rehabilitation period. It must be noted that in the analysis of intra and inter observer reproducibility, the response to the questionnaire was always given by the patient, and the analyses explored the reproducibility of the patient point of view (test–retest reliability); however, the presentation of each item and the general behaviour of the observer could also influence the patient responses. With this consideration, we used the classical terms of "intra-observer" and "inter-observer" reproducibility, as yet presented for other questionnaires [19].

2.3. Patients

Sixty-two French-speaking inpatients admitted for a relatively recent ischaemic or haemorrhagic stroke (1 to 6 months previously) were enrolled in the study. We excluded patients with impaired communication due to severe aphasia (a Boston Diagnostic Aphasia Examination global severity score ≤3 of 5) or behavioural disorders (severe disorientation or confusion). All patients received detailed information on the study and provided their informed consent to participation prior to any study-specific procedures. This observational study was approved by the French Data Protection Authority (Commission nationale de l'informatique et des libertés).

2.4. General design and end points

The questionnaire was administered by one observer on day 1, days 6–7 and week 6 and by another observer on days 2–3. All the observers were physicians. For the first 37 patients, the observer performing the first assessment was selected at random. Two other observers were recruited for a second set of 25 patients and evaluated the patients in sequential order. In 56 cases, the questionnaire was also administered to a close caregiver (a nurse in charge of the patient).

The first observer also evaluated disability (on the modified Rankin scale (MRS), ranging from 0 to 5 [20]), dependency (with the French version of the Functional Independence Measure (FIM), ranging from 18 to 126) [21] and QoL (with the 12-item Short-Form Health Survey (SF-12) [22] and a VAS (similar to that used for the assessment of comfort, and ranging from 0 to 10) [23]). The observers also collected general information about the patient (such as age, gender, educational level (the number of years spent in fulltime education), the time since stroke, the patient's overall degree of cooperation in completing the questionnaire and the burden of care as perceived by a caregiver (on a 0–10 VAS).

2.5. Statistical methods

All the statistical analyses were performed with SPSS software (version 15.0, SPSS Inc., USA). Intra-observer and inter-observer reliability were assessed by calculating the intra-class correlation coefficient (ICC) [24] and by using the Bland–Altman method [25,26]. An ICC value ≤0.30 indicates no agreement, a value >0.30 and ≤0.50 indicates poor agreement, a value >0.50 and ≤0.70 indicates moderate agreement, a value >0.70 and ≤0.90 indicates fair agreement and a value > 0.90 indicates excellent agreement [27]. Internal consistency was analysed with Cronbach's alpha coefficient. Pearson's correlation coefficient was used to study the relationship between the mean questionnaire score on one hand and the measures of disability, dependence and QoL on the other. To analyse sensitivity to change, we measured the effect size and the standardised response mean [27]. All statistical tests

Table 1
Comfort/discomfort levels (0–10) and inter- and intra-observer reliability.

	Observer 1a	Observer 2	Interobserver (ICC)	Observer 1b (day 7)	Intraobserver (ICC)
Eating	6.63 (2.75)	5.59 (3.04)	0.710	6.65 (2.74)	0.880
Toileting—upper body	6.41 (2.85)	6.58 (2.52)	0.746	6.98 (2.83)	0.822
Toileting—lower body	6.35 (2.77)	6.33 (2.70)	0.817	6.73 (2.98)	0.783
Dressing—upper body	6.98 (2.54)	6.65 (2.29)	0.702	7.40 (2.50)	0.714
Dressing—lower body	6.08 (2.70)	6.09 (2.57)	0.710	6.88 (2.78)	0.736
Urine elimination	7.06 (2.89)	6.23 (3.42)	0.714	6.97 (3.14)	0.842
Faeces elimination	6.59 (3.26)	6.22 (3.55)	0.846	6.73 (3.22)	0.805
Transfers	7.31 (2.59)	7.11 (2.93)	0.769	7.51 (2.47)	0.789
Sitting down on a chair	6.79 (2.84)	6.96 (2.77)	0.892	7.11 (2.94)	0.865
Getting into bed	7.53 (2.60)	7.53 (2.27)	0.810	7.81 (2.41)	0.809
Sleeping	6.77 (2.98)	6.46 (2.57)	0.781	7.13 (2.75)	0.855
Nursing care	8.15 (2.07	7.70 (2.55)	0.709	8.14 (2.11)	0.764
Using a wheelchair	6.60 (2.99)	6.33 (2.87)	0.709	6.59 (3.11)	0.813
Walking	6.30 (2.58)	6.20 (2.28)	0.787	7.02 (2.51)	0.850
Sexual activity	7.00 (1.73)	7.33 (1.88)	0.998	7.30 (2.17)	0.946
Mean for items 1 to 12	6.90 (1.89)	6.63 (2.01)	0.925	7.17 (2.13)	0.919
Mean for items 1 to 15	6.82 (1.89)	6.56 (1.97)	0.920	7.10 (2.11)	0.927