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Reporting "specific abilities" after major stroke to better describe prognosis

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Introduction: If health professionals are to involve major stroke patients and their families in making decisions about treatments, they need to describe prognosis in terms that are easily understood. We suggest that referring to "specific abilities", such as ability to be independent, walk, talk, eat normally, be continent, live without severe pain, live without major anxiety or depression and to live at home may be more easily understood than terms such as disabled based on the modified Rankin scale (mRs). *Objective:* We aimed to describe the "specific abilities" and quality of life of patients in each mRs level at six months after major stroke. *Patients and methods:* A longitudinal cohort study of patients admitted to hospital with major stroke with follow up at six months. *Results:* We recruited 403 patients, mean age 77.5yrs. The number (%) in each mRs level at six months was 0 (no problems): 8 (2%), 1: 45(11.2%), 2: 7(1.7%), 3: 149(37.1%), 4: 46(11.4%), 5: 36(9.0%) and 6(dead) 111(27.6%). Patients within each mRs level varied with respect to their "specific abilities" and quality of life. For example, of the 36(9%) patients with mRs 5, 30 (83%) could talk, 14(39%) were continent, 33(92%) were not in severe pain, 22(61%) did not have major anxiety/depression and 5(14%) could live at home. Their median utility (derived from HRQoL) was -0.08 (range -0.35 to 0.43). *Discussion and Conclusions:* Describing prognosis with the mRs does not convey the variation in specific abilities and HRQoL amongst patients with major stroke. Therefore, describing prognosis in terms of "specific abilities" may be more appropriate.
Key Words: Major strok—Specific abilities—Prognosis—Communication

Introduction

Health professionals are encouraged to involve patients and families in making treatment decisions.[1] This is particularly relevant in the context of a major stroke where an early treatment decision to accept or decline treatments may influence outcomes.[2] For example, accepting treatments such as intermittent pneumatic compression[3] and early tube feeding[4] increase the likelihood that the patient will survive, but be left with significant disability whereas declining these treatments may result in earlier death. However, terms such as 'disability' may have varied meanings to different people. Similarly, where health related quality of life (HRQoL) is reported, this is expressed as utilities (i.e. the desirability of a health outcome between -1 (worse health state) to 1 (excellent health state)) derived from the EQ5D or similar scales.[5] However, this may not be easily communicated. Furthermore, different individuals would have different perceptions of their HRQoL.

Although the deficits and needs of stroke survivors with respect to their mobility, communication and psychological well-being has been reported,[6] treatment

decisions early on after a major stroke are often made based on predictions of death or severe disability.[7] This is because disability scales such as the modified Rankin scale (mRs) which has seven levels ranging from 0 (No problems) to 6 (Dead)[8] and the Barthel Index (BI), a functional scale describing the ability of patients to perform several different activities of daily living are familiar to health professionals.[9] Furthermore, there are statistical models which have been validated for use in research to predict death and disability.[10] In contrast, there is considerable uncertainty with respect to the recovery of patients' specific abilities (e.g. mobility, speech) and a lack of adequately validated statistical models to predict these abilities.[11]

An important step in involving patients and families in decision-making is for health professionals to be able to effectively communicate information on patient prognosis in terms that are easily understood and on which they might base their decisions.

We hypothesised that patients and their families might find it more helpful if we described patients' prognosis in terms of "specific abilities";[2] i.e. ability to be independent, to walk, to talk, to eat normally, to be continent, to live without severe pain, to live without major anxiety or depression and to live at home. Patients admitted with major stroke described seeking hope, so expressing outcomes in positive terms (abilities), rather than negative ones (disabilities) may be more appropriate.[12] A first step towards communicating prognosis effectively was to describe the "specific abilities" and HRQoL of patients six months after major stroke and to relate these to their mRs.

Materials and Methods

We adhered to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for cohort studies.[13]

We prospectively recruited a longitudinal cohort of adults (>18 years) within 10 days of a major stroke in a UK teaching hospital and followed them up at about six months. Eligible patients had mRs 3-5 (described as a 'poor' outcome in clinical trials)[14] or mRs 0-2 (a 'good' outcome) but a deficiency due to the stroke with respect to at least two specific abilities. Patients or proxies (where the patient lacked capacity) provided written informed consent.

At baseline and at six months, we determined patients' mRs using the simplified modified Rankin scale questionnaire (smRsq),[15] their BI (scored 0-100)[8] and HRQoL with the EQ5D-5L.[5] We derived utilities using the published crosswalk calculator.[16] Proxies completed assessments where patients were unable to do so. We derived "specific abilities" based on single items from these commonly used and validated scales or for abilities which were not addressed by these scales i.e. eating, talking and living at home, by asking a specific question. For example, we derived 'able to be continent' from answers provided to urine and bowel continence items on BI and 'able to eat normally' by asking patients/ families the patients' ability to eat food at six months (i.e. normal diet, oral modified diet, nasogastric feed, feed through percutaneous endoscopic gastrostomy or radiologically inserted gastrostomy). We dichotomised each "specific ability" into 'able' or 'unable' based on judgements of stroke professionals at the recruiting hospital. (Table 1).

The Scotland A Research Ethics Committee (Ref: 17/SS/ 0029) approved our protocol. We used Stata 15 (Timberlake, 2017) for analyses.

Table 1. *Definitions of "specific abilities" after stroke based on dichotomies on single items from smRsq, BI, EQ5D-5L, or specific questions.*

Specific abilities at six months	Measure	Able	Unable
To be independent	smRsq	0-2	3-5
To walk	smRsq	Able	Unable
To talk*	Specific question**	No dysphasia, Mild or Moderate dysphasia	Severe dysphasia, Mute
To eat normally	Specific question**	Normal or Oral modified	Nasogastric tube, Percutaneous gastrostomy or Radiologically inserted gastrostomy
To be continent	BI	Continent or occasional accidents	Incontinent/catheterised
To live without severe pain	EQ5D 5L	No pain, mild or moderate pain or discomfort	Severe or extreme pain or discomfort
To live without major anxiety or depression	EQ5D 5L	Not anxious/ depressed, slightly or moderately anxious/ depressed	Severely or extremely anxious/ depressed
To live at home	Specific question**	Own home or families home	Residential home, Care home or Hospital

*language assessment only.
**options given and dichotomised.

Results

We recruited 403 patients between 10th May 2017 and 25th May 2018. Their mean age was 77.5 (SD 11.7) and 209/403 (52%) had a baseline mRs of five. (Table 2)

At six months the number and percentage of patients in each mRs level was 0 (no problems): 8(2%), 1: 45(11.2%), 2: 7 (1.7%), 3: 149(37.1%), 4: 46(11.4%), 5: 36(9.0%) and 6 (dead) 111(27.6%). Few (60/402, 15%) had a 'good' outcome, i.e. mRs 0-2. One patient was uncontactable. (Table 3)

Patients within each mRs level, especially mRs 3, 4 and 5, varied with respect to their "specific abilities" and HRQoL (Table 3). For example, of the 36 (9%) patients with mRs 5, 30(83%) could talk, 14(39%) were continent, 33 (92%) were not in severe pain, 22(61%) did not have major anxiety/depression and 5(14%) could live at home. Their median utility was -0.08 but ranged from -0.35 to 0.43. Of the 45 (11.2%) patients with mRs 1, all were able to talk, eat normally, be continent, not have major anxiety/depression and live at home, but two patients (4%) were in severe pain. Their median utility was 0.84 but ranged from 0.32 to 1.

Table 2. *Baseline characteristics of cohort*

Variable	Categories	Total n=403	%
Age (years) mean (Standard Deviation (SD))		77.5 (11.7)	
Gender	Male	179	44.4
	Female	224	55.6
Independent before stroke*		308	76.4
Living alone before stroke*		158	39.2
Pre-existing dementia		49	12.2
Atrial fibrillation	Current	47	11.7
	Past	89	22.1
Previous stroke or transient ischaemic attack		123	30.5
Stroke Subtype	Haemorrhagic	63	15.6
	Ischaemic	340	84.4
Able to lift arms after stroke*		152	37.8
Able to walk after stroke*		28	6.9
Able to talk*		248	61.5
Baseline mRs	0	0	0
	1	2	0.5
	2	4	1
	3	17	4.2
	4	171	42.4
	5	209	51.9
Baseline Barthel Index (BI) Mean (SD)		31.5 (25.6)	
Baseline Utility Mean (SD)		0.23 (0.36)	

*Six Simple variable.

Discussion/Conclusion

In this cohort of patients with major stroke, few had a 'good' outcome based on their mRs (mRs 0-2) at six months. There was considerable variation in "specific abilities" and HRQoL within each mRs level, especially amongst those with mRs 3-5 at six months after major stroke. Therefore, by describing patients' "specific abilities," health professionals may be able to give patients and their families a fuller picture of what the patients' future life might look like. This may allow better discussion of patient preferences and involvement in making treatment decisions.

Several previous attempts have been made to relate physical disability to HRQoL by assigning utility scores to mRs levels.[17,18] Our findings broadly agree with their findings; i.e. patients with higher mRs tended to have lower utilities. However, we have also shown that utilities varied, with a wide range within each mRs level.

Studies have reported that patients and their caregivers (often family members) require psychological support after major stroke[6,19] and have also described how the psychological support needs of caregivers of patients who are physically dependent after stroke may differ.[20] Our findings add to this; for instance, the knowledge that a proportion of physically disabled patients may also suffer from major anxiety and depression may allow health professionals to assess these patients and deliver early tailored information to them and their family members. This may include information on relevant support services for both patients and their families e.g. counselling and neuropsychology.[21]

Strengths and limitations

We have successfully recruited and followed up patients with major stroke who are often excluded from research studies. Our cohort was of modest size (n=403), were recruited prospectively and with minimal loss to follow up.

However, based on our inclusion criteria of major stroke patients, some mRs levels at six months included only small numbers of patients. Therefore, estimates based on these groups may be imprecise. We also recruited patients from a single centre only which may reduce the generalisability of our results. HRQoL assessments were completed by proxies where the patient was unable to do so. Therefore, for some "specific abilities" which were derived from EQ5D-5L (e.g. to live without severe pain and to live without major anxiety/depression), it is impossible to know if the answers provided by proxies were the same as the patients would have provided.[22−24] Utilities are also derived from assessments completed by healthy (non-disabled) individuals rather than those who are disabled. However, in the absence of alternative methods to obtain patients' assessments of their HRQoL (where patients lacked capacity) and deriving utilities, it is difficult to know how these could be improved.

Table 3. *Specific abilities and utilities in each mRs level at six months, n=402*

	mRs at about six months after stroke							All
	0	1	2	3	4	5	6	
Number (%)	8(2.0)	45(11.2)	7(1.7)	149(37.1)	46(11.4)	36(9.0)	111(27.6)	402(100)
Mean utility (Standard Deviation)	0.90(0.09)	0.82(0.14)	0.78(0.12)	0.37(0.37)	0.20(0.19)	-0.08(0.15)	0	0.50 (0.36)
Median Utility (total range)	0.88 (0.74 to 1)	0.84 (0.32 to 1)	0.84 (0.61 to 0.91)	0.32 (-0.01 to 1)	0.21 (-0.26 to 0.72)	-0.08 (-0.35 to 0.43)	0	0.62 (-0.35 to 1)
Specific abilities: n (% in mRs category)								
Live independently (smRsq)	8(100)	45(100)	7(100)	0	0	0	0	60(15)
Walk (smRsq)	8(100)	45(100)	7(100)	149(100)	0	0	0	209(52)
Talk	8(100)	45(100)	7(100)	137(92)	43(93)	30(83)	0	270(67)
Eat normally	8(100)	45(100)	7(100)	149(100)	45(98)	33(92)	0	287(71)
Be continent (BI)	8(100)	45(100)	7(100)	147(99)	38(83)	14(39)	0	259(64)
Live without major anxiety or depression (EQ5D-5L)	8(100)	45(100)	6(86)	132(89)	37(80)	22(61)	0	250(62)
Live without severe pain (EQ5D-5L)	8 (100)	43 (96)	7(100)	143 (96)	41 (89)	33 (92)	0	275(68)
Live at home	8(100)	45(100)	7(100)	137(92)	17(37)	5(14)	0	219 (54)

We collected data on "specific abilities" judged to be useful to patients and their family members by stroke doctors in the hospital where recruitment took place. We acknowledge that different individuals may have different opinions on "specific abilities" that may be useful and how these should be defined.

Some specific abilities could have been derived from several measures in our cohort. For instance, 'to walk' could have been derived from three measures: a) smRsq specific question: 'Can you walk from one room to another without the aid from another person?' b) Single item from BI: Mobility on a level surface or c) Dimension from EQ5D-5L: Mobility. We used the smRsq as our primary measure to define 'to walk' as we felt that there was less ambiguity in defining 'able' and 'unable' based on 'yes' or 'no' to the specific question. This is in contrast to BI and EQ5D which have several levels or dimensions respectively and we would need to decide a cut-off to define 'able' and 'unable'. As shown in Supplementary tables 1 and 2, each measure would categorise different numbers of patients as being 'able' or 'unable' to walk. Varying our cut-offs for 'able' and 'unable' would also change our results.

A useful next step would be to obtain feedback from patients and families on how they wish prognosis to be communicated to them in the context of a major stroke. Beyond that, we could develop statistical models to predict patients' "specific abilities". These might allow clinicians to provide more formal predictions of patients having a "specific ability" in the future and guide shared decision-making regarding treatments after major stroke.

Conclusions

We have shown that describing prognosis based on mRs does not convey the variation in "specific abilities" and HRQoL amongst patients with major stroke. Therefore, describing patients' "specific abilities" may be more appropriate. This may help patients and families prepare for the potential impact of major stroke and also to be involved in making treatment decisions.

Acknowledgement

None

Statement of Ethics

The Scotland A Research Ethics Committee (Ref: 17/SS/0029) approved our protocol
All participants provided informed written consent

Disclosure Statement

Funding Sources

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jstrokecerebrovasdis.2020.104993.

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