CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Transitions and Community Participation following Stroke

Table 1: Tools to Assess Participation and Quality of Life

Mountain A, Cameron JI (Writing Group Chairs)
on Behalf of the Canadian Stroke Best Practice Recommendations
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Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
Health Status				
Stroke Impact Scale (SIS) **Duncan et al. 2003**	The SIS is a measure of health status following stroke	59-items representing 8 domains: strength, hand function, ADL/IADL, Mobility, Communication, Emotion, Memory and Thinking, and Participation/Role Function. Each item is rated on a 5-point ordinal scale, with the exception of a single item rated on a 100-point visual analog scale. Score Interpretation: Scores are summed for each domain and range from 0-100, with higher scores indicating more recovery. Administration: Self-report; 15-20 minutes to administer	The SIS is easy to administer, does not require any additional equipment, and can be administered by mail or telephone. The measure can also be completed by proxy respondents, although there is some evidence that proxies tend to rate patients as being more impaired. Some ceiling effects have been observed for individuals with mild impairment, particularly, in the Emotion, Communication, and Memory and Thinking domains. Specialized Training: None required.	Free for non-profit use after signing a licensing agreement http://www.strokengine.ca/assess/sis/
Medical Outcomes Study Short Form 36 **SF-36** **(Ware & Sherbourne 1992)**	The SF-36 was designed as a generic health survey for the assessment of health status in the general population.	36 items are organized into 8 subscales; physical functioning, role limitations- physical, bodily pain, social functioning, general mental health, role limitations – emotional, vitality, and general health perceptions. 2 additional questions estimate change in overall health status over the past year. With the exception of the general change in health status questions, subjects are asked to respond with reference to the past 4 weeks. Items are scored using a weighted Likert system. Items are summed to provide subscale scores which are transformed linearly to provide a score from 0-100 for each subscale. In addition, a physical component (PCS) and mental component (MCS) score may be derived. The 2 health status questions remain separate from the 8 subscales and are not scored.	The SF-36 questionnaire can be administered by self-completion questionnaire or by interview (either on the telephone or in-person). It has been used as a mail survey with reasonably high completion rates reported, however, data obtained are more complete when interview administration is used. It should be noted that some items have been questioned as less relevant for use in the assessment of elderly populations. The SF-36 has been studied for use by proxy, however, reliability of the	Available without charge http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html There are terms and conditions for use posted on the site.

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		Score Interpretation: There are normative subscale scores based on population data available for a number of different countries. In addition, component scores have also been standardized with a mean of 50 and a standard deviation of 10. Administration: Approx. 10 minutes. Self-report or by interview.	test decreased when proxy respondents completed assessments. Specialized training: None required.	
Participation/Extended Activities of Daily Living				
Assessment of Life Habits (LIFE-H 3.1) **Fougeyrollas et al. 2001**	The LIFE-H is a measure of the accomplishment of daily activities and social roles.	77-items representing 12 domains. Items are rated on two-scales: 1) level of difficulty/type of assistance required (10-point ordinal scale) and 2) satisfaction with performance (5-point ordinal scale). Score Interpretation: Scores are summed and presented as an average of items answered, with lower scores indicating less optimal subjective participation. Ratings on the Satisfaction with Performance scale are not included as part of the total score. Administration: self-report; 20-30 minutes to administer.	The LIFE-H is easy to administer and does not require specialized equipment. The scale is not available for free, is somewhat lengthy, and some concern has been expressed regarding ceiling effects in patients with mild stroke (Rochette et al. 2007). Specialized Training: Recommended.	Available for purchase by request http://www.strokengine.ca/assess/lifeh/
Frenchay Activities Index (FAI) **(Holbrook & Skilbeck 1983)**	The FAI provides an assessment of a broad range of activities associated with everyday life.	The FAI contains 15 items or activities that can be separated into 3 factors; domestic chores, leisure/work and outdoor activities. The frequency with which each item or activity is undertaken over the past 3 or 6 months (depending on the nature of the activity) is assigned a score of 1 – 4 where a score of 1 is indicative of the lowest level of activity.	Simple and brief. Well suited to use in most clinical settings. However, lack of standardized guidelines for administration or interpretation may reduce comparability between settings, groups or studies. The FAI extends information about function along the ADL continuum in terms of item difficulty. It should be	Free of charge http://www.strokengine.ca/assess/fai/

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		Score Interpretation: Summed scores range from 15-60. Administration: 5 minutes or less. Self-report or interview.	noted that FAI scores may be influenced by both gender and age. The FAI is suitable for use with proxy respondents. The scale is based on behaviour and the emphasis placed on frequency rather than quality of activity. This reduces elements of subjectivity which can undermine reliability of proxy assessment. Specialized Training: None required.	
London Handicap Scale (LHS) **Harwood & Gompetz, 1994**	The LHS is a measure of the degree of disadvantage perceived by an individual as the result of an illness/handicap.	6-items, each representing a single dimension: Mobility, Physical Independence, Occupation, Social Integration, Orientation, and Economic Self Sufficiency. Reponses are rated on a 6-point ordinal scale relating to the degree of perceived disadvantage. Score Interpretation: The LHS provides a profile of handicap based on the responses within each of the 6 dimensions as well as a weighted total handicap score. This overall weighted score should be interpreted as an estimate of the desirability of the health state described by the respondent's profile. Scale weights are used to calculate total scores, which range from 0 to 1.0, with lower scores indicating more disability. Administration: Self-report; approximately 5 minutes to administer	LHS appears to facilitate the assessment of 'participation', though response statements span all domains of the ICF. Statements that describe body functions are typically associated with greater degrees of restriction in participation (Perenboom and Chorus 2003). The LHS is brief, easy to administer and does not require any specialized equipment. It can be administered via mail or completed by a proxy respondent. Use of a weighted scale makes calculation of total scores relatively arduous, as compared to other measures. More independent research is required to assess the psychometric properties of the LHS (Salter et al. 2012). Specialized Training: Not required.	Free http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=929

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
Reintegration to Normal Living Index (RNLI) **Wood-Dauphinee et al. 1988**	The RNLI is a measure of reintegration to normal activities following illness of trauma.	11 declarative statements rated by respondents on a 10cm visual analogue scale. Score Interpretation: Summed scores are reported as a percentage out of 100, with lower scores indicating poorer perceptions of reintegration. Scores can also be calculated for Daily Functioning and Perceptions of Self subscales. Administration: Self-report; approximately 10 minutes to administer.	The tool focuses on the perception of the individual with regard to personal capability and/or autonomy. It may be considered a person-centred assessment of re-integration. Quick, easy to administer, and does not require any additional equipment. The visual analogue response format may not be appropriate for use with some stroke patients (e.g., those with neglect or visuospatial deficits). Concern has been expressed regarding the use of proxy respondents (Tooth et al. 2003). Specialized Training: Not required.	Free http://www.strokengine.ca/assess/rnli/
Health-related Quality of Life				
EuroQol Quality of Life Scale (EQ-5D) **EuroQol Group, 1990**	The EQ-5D is a measure of health-related quality of life.	Part 1 consists of 5 domains: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. For each domain, respondents are asked to indicate which 1 of 3 statements best describes their current health state. Part 2 consists of a 100 cm visual analog scale representing “your own health state today.” Score Interpretation: Weights are applied to calculate a summary index score, which range from 0 to 1, with higher scores indicating more quality of life.	The EQ-5D is short, easy to administer, and does not require any specialized equipment. The measure can be administered in person or by mail Although the EQ-5D can be completed by a proxy respondent, decreased reliability has been reported (Dorman et al. 1998). Patient-proxy agreement rates have also been reported to be low on the more subjective domains (e.g.,	Licensing fees may be required http://www.euroqol.org/

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		Administration: Self-report; approximately 3 minutes to administer.	anxiety/depression, and pain/discomfort) (Picard et al. 2004). Specialized Training: Not required.	
Stroke Specific Quality of Life Scale (SS-QOL) **Williams et al. 1999**	The SS-QOL is a measure of health-related quality of life.	49-items representing 12 domains: energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision, and work/productivity. Items are rated on a 5-point ordinal scale. Score Interpretation: Summation yields a total score ranging from 49 to 245, with higher scores indicating better functioning. Subscale scores can also be calculated. Administration: Self-report; approximately 10-15 minutes to administer.	Quick, easy to administer, and does not require any additional equipment. The SS-QOL can be completed by proxy respondents; however, agreement rates have been reported to be weaker for items that are more subjective as compared to those that are more observable (Williams et al. 2000). Some concern has been expressed regarding floor and ceiling effects (Czechowsky & Hill, 2002). Specialized Training: Not required.	Free http://www.strokengine.ca/assess/ssqol/
Stroke-Adapted Sickness Impact Profile (SA-SIP-30) **Van Straten et al. 1997**	The SA-SIP-30 is a measure of health-related quality of life	30-items representing 8 domains: Body Care and Movement, Social Interaction, Mobility, Communication, Emotional Behavior, Household Management, Alertness Behavior, and Ambulation. Respondents are asked to mark “yes” for each item that is descriptive of the impact of illness on their daily life. Score Interpretation: Items are weighted, summed, and expressed as a percentage, with higher scores indicating less quality of life. Subscale cores can also be calculated. The scale authors have suggested a cut-off score of >33 as being indicative of poor health.	The SA-SIP-30 is much shorter and easier to administer than the original 136-item scale. However, evidence suggests that the shorter version may not perform as well when used with patients with more severe stroke (van Straten et al. 1997). No specialized equipment is required. Specialized Training: Not required.	Free http://www.strokengine.ca/assess/sasip30/

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		Administration: Self-report; approximately 10 minutes to administer.		
Assessment of Caregiver Burden				
Bakas Caregiving Outcomes Scale **(Bakas et al. 1999, 2006)**	Assesses adaptation to caregiving in informal carers of individuals with stroke.	Originally a 10 item scale, the 15-item version is used more often. Items reflect changes in social functioning, subjective well-being and perceived health attributable to fulfilling the role of informal carer. Each item is rated on a 7-point Likert scale ranging from -3 (changed for the worst) to +3 (changed for the best). **Scores and interpretation**: Item scores transformed to 1-7, then summed to provide total scale scores ranging from 15 – 105. **Administration**: Self-report. Requires 2-4 minutes to complete	Assesses both the positive and negative aspects of the caregiving role. Emphasis is placed on the subjective, social aspects of change associated with caregiving. **Specialized training**: None required	The 15-Item BCOS is available upon request from Dr Tamilyn Bakas (Bakas et al. 2006)
Caregiver Strain Index **(Robinson 1983)**	Originally developed as a screening instrument to detect strain (stress) in carers of individuals with hip surgery and heart disease.	13 items rated as yes or no. Positive responses receive 1 point; negative receive no score. **Scores and Interpretation**: Item scores are summed to create total scores out of a possible 13. **Administration**: Self-report.	Short and simple. Most commonly used scale for the assessment of burden, particularly in research settings. Although used frequently, its psychometric properties have not been well-studied in populations of individuals with stroke. **Specialized Training**: None required.	Free. Available via: http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=1099
Zarit Burden Interview	Measures the degree to which responsibilities	29-item instrument includes items addressing caregiver health, well-being, finances, social life and the relationship between carer and the	Shorter 22, 18 and 12-item versions of the interview are also available. The 22-item version is used most	Free for use in non-funded studies only. Funded research or

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
(Zarit et al. 1980)	associated with informal caregiving role have affected health, personal and social well-being. Originally developed to assess carers of individuals with dementia.	individual being cared for. 25 questions represent negative aspects of caring; 4 items represent positive aspects. Items are scored on a 5-point Likert scale (0-4). There are no subscales. **Scores and Interpretation**: Scores for 'negative' items are totaled, then 'positive' items subtracted to create an overall total score. Total scores are intended to reflect degree of burden. **Administration**: Self-report. Pen and paper or interview-administered.	frequently. Scores appear unaffected by age, gender language, marital or employment status, geographic locale suggesting the scale may be acceptable for a variety of assessment populations (Hebert et al. 2000). The Interview examines burden that is associated with both functional and behavioural impairments and with the situation in the home. Items focus on the subjective response of the carer. **Specialized training**: None required.	commercial use requires purchase/permission. http://www.proqolid.org/instruments/zarit_burden_interview_zbi

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