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Choosing relevant outcomes for Aphasia:

Comment on 'Advancing appraisal: Aphasia and the WHO'

Short title: Choosing relevant outcomes for Aphasia

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In 1948, the World Health Organisation (WHO) defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Baumann (1961) looked into lay definitions of health and reported three main orientations: a general feeling of well-being, the absence of illnesses and the ability to perform social roles. Although there is no consensus on an exact definition of health, it is generally accepted in health-related research, that health is related to well-being and that it incorporates physical, mental and social components (Berzon, Hays & Shumaker, 1993). This broader conceptualisation of health is reflected in the way health care interventions are evaluated. It is now thought that the effectiveness of interventions should be based on critical, objective and rigorous scientific evidence using a wide range of outcome measures (evidence-based practice) (NHS Executive, 1996).

Ross & Wertz advocate the use of a wide range of outcomes that can capture the entire consequences of aphasia for each individual. They provide a comprehensive review of a range of aphasia measures and discuss these in relation to the ICF framework (WHO, 2001). They argue that "placing appraisal within the WHO context should permit not only more appropriate treatment planning, [...], but also more meaningful comparison of treatment outcomes, within and among healthcare disciplines and providers".

Placing appraisal within the WHO context should indeed allow for a comprehensive description of an individual's experience and should also facilitate communication about health and healthcare among different professional groups. After all the aim of the ICF is to provide 'a unified and standard language and framework for the description of health and health-related states' (WHO, 2001, p. 3). Ross & Wertz, however, also suggest the following. Firstly, that new measures for aphasia are needed at all ICF levels, i. e. , at the

body level (language impairment), at the activity and participation level and at the contextual factors (environmental and personal) level; and, in addition to these, at the quality of life level. Secondly, that appropriate and socially valid treatment for aphasia can only be planned if information has been collected in all these areas. This paper will address these two points, starting with the latter. The quality of life level will be considered separately and in more depth, as it is a relatively new area of assessment, which is often inadequately defined and understood.

Appraisal in relation to treatment planning

Health professionals thinking within the ICF framework are likely to carry out comprehensive assessments of their clients and attempt to obtain a holistic view of the effects of communication disability on their everyday lives. Still, there are other conditions that need to be met in order to plan socially relevant treatment. Firstly, there needs to be good communication between the client and the clinician on all aspects of intervention and its delivery; for example discussing expectations, priorities and goals or their satisfaction with the intervention or service (Pound, Parr, Lindsay & Woolf, 2000; Kagan & Duchan, 2004). Good communication can ensure that the client is well informed about different treatment options and their effectiveness and can be meaningfully involved in the decision making process. Although the ICF framework can facilitate communication between different disciplines, it is difficult to see it playing the same role for clinician-client communication. Its complexity and its questionable applicability to lay perceptions of health constitute limitations in this area.

Secondly, in clinical practice, appraisal is generally hypothesis driven and therapy oriented. Different areas are assessed with the primary aim of determining what areas need further intervention and what type of intervention is required. Clients are aware of

this process and expect to complete tests and assessments that will guide their therapy. Following an ICF - driven approach to appraisal in clinical practice has ethical implications. Clinicians need to be selective in their approach. Exploring areas like psychological state and social relationships, is probably unethical unless something is done with the information obtained, such as offering appropriate services or timely onward referral (Hilari, Wiggins, Roy, Byng & Smith, 2003).

Is there a need for new measures?

Ross & Wertz conclude that, for aphasia, there is a need to develop body-level measures, activity-level measures, participation-level measures, protocols for appraising personal and environmental variables, and disease-specific quality of life measures. Indeed, there is a dearth of measures to assess participation and contextual variables specifically developed for people with aphasia. Yet for the other areas, conceptually sound and psychometrically robust measures exist; and for the language impairment level, a wide range of measures is available. A proliferation of measures addressing the same or similar domains is not necessarily beneficial. It leads to studies using different tools to measure the same construct, which in turn leads to significant problems in generalizing from one set of findings to another.

Ross & Wertz raise some of the limitations of existing measures. It is important, however, to bear in mind that all measures have limitations and there is no such thing as a perfect measure. Rather, researchers and clinicians need to understand and apply criteria for judging how appropriate a measure is for use with their clients (Streiner & Norman, 1995). These criteria include the conceptual basis of the measure and what it aims to cover (e.g., is it relevant for and applicable to their clients?); and the psychometric properties of the measure: acceptability, reliability, validity and sensitivity to change (e.g., can the

clients complete the measure? Is the measure stable and consistent? Is it actually measuring what it intends to measure? Will it pick up small but perhaps clinically important changes?). In aphasiology, we need to avoid the problem that Streiner & Norman (1995) highlight, in their seminal textbook on health-measurement scales: "[...] perhaps the most common error committed by clinical researchers is to dismiss existing scales too lightly and embark on the development of a new instrument with an unjustifiably optimistic and naïve expectation that they can do better" (p. 4).

Quality of life

As indicated by Ross & Wertz, the WHO defines quality of life as:

"...an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment".

(The WHOQOL Group, 1998, p. 1570)

This definition is conceptually broad, incorporating a person's culture and value systems and encompassing factors like a safe environment and material well-being. Still, the health care system and its providers usually do not assume responsibility for these more global human concerns even though they may be adversely affected by disease (Patrick & Erickson, 1993).

Moreover, research into the views of lay people has shown that these factors are essential components of quality of life for healthy people but not as essential for people

with chronic diseases and disabilities (Bowling, 1995; Pearlman & Uhlman, 1988; 1991). For example, Bowling (1995) questioned a random sample of 2000 adult members of the population of UK on the domains of quality of life and the importance of these domains on their lives. Respondents were most likely to mention as the first most important thing in their lives: *relationships with family or relatives*, followed by *their own health*, the health of another (close) person and *finances/standard of living /housing*. Respondents with a long-standing illness, however, identified as most important: *the ability to get out and about/stand/walk/go out shopping*, *being able to work/find a job* and *effects of illness on social life/leisure activities*.

In the light of the priorities of health care professionals and the views of people with chronic disabilities on what the essential domains of quality of life are, it may be that quality of life, as defined by the WHO, is not necessarily a primary focus of intervention and outcome measurement. A more relevant outcome seems to be what is called health-related quality of life (HRQL). HRQL is about the impact of a health state (e.g., aphasia) on a person's ability to lead a fulfilling life (Bullinger, Anderson, Cella & Aaronson, 1993). It incorporates the individual's subjective evaluation of his/her physical, mental/emotional, family and social functioning (Berzon et al., 1993; Hays, Anderson & Revicki, 1993; de Haan, Horn, Limburg, Van Der & Bossuyt, 1993). Together with these essential domains, disease-specific HRQL scales will incorporate other domains that are relevant to the population under study. For example, a HRQL scale for people with arthritis should be expected to include a domain on pain, whereas one for people with aphasia should be expected to include a communication domain.

Ross & Wertz criticize the Stroke and Aphasia Quality Of Life scale (SAQOL-39) (Hilari, Byng, Lamping & Smith, 2003) for not incorporating spiritual and environmental factors.

The SAQOL-39 was never intended to capture these aspects, as it focuses on HRQL and the domains identified by stroke survivors as most affected by their stroke. The 'physical', 'psychosocial' and 'energy' domains of the SAQOL-39 capture the individual's subjective evaluation of his/her physical, mental/emotional, family and social functioning. The measure also includes a 'communication' domain, which is most relevant to people with aphasia. Communication/language was, also, one of the most frequently mentioned domains when stroke survivors without aphasia were asked about the areas most affected by their stroke (Williams, Weinberger, Harris, Clark, & Biller, 1999).

Ross & Wertz also suggest that most of the SAQOL-39 items appraise activities of daily living. This is inaccurate, as the measure does not address individuals' performance on activities of daily living. Instead, as intended, it addresses how individuals feel about their functioning in various domains. For example, for the physical domain there is a practice item on 'how much trouble you had tying your shoelaces'. One respondent with a right hemiplegia said: "I have no trouble at all. I can't do it, but it's no trouble. See . . ." (and pointed to her trainers which had velcro fastenings). This response reflects the difference between an activities measure (where this respondent would score as severely affected) and an HRQL measure, which is about subjective evaluation of functioning (where this respondent would score as not affected). The phrasing of HRQL measures often allows the importance of different aspects of functioning for individuals to be reflected.

Conclusions

As Ross & Wertz suggest, there are many reasons to embrace the ICF. The framework has a number of advantages and potential applications, which have been previously discussed thoroughly and reflectively (see Threats, 2002; Threats & Worrall, 2004 clinical forum paper and subsequent commentaries). A key contribution is that it provides a

common language for different disciplines to describe health and its effects in a detailed and systematic way. It also makes us consider the impact of a person's condition on all areas, which has a positive effect on attitudes to assessment and intervention.

Embracing the framework does not dictate the development of new measures. A plethora of reliable and valid measures exist to assess the language impairment and communication disability resulting from aphasia. Promising new measures have recently been developed for health status (Doyle, McNeil, Mikolic, Prieto, Hula et al., in press) and HRQL for people with aphasia. A range of non aphasia-specific measures also exists for domains like social adjustment and roles, handicap, psychological well-being (see McDowell & Newell, 1996). For clinicians, eclectic use of these measures and good communication with their clients can guide socially relevant treatment and appropriate outcome measurement.

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