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The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders

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Running head: ICF and quality of life

Abstract

Past discussions of the *International Classification of Functioning, Disability and Health* (ICF) have focused minimally, if at all, on quality of life. This paper critically discusses the contribution of the ICF to quality of life concept development, and the impact that the ICF has had thus far on health-related quality of life measurement. 'Contribution' focuses on modelling the relationship between disablement and quality of life, evaluating the content of existing instruments, and thinking holistically about the individual. 'Impact' relates to the association of quality of life with functioning, pathology and outcomes, the trend towards life compartmentalisation, and the disproportionate emphasis on individuals' functioning at the expense of their life context. Examples are drawn from adult acquired conditions (mainly aphasia), and terminology used in the paper reflects a rehabilitation stage of service provision. The World Health Organization's (WHO; 2001) approach to quality of life definition and measurement is also discussed. An operational definition of quality of life for adults with acquired communication and swallowing disorders is presented, alongside an alternative conceptualisation of quality of life. This paper ends with recommendations for future research concerning the importance of context, the subjective or personal perspective, and having a goals orientation for life as well as rehabilitation. It is also argued here that the ICF and quality of life are different constructs and that quality of life should be the starting point for understanding the client's perspective of his/her goals and/or his/her disability.

Key words: ICF, World Health Organization, speech-language pathology, quality of life, aphasia

The *International Classification of Functioning, Disability and Health* (ICF) is the focus of this special issue, but it has also been a source of much debate in the recent past (see *Advances in Speech-Language Pathology* Special Issue 2001, *Aphasiology* Special Issue 2005, and *Seminars in Speech and Language* Special Issue 2007). Although speech-language pathology (SLP) clients care little for our theoretical philosophies, it *is* useful to debate the merits and limitations of the ICF around the world, as SLP practices are moving towards using the ICF more in clinical application (Threats, 2006). This paper assumes prior knowledge of the ICF. It is framed within the recognition that *context* has been undervalued in the ICF, and continues to be problematic for clinicians and researchers who wish to discuss the importance of Personal Factors and Environmental Factors within client centred intervention and health care provision. This paper focuses on client-centred approaches to quality of life, as clinical practice is about "adjusting a general type of treatment to the specific requirements dictated by the unique problems surrounding the patient" [and] "emphasiz[ing] the uniqueness of each person's response to disease and treatment" (Ebrahim, 1995, p. 1384).

The positive contribution of the ICF to quality of life

Marcus Fuhrer, a practitioner and researcher in spinal cord injury (1994) stated that in order to evaluate the success of rehabilitation, "rehabilitation outcomes must embody concepts outside the disablement model, in particular, the concept of subjective wellbeing" (p358). Certainly in the United Kingdom, the aims of stroke rehabilitation are considered to be: (1) to maximize the patient's social rehabilitation; (2) to maximize the patient's sense of wellbeing (QoL) (and to maximise satisfaction with life); and (3) to minimize stress on and distress of the family (Royal College of Physicians, 2004, p26). According to American Speech-Language-Hearing

Association's (ASHA) Scope of Practice Statement, "the overall objective of speech-language pathology services is to optimize the individual's ability to communicate and/or swallow in natural environments, and thus improve [his/her] quality of life" (ASHA, 2001, p. 22). Furthermore, this association has been operationalised for adults with language, speech and cognitive-communication disorders, with the development of the ASHA Quality of Communication Life Scale (QCL) (Paul, Frattali, Holland, Thompson, Caperton, & Slater, 2004). Thus, there is significant emphasis as quality of life in speech-language pathology and in rehabilitation, yet very little discussion has focused on how quality of life articulates with our dominant conceptual framework of disablement. This section here focuses on how the ICF has contributed to our practice, in terms of (1) modelling the relationship between disablement and quality of life; (2) evaluating the content validity of quality of life measures; and (3) thinking holistically about the individual for quality in life.

Initially however it is important that clinicians and researchers briefly revisit their understanding of the ICF, as much has changed since the original ICIDH structure of the early 80s. There is ongoing work to make the framework and its classification system accessible to healthcare professionals, including the 2008 scheduled publication of the *Procedural Manual* and Guide for the Standardized Application of the ICF: A Manual for Health Professionals which will be jointly published by the American Psychological Association (APA) and the WHO (see Threats, 2008). Three key revisions that are now embedded in the ICF are raised briefly here, as they are relevant to the later discussion of quality of life. Firstly, when considering a person's activities and participation, both capacity and performance are now conceptualised. That is, the framework makes a distinction between functioning in a *standard or uniform environment* (capacity) and functioning in the person's own or *actual environment* (performance). Secondly, environmental

factors are well detailed. A substantial literature review on environmental factors is available through the main ICF website (see http://www3.who.int/icf/icftemplate.cfm?myurl=homepage.html&mytitle=Home%20Page). Both these references to the *environment*, rather than the *context*, suggest that the ICF framework continues to standardize Environmental Factors, whilst Personal Factors remain open for individual interpretation. Thirdly, qualifiers for capacity now identify whether the person uses *assistance or not* in achieving that level of functioning. Other more detailed aspects of the ICF have already been covered in this special issue.

Modelling the relationship between disablement and quality of life

In 1996, Tate and colleagues recommended that quality of life be linked to other conceptual models that were more consensual, in order that some degree of clarity was achieved in future quality of life research. Several researchers have done exactly that using the ICF framework (or ICIDH as it was then) with quality of life (see Enderby, 1992; Fuhrer, 1996; Pope & Tarlov, 1991; Wyller, 1997). Two main views exist as to how disablement relates to quality of life. The first holds that health-related quality of life is the final common outcome or pathway, wherein impairments give rise to disabilities, which in turn give rise to handicaps, which subsequently influence health-related or overall quality of life (Ebrahim, 1995). A slightly more advanced and multifactorial model of that same view is that of Wilson and Cleary (1995), who also include the characteristics of the individual and the environment. These models are typically represented in the horizontal plane, with impairments on the far left of the model, and quality of life on the far right (see Figure 1). The second view interprets health-related quality of life as an umbrella concept, encompassing impairment, disability and handicap (to varying degrees). This second view has shaped our thinking so much that there is a temptation to think that quality of life is

simply comprised of Body Functions, Body Structures, Activities and Participation. The disadvantages of this thinking will be explored later in this paper. These models are typically represented in the vertical plane with quality of life above or alongside a vertical arrangement of impairment, disability and handicap (see Figure 2). Wyller (1997) published four different versions of this second view, which differed depending on the relative contribution of each disablement component to overall quality of life. That is, do all three components equally impact on quality of life or is one component, for example, handicap (participation restriction), more influential? This issue is important for clinicians, because as stated by Fuhrer (1996, p. 56), "if changes in subjective wellbeing [quality of life] are to be considered in their own right as a result of conditions that lead to disablement, then the empirical relationships of subjective wellbeing to impairment, disability, and handicap, need to be established".

Insert Figures 1 & 2 about here

A review of 19 studies of people with spinal cord injury found that subjective wellbeing was commonly correlated with and predicted measures of handicap, inconsistently associated with disability, and minimally associated with impairments (Fuhrer, 1996). In head and neck cancer outcome studies, participation is the strongest correlate of quality of life (Eadie, 2007). In aphasia, overlap between constructs of participation and quality of life has been noted (Hirsch & Holland, 2000), and researchers frequently choose participation instruments to assess alleged quality of life. It is not known whether participation correlates most strongly because the measurement instruments in fact assess the same concepts, or whether participation level functioning does indeed determine a significant extent of an individual's quality of life. Research discussed immediately below suggests another level of functioning is more crucial in determining

quality of life. The boundaries between Participation and quality of life constructs may be even more difficult to discern as the ICF now has an option of merging Activities and Participation constructs together. It is possible that the "communication acts" in the ASHA QCL Scale (Paul et al., 2004) and the focus on meaningful participation in life situations addresses both of these ICF constructs.

None of the above models particularly accounts for the relationship between communication and/or swallowing, and quality of life and/or wellbeing in adults with acquired disorders. In response to this, the author's own research set about to produce an operational model of communication and quality of life in aphasia. Generated on 30 older Australians with chronic aphasia, the final model has been published (see Cruice, Worrall, Hickson, & Murison, 2003), and requires further testing to identify whether the associations are maintained over time and through change brought about by intervention. This particular research identified that aphasic individuals' functional communication ability (Activity) was the most powerful predictor of their social health-related quality of life and psychological wellbeing (Cruice et al., 2003). An individual's language functioning (i.e., the severity of linguistic impairment) was secondary in predicting his/her quality of life. However, it is important to note that there was a strong relationship between linguistic functioning and communication ability in the sample. Isolating these different areas in relation to quality of life enables us to identify areas of treatment that could be most beneficial to the client, and thus in time and resource-poor climates, we can provide maximum intervention in the targeted areas.

Modelling quality of life alongside the ICF disablement framework has not come without its concerns. Firstly, disablement frameworks themselves need further development. According to

Fuhrer (1994), existing models (of which the ICF is one) are under-developed in their subjective aspects. They minimize the role of personal values and people's goals, and self-reported information is given little emphasis. Whilst the first two concerns remain equally valid in today's health care and evaluation climate, the third has substantially changed in the last five years or so, particularly within the United Kingdom. There has been increasing recognition of, and some would argue possibly *over*-emphasis on, the patient's or client's self-report in the United Kingdom. In the United States, the new term "patient-reported-outcomes" or PROs have come into regular usage. These PROs however are typically separate instruments from the disablement framework instruments. Secondly, a tension that clinicians and researchers still need to grapple with is recognizing that fundamentally the ICF framework is based on objective assessment, typically by a professional; whereas quality of life is inherently subjective, with evaluations made by the patient or client him/herself (Wyller, 1997). How these two methodologies interrelate requires much further investigation. Thirdly, linking quality of life with health through the ICF has led to dilemmas in considering health provision. Ebrahim (1995) raises the point of individualisation potentially being at odds with societal health care provision. As is stated, "ultimately, society has a responsibility for paying the bulk of the health and social care costs in this country [United Kingdom] and it could be argued that societal values are the most important. In societies where the individual is responsible for meeting these costs it is presumably more reasonable for the individual to determine how much value is to be ascribed to achieving particular health status benefits at defined costs" (p.1392).

Using the ICF coding in judging content validity

The coding of the ICF framework, which is less frequently used than the overarching conceptual framework, enables researchers to compare and contrast the conceptual bases of test items (including quality of life measures) and judge content validity of the measure. For some time, quality of life measures have been criticized for measuring functioning rather than quality of life per se, yet little rigorous evidence has been forthcoming. Professionals are now in a more fortunate position, with the recent publication of a systematic review of six generic and seven stroke-specific health-related quality of life measures (Geyh, Cieza, Kollerits, Grimby, & Stucki, 2007). The contents of these 13 measures were compared using the ICF codes as a frame of reference. Using a systematic formulaic process called linkage procedure, researchers scrutinised each item and attempted to map its content a specific ICF code. The research has identified that across the 13 measures, Activities and Participation codes were most prevalent, followed by Body Functions, and then Environmental Factors, with the latter constituting only 5% of all coding. For more detailed information about the interesting comparisons found in this study, see original article. Each of the 13 measures is well described, and the coded units of ICF for each measure are included in a series of useful and accessible tables. Publications such as this enable professionals to choose measures that might be more physically based, such as the London Handicap Scale; measures with more communication weighting, such as the Stroke and Aphasia Quality of Life Scale 39; or measures with both communication and environmental factors, such as the Sickness Impact Profile. Finally, equally interesting from this research were the 113 items (of a total of 979 concepts) that were "not able to be defined" or were "not covered" by the ICF. Quite important items such as "how satisfied are you with your life in general?" and "would you say changes you have noticed in your physical functioning that have resulted from your bleed have increased, decreased, or not changed your quality of life?" fall into this group of

'unmappable' items. And thus, there is an evident limitation of only using ICF codes to map quality of life areas.

Thinking holistically about the individual

Possibly the most profound contribution the ICF has had on quality of life is focusing on the individual person and thus encouraging clinicians and researchers to think beyond their own discipline. One specific illustration of this is the 'ICF Core Sets' concept. Researchers, several of whom are based in Germany's WHO Collaborating Centre, have been liaising with the WHO and establishing what are now termed 'core sets' for chronic health conditions. These core sets comprise relevant categories from Body Functions and Structures, Activities and Participation, and Environmental Factors, which have been judged to be relevant to an individual experiencing the said health condition. The first version of the core sets for stroke (*comprehensive* and *brief*) was published a few years ago (Geyh, Cieza, Schouten, Dickson, Frommelt, Omar, Kostanjsek, Ring, & Stucki, 2004). This paper reports 448 ICF categories (at 2nd, 3rd and 4th levels) that can be used to 'checklist' a stroke patient's experience of their disablement. Importantly, Environmental Factors such as products and technology for personal use in daily living, and individual attitudes of family members, have been included, albeit more in the *comprehensive* set than the *brief* set. Whilst undoubtedly there will be criticisms of this programmatic approach to profiling and the impossibility of capturing what is relevant for individual patients, the core sets approach reminds the clinician and researcher to think about the whole person's needs and issues, and not just communication and swallowing, which bodes well for considering quality of life issues for clients. A second illustration of how the ICF has contributed to quality of life is the multiple domain structure of Activities and Participation, such as communication, mobility, self-care, domestic life, community, social and civic life, and so on. Such domains have been used to

structure the ASHA QCL Scale (Paul et al., 2004), as well as evidently considering personal and environmental factors in quality of life. This encourages us to consider the person holistically and consider a range of factors, which in turn is helpful in understanding the multifactorial nature of quality of life. In non-pathological ageing research (where quality of life is well documented), the following factors are the most consistently reported: health and physical functioning, activities, family, relationships and companionship, social and leisure activities, social contacts, attitudes, and the community and society (Cruice, 2001).

The ICF framework enables clinicians and researchers to *view clients in the round*, and in doing so, identify features that may otherwise not have been considered important for a client's situation and intervention but are beneficial to overall quality of life. This point is best illustrated through a case example, and the reader is referred here to the hypothetical but typical case of Evelyn, a lady with dementia, who is newly admitted to a nursing home (Brush, Threats, & Calkins, 2003). As one part of this paper, Evelyn's physical fitness is assessed and described within normal limits, and subsequently, she does not receive any physical intervention in her residence. The paper makes the following points about Evelyn's situation: (1) she does not have to have an impairment in order to benefit from intervention; (2) maintaining current fitness and improving fitness would be a reasonable goal for Evelyn as an older person; (3) there is substantial research to support the benefits of physical exercise on fitness, endurance, strength, weight, depression, mood and cognitive functioning; (4) walking around her residence on specific routes will help her to learn and identify areas of the residence, as well as possibly facilitate some discussion around which areas are appropriate to enter (e.g., *not* wandering into other residents' rooms); and (5) walking outside may be beneficial as Evelyn enjoys this past-time, and research shows that being in a sunlight environment helps reduce agitation and sleep

problems in some people with dementia (see Brush et al., 2003, p.385-6). Thus, it is important to consider what is likely to impact a client's quality of life, and not simply which areas are impaired, limited and/or restricted when determining intervention.

In summary, the ICF has contributed towards our understanding of quality of life by providing a conceptual structure that enables clinicians and researchers to reflect on how functioning and disability interrelate with the client's quality of life. Supporters and users of the ICF conceptual framework will appreciate how Activities and Participation, and Context, have driven the professional in the direction of a more holistic client-focused understanding in clinical practice. These positive influences on our perception of quality of life do not come without their limitations (e.g., constraints in thinking, pathologizing of normal concepts), which are the focus of the next section of this paper.

The negative impact of the ICF on quality of life

The ICF can have a negative influence on professionals' understanding and practice when it comes to quality of life issues for clients with acquired disorders. The concerns arise primarily from quality of life being (1) associated with functioning, pathology, and outcomes; (2) compartmentalised by professionals which is at odds with how individuals experience their lives; and (3) focused on the individual's functioning, without due consideration of that individual's life context. These will be elaborated on in turn below.

Association with functioning, pathology, and outcomes

In some cases, quality of life has become synonymous with functioning, and therefore a measurable and treatable target within healthcare provision. With the primary focus on functioning, it is possible that we have lost sight of the importance of the goal-oriented basis of our profession's intervention, which in fact could be very influential in improving quality of life for adult clients. This will be discussed later in this paper. Simultaneously, quality of life has become "pathologized," partly because measurement instruments often contain more negative items than positive items. Furthermore, quality of life in general has been taken to mean *health-related* quality of life, and the wellbeing or subjective experience has not been focused on in evaluation and intervention. The ICF is not at fault for contributing to this bias, as researchers and creators of quality of life tools seem driven to focus on health independent of the ICF and the WHO, however one wonders whether an implicit impact is evident there. This pre-occupation is not helpful for people who do not have a health condition as aetiology, such as adults with psychogenic voice disorders or children with functional speech and language disorders. Finally, in treating quality of life as an extension of outcome measurement in disablement, there is the potential to measure only end point outcomes and inadvertently miss the process of improving life quality. We need to remember that patients or clients judge their life quality based on individual assumptions, perceptions, goals and values. Therefore in any evaluation process, exploring each client's assumptions, perceptions, goals and values will be a true way to move forward in client-centred practice and thereby identify interventions that improve clients' quality of life. Although not discussing specifically quality of life issues, in the ICF itself, it states in Annex 6 "Ethical guidelines for the use of the ICF" the following:

> "Every scientific tool can be misused and abused. It would be naïve to believe that a classification system such as the ICF will never be used in ways that are harmful to people. . . Individuals classed together under ICF may still differ in many ways. Laws and

> regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals" (WHO, 2001, p. 244-245)

Compartmentalisation – separation and aggregation

The ways in which the relationship between the ICF framework and quality of life have been previously pictorially represented, have led to a sort of "bottom-up" understanding of quality of life. That is, overall quality of life is seen in some way as representing an aggregate of components of functioning, activity and participation (or impairment, disability and handicap). Furthermore, the combination of the ICF with quality of life has led to a sense of impairment or condition specific quality of life. Whilst this is useful for professionals to begin with the impairment and explore the impact on a client's life, it reinforces professional compartmentalisation because even though the model is person focused, professionals continue to use the ICF framework in a uni-professional manner. This separation and aggregation is also at odds with how individuals generally think about their lives. Individuals do not tend to think of life as domains of functioning, with different disabilities acting as barriers, but instead tend to think of life in terms of activities, relationships with people, and events in their lives. It is difficult to truly focus on the holistic and the person, when we remain foremost interested in justifying our role in intervention and rehabilitation.

Disproportionate emphasis on the functioning at the expense of context

We need to recognize that for a "balanced analysis of disability, [we should be looking] not only at the disabled *individual*, but also the disabling *environment*" (Marks in Wyller, 1997, p. 481; emphasis added). Despite the modifications to the ICF, even in its latest iteration, it remains an

individual focused framework. The growing knowledge base on the impact of the environment on functioning and quality of life will make substantial contributions to our thinking in the future. Overall in the literature there is much less emphasis on environmental approaches to quality of life compared to health-related approaches, however some research does stimulate thought. Rogerson (1995, p.1375) wrote about the "material life arena", which comprises "goods, services and attributes of the social, physical and economic environment in geographical space within which people live". These give rise to quality of life opportunities, which are assessed based on whether they are present or absent in a person's place or region. The notion that various objective conditions must be present to afford opportunities for quality in life is also echoed in the Toronto Quality of Life Research Unit's definition later in this paper, and is unsurprisingly evident in other discussions about the quality of life of adults with developmental disabilities, who typically have widely altered life opportunities. Furthermore, the ASHA QCL Scale (Paul et al., 2004) suggests that "the more positive the personal and environmental factors, the more successful the [person's] communication acts, the better the quality of communication life" (p.2). Finally, to conclude this point, readers are referred to a review of research literature of the environment as relevant to people living with aphasia, written by Howe and colleagues (2004). This paper uses the five domains of environmental factors from the ICF (support and relationships; attitudes; products and technology; natural environment and human-made changes to environment; and services, systems and policies) to summarize a wealth of research findings. The critique of the papers is especially useful in identifying the future directions for research that will move us beyond the current point of *documenting* the environment for adults with communication and/or swallowing difficulties.

The World Health Organization's perspective on quality of life

In 1991, the World Health Organization initiated the WHOQoL project, through its Division of Mental Health. The purpose of the project was to develop an instrument that would have international and cross-cultural application. It began with 15 centres, and now currently has more than 30 centres internationally involved in developing and testing new national versions of the WHOQoL instrument. These centres are collectively referred to as the WHOQoL Group. As examples, the Australian WHOQoL Field Centre is hosted by the Australian Centre for Posttraumatic Mental Health within the University of Melbourne (see http://www.acpmh.unimelb.edu.au/whoqol/default.html), and the UK Field Centre is based at the University of Bath (see http://www.bath.ac.uk/whoqol/).

The WHOQoL Group is a significant separate entity to the WHO proper. It is not explicitly linked to the ICF, and in fact, they are at pains to make their distinction clear. Having said this, the rationale for assessing quality of life is clear: improvements in quality of life are an outcome of health and health care, and require measurement just as frequency, severity and consequences of diseases are measured. The WHOQoL Group released their definition of quality of life over a decade ago, and this definition is widely quoted in the quality of life literature. Quality of life is:

> "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and [his/her] relationship to salient features of their environment" (The WHOQoL Group, 1994, p.43)

The WHOQoL Group has drawn on developments in the quality of life field, and has created the instrument based on four main principles. These comprise: (1) a comprehensive scope; (2) subjective assessment by the patient him/herself; (3) evaluating the relative importance of the different facets or areas of quality of life; and (4) considering cultural relevance, including culturally relevant issues and language. The WHOQoL Group has developed two instruments: the WHOQOL-100 instrument and the WHOQOL BREF (26 items only). The WHOQOL-100 produces three types of information: scores about specific facets of quality of life; scores about larger domains of quality of life; and one score for overall quality of life and general health. Content for the WHOQOL-100 was drawn from both scientific experts and lay field in the collaborating centres. It contains six domains, and 24 facets that are grouped under these domains. The conceptualisation of the WHOQOL-100 structure is reproduced in Table 1 below. The WHOQOL-BREF contains only physical, psychological, social relationships and environment domains (see Skevington, Lofty & O'Connell, 2004). The WHOQOL-100 taps functioning and satisfaction over a two-week time frame, and includes questions that are framed to include negative and positive concepts. Respondents rate their quality of life using a five-point scale that changes depending on the section of the instrument.

Different international centres are developing extra items that are essentially "add-on" components that compliment the WHOQOL-100, for older adults, pain, Human Immunodeficiency Virus (HIV) and a lengthier instrument exploring spirituality, religion and personal beliefs only. Again as an example, readers can view the Australian version of the WHOQOL-100 at http://www.psychiatry.unimelb.edu.au/qol/whoqol/whoqol-insruments.html#instruments.

Insert Table 1 About Here

Relevance of the WHOQOL-100 for adults with communication and swallowing disorders

The WHOQOL-100 is an instrument that is implicitly designed for adults. Items specifically for older persons are under development (Power, Quinn, & Schmidt, 2005). The instrument has seen little use in speech pathology so far (possibly due to its length). Key word searching through Medline, PsychInfo, and Cinahl databases on 23 April 2007 using WHOQOL-100, WHOQOL-BREF and speech therapy/ pathology/ communication/ swallowing/ language/ speech/ stroke yielded no studies have been published. However the WHOQOL-BREF has been used with adults *with* chronic aphasia, and can differentiate from adults *without* aphasia (Ross, 1999; see Ross & Wertz, 2003). It is a unique instrument because it is not health-specific and asks about functioning *and* satisfaction. For example, with respect to transport, the WHOQOL-100 asks: "to what extent do you have problems with transport?", "how much do difficulties with transport restrict your life?", "to what extent do you have adequate means of transport?", and "how satisfied are you with your transport?" This 360-degree view of a concept is rarely seen within quality of life instruments.

However, there are three possible concerns in using this measurement instrument. Firstly, the WHOQOL instruments are designed for self-administration, or in difficult cases, interviewer-assisted or interviewer-administered. They are explicitly not designed for people who are unable to communicate, meaning clinicians and researchers should not elicit a patient or client's views using a proxy with these instruments. For clients with linguistic or cognitive impairments, the administration of the WHOQOL-100 will be problematic, and other instruments will be

necessary. Secondly, the WHOQOL-100 does not contain specific items on communication and swallowing, so specific attribution of quality of life to these areas is not possible. Thirdly, the WHOQOL-100 does not clearly tap importance, and both satisfaction and importance need separate consideration in quality of life self-assessment. Readers who are interested in learning more about attributes of health status and quality of life measures, are directed to a paper by the Scientific Advisory Committee of the Medical Outcomes Trust (2002) entitled "Assessing health status and quality-of-life instruments: attributes and review criteria" in Quality of Life Research, Volume 11. This paper defines and describes eight attributes of measurement instruments as: conceptual and measurement model; reliability; validity; responsiveness; interpretability; respondent and administrative burden; alternative forms; and cultural and language adaptations. Guidelines for those developing new instruments are also included. An equally informative paper is provided by Ebrahim (1995) and is still applicable in today's quality of life debates.

Defining and operationalizing quality of life of adults with acquired communication and swallowing disorders

In 2001, the author published a definition of quality of life for older adults with aphasia and healthy older people. A model was also provided and has been published (see Cruice et al., 2003). This definition was formulated in 1998, and reads as follows:

> "the guiding overall concept of this research was that quality of life is the collective life experience of older adults, and may be affected by the health conditions of stroke and ageing, in the clinical dimensions of language and sensory functioning, communicative activity, and social participation. The quality of life of people with communication

> disabilities is the association of the disability experience with their health and well-being. Quality of life is described in personal terms, as well as physical, social emotional and mental health, and psychological well-being, and was evaluated in terms of its associations with language, vision and hearing impairments, communicative ability and activity, social network relationships and social activities" (Cruice, 2001, p. 41).

Readers will note that Environmental and Personal Factors were missing from this definition (with the exception of an individual's emotional health). The process of undertaking the research and reviewing the findings lead to a revision of the original model and a proposed new model of communication-related quality of life for older people with aphasia, for speech pathology clinical use (see Cruice et al., 2003). The detailed rationale for this update has been published (see Cruice et al., 2003); however an updated definition was still warranted. An example of the updated definition is provided here as:

> Quality of life for older people with aphasia is determined by the individual, as well as being construed as psychological well-being and social-health-related quality of life. It is evaluated in terms of its associations with the person's functional communication ability, overall language functioning (specifically spontaneous speech and auditory comprehension), social networks and social activities with others, in the person's life context. Personal life context includes the person's emotional health, physical functioning, age, gender and coping skills. Environmental life context includes caregiver welfare, family and friends' support, society's attitudes towards communication, family and friends' communicative competence, knowledge of aphasia, and physical access and communication access in the community.

In addition to the above and in the light of the development of the field in the past five years, a definition should also include (1) importance and satisfaction ratings of the areas mentioned; (2) exploration of the meaning or purpose of social activities participation; and (3) documentation of current and future aspirations (both within the areas mentioned and for life in general).

An alternative to the above definition is the 'being, belonging and becoming' framework designed by the research team in the Toronto Quality of Life Research Unit. Researchers have a background in occupational therapy with adults with developmental disabilities. They describe QoL as

> "the degree to which a person enjoys the important possibilities of his or her life. Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors. Enjoyment has two components: the experience of satisfaction or the possession or achievement of some characteristic" (retrieved from http://www.utoronto.ca/qol/concepts.htm on 12 March 2007).

Whilst their definition is not exactly operational (i.e., it does not exactly specify what is to be evaluated), their quite different interpretation of the meaning of quality of life is worthy of serious consideration within speech pathology. The Toronto conceptualisation of QoL is as three domains, which is further subdivided again into three: (1) being (physical, psychological, and spiritual); (2) belonging (physical, social, and community); and (3) becoming (practical, leisure, and growth). This alternative is attractive because it suggests the dynamic nature of quality of life (i.e., domains are stated as verbs and not nouns, unlike other conceptualizations), there is a sense of future life development, which is important for all persons irrespective of whether they have a disorder, and it recognises the important contribution of the environment to life possibilities.

In summary, an operational definition for quality of life for adults with acquired communication and swallowing disorders may be proposed as follows (n.b. it is important to note that this is not evidence based and needs to be empirically tested):

> Quality of life for adults with acquired communication and swallowing disorders is determined by the individual, as well as being construed in the clinical sense as psychological well-being and social-health-related quality of life. Quality of life reflects the whole life experience for the individual, of which the presence and the consequences of the communication and/or swallowing disorder is a part (not the whole). It is self-evaluated in the context of the person's life, in consideration of the influence of the following factors: emotional health, physical functioning, age, gender, coping skills (personal factors); and caregiver welfare, family and friends' support, society's attitudes towards communication and swallowing, family and friends' communicative competence, knowledge of disorder, and physical access and communication access in the community (environmental factors). In the clinical domains, the areas of functional communication ability, overall speech, language and/or swallowing functioning, and social networks and activities deserve exploration for performance, importance, satisfaction, personal meaning, and current and future aspirations.

Suggestions for future research: Within and beyond the ICF

The field of quality of life continues to develop with substantial speed, and debates and discussion of the ICF in research and clinical practice are becoming more frequent. In recognition

of this, a substantial proportion of this paper is devoted to identifying some of the key directions for future investigation into quality of life of people with communication and swallowing disorders. Some are conceived within the ICF conceptual framework, and require us to readjust the emphasis placed on features of this framework. Others go beyond the ICF to encourage us to think differently about quality of life in academic and clinical practice. They comprise: (1) more recognition of context; (2) better understanding of the contribution of personal factors; (3) recognition of the interdependence of environmental and personal factors within context; (4) recognition of disability as separate from health; (5) exploration of personal perspective of life with communication and swallowing difficulties (including impact and change); (6) greater recognition of importance ratings in subjective assessment; (7) inclusion of wellbeing in quality of life assessment; (8) re-engaging with an explicit goals framework in rehabilitation; and (9) the development of accessible procedures for self-report from individuals with atypical communication. These nine points are elaborated on in turn now.

Even though advocates for the ICF insist that an individual's activities and participation can be reflected in the round, by recording performance, capacity, assistance, barriers and facilitators, there is still a strong sense that each of the five components of the ICF framework (functioning, activity, participation, personal factors, and environmental factors) is evaluated separately. Certainly the structure of the ICF Checklist Version 2.1a suggests this to be true (see http://www3.who.int/icf/icftemplate.cfm?myurl=checklist.html&mytitle=ICF%20Checklist). Furthermore, in virtually all documentation about the ICF, the functioning aspect of the framework is always represented, defined and described first, and the context aspect of the framework follows that. Yet clinicians and individuals with disabilities would largely agree that context has a huge influence on a person's functioning, and can explain for example, why some

people find it easier to talk at home with their long-standing familiar communication partner, than under pressure with the stranger in a noisy shopping centre. Thus, in future research, more emphasis is needed on defining and manipulating the contextual factors in studies of intervention and/or quality of life. This requires research to develop appropriate instruments for capturing environmental factors, and their influence on the individual. As individuals function and perform differently in different contexts, a profile or portfolio approach (one ICF Checklist for each context or situation that is assessed) may give a more comprehensive picture of an individual's life, than an assessment made in the hospital, clinic, community or home.

If we continue to use the ICF framework as a guide in quality of life instrument development, it will be important to raise the status of Personal Factors in the overall framework. The current ICF documentation lists Personal Factors as

> "gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level" (WHO, 2007, p. 17).

It is well understood that many factors that lie within a person, such as coping style, level of motivation, or locus of control, influence the person's attitude to their disability, their response to intervention or rehabilitation, and can affect their rate of recovery. Furthermore, past experiences of therapeutic situations influence expectations of current intervention, as well as influencing attitudes towards professionals and health care in general. As quality of life is ultimately a subjective judgement made by one person, it is essential that we develop a better understanding

of the contribution of personal factors to quality of life, as well as understanding their role in a person's body functioning, activities and participation.

Within the current ICF diagrammatic representation and explanation, there is an implicit suggestion that Personal Factors and Environmental Factors are separate entities that do not relate to one another. Everyday clinical practice suggests the contrary. For example, a person's coping style and mood can be influenced by the attitudes of others in the social environment (environment → person) and a person's personality and attitude towards using (potentially stigmatising) equipment can influence their desire and use of a voice output communication aid (person → environment). This interdependence of Personal and Environmental Factors deserves more consideration in future studies, specifically when it comes to finding out exactly what in any one intervention has produced the change that was desired.

Individuals with permanently altered health states (e.g., stroke) cannot use health-related quality of life instruments to self-assess their quality of life. Individuals can find much of the content of these instruments irrelevant to their situation. Research participants with aphasic and hemiplegic impairments found the concept of physical health in the Short Form 36 Health Survey (Ware & Sherbourne, 1992) difficult to relate to, as their bodily health was good but half of their body functioned abnormally (Cruice, 2001). Individuals with permanently altered states also need to achieve quality in life through acceptance, adjustment and achievement. There is a suggestion that individuals do this best when their basis for comparison is their initial post-stroke or post-injury state (to identify how much change they have achieved since) and not their premorbid state. It is interesting to note that when determining how much assistance an individual needs to qualify his or her capacity (ICF Checklist, p.4), the professional is instructed to compare back to

premorbid functioning. As clinicians, it is important that we are aware what bases for comparison we and our clients are using.

In general, patients or clients are infrequently included in the development of quality of life instruments. Typically, a scientific expert panel designs the content and structure of the instrument, and then patients or clients are involved in large scale field-testing. Yet qualitative research is greatly needed to explore what life quality is like when living with a communication or swallowing disorder, and this to be reflected in the measurement instruments devised. The research could investigate general life quality, life quality specific to living with the disorder, the impact of the disorder on life, how life has changed since the disorder, how individuals now found quality in their lives, what individuals wish will change in the future, and what they desire in future life quality for themselves.

Currently in the literature, research is strong on measuring static quality of life, but weak on measuring the process or the mechanism for actually improving an individual's quality of life (which, for individuals with disabilities, is the goal of health care interventions). This is especially important as individuals with chronic disabilities use several strategies to adjust to their new lives. For example, a study of 30 individuals found that after stroke and aphasia, individuals changed the way they did activities, accepted doing their activities differently, and tried new activities (Cruice, Hill, Worrall, & Hickson, 2007) as a means for finding quality in life. Quality of life instruments do not inquire about whether respondents have changed how they do activities (including whether assistance from others or equipment is now involved), whether they do their activities differently and whether they are satisfied with that, and whether they have replaced old and 'impossible' activities with new activities. This suggests that quality of life

instruments are not yet sensitive to the client's process of finding quality in life or indeed sensitive to how intervention might contribute to quality of life.

Clinicians rarely work on life goals that are unimportant or irrelevant to the client, yet quality of life instruments do not routinely identify the importance of the different domains for each individual. Asking clients to self-assess their functioning and satisfaction in unimportant quality of life domains is inefficient and counterproductive. Rating the importance of different domains (separate from one another) will become more typical in the future, as clinicians increasingly have to provide the maximum level of service with the least amount of resource. To date, few instruments do this. One exception is the instrument designed for adults with intellectual impairment (see Cummins, 1997).

Wellbeing deserves more recognition in overall quality of life assessment. Wellbeing is a completely separate conceptualisation of health-related quality of life, and the term subjective wellbeing (SWB) is possibly the best understood within the wellbeing field. Subjective wellbeing is determined by a cognitive evaluation of global life satisfaction, and an affective or emotional judgement of both positive affect and negative affect (George & Bearon, 1980). Life satisfaction is derived by evaluating the overall condition of one's existence, comparing one's aspirations with one's achievements (George & Bearon, 1980). Here again, goals or aspirations are relevant to the discussion of clients' quality of life. More emphasis on the goal process (and possibly less on the end point functioning) may give insight into how clinicians can assist clients in achieving life satisfaction. The following are likely to be important in the goal process: (1) understanding the client's interests and life goals; (2) discussing what is possible to achieve within a given time period; (3) jointly setting goals that include rationale for the goal, statements of functioning, time

periods for reviewing, and the methods for determining whether goals have been met (objective versus subjective evaluations); (4) framing all intervention sessions in relation to goal achievement; and (5) documenting and discussing progress towards goals each session. We know from research that the individual's affective or emotional experience is equally important in subjective wellbeing (Birren, Lubben, Cichowlas Rowe, & Deutchman, 1991), and appears linked to people's daily events and experiences and how those events or activities relate to life goals (Oishi, Diener, Suh, & Lucas, 1999).

Because individuals make judgements about their life satisfaction by comparing their aspirations (goals) with their achievements, the clinician's role in appropriate goal setting with patients or clients is especially important. The greatest challenge often lies in making the goals realistic and achievable. Research suggests that patients need experience in understanding the rate of their own progress, before they are able to realistically predict their functioning in the situation, and subsequently set attainable, appropriate goals (Ozer, 1999). Patients in this study reported having a positive attitude, seeing progress, having hope and pushing one's self, determination and a desire to get better as the reasons for making progress post-stroke.

Last, but by no means least, the issue of communication accessibility of quality of life instruments is raised. Preliminary research has been conducted with aphasic adults to modify the content and layout of existing quality of life instruments (Cruice, 2001; Hilari & Byng, 2001). This research revealed that the following conditions and adjustments make instruments more accessible for adults with a moderate level of auditory comprehension ability: font size 18 point Times New Roman; one question per page of instrument; response scale repeated on each page; response scales with defined points, not visual analog; consistent question frames; consistent time

frame; and a consistent response format, that is, one that *doesn't* switch between yes/no, true/false, agree/disagree, and 'not at all' to 'completely'. Furthermore, cognitive issues in self-assessment are important, and are illustrated in one existing measure – the Comprehensive Quality of Life Scale –Intellectual/ Cognitive Disability (Cummins, 1997) – which incorporates a pre-instrument testing protocol to determine how many levels of cognitive abstraction the respondent can comfortably deal with (see http://www.deakin.edu.au/research/acqol/instruments/com_scale.htm). More research is urgently needed to develop accessible procedures for existing quality of life instruments, especially wellbeing scales, which are considered relevant (content-wise) for adults with communication and swallowing disorders as they tap larger life issues.

Concluding remarks

Quality of life is not another level of the ICF that we need to measure functioning at with clients. The two concepts are fundamentally different: the ICF framework helps us to structure what the individual can and cannot do; quality of life reminds us to consider who the individual is, what he or she wants in life, and who he or she wants to be. Work on both "doing" and "being" are needed in intervention with people with communication and swallowing disorders, but perhaps with different emphases than we had before – more on "being" in general, and more about the relationship between the two. In moving our understanding of the ICF's potential forward, I propose we turn the framework upside down, and start our discussions, our writing, our assessments and our intervention with the personal and environmental life contexts of our clients, and let our clinical discussions with clients about their goals, values, standards, perceptions,

functioning and so on, follow on from there. This would be the ultimate best use of both of these concepts.

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Table 1. The domain and facet structure of the WHOQOL-100.

Domain	***Facet***
	Overall Quality of Life and General Health
Physical Health	Energy and fatigue Pain and discomfort Sleep and rest
Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Thinking, learning, memory and concentration
Level of Independence	Mobility Activities of daily living Dependence on medicinal substances and medical aids Work capacity
Social Relations	Personal relationships Social support Sexual activity
Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment

	Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure Physical environment (Pollution/noise/traffic/climate) Transport
Spirituality/ Religion/ Personal beliefs	Religion/Spirituality/Personal beliefs (Single facet)

Figure 1. Typical representation of disablement and quality of life.

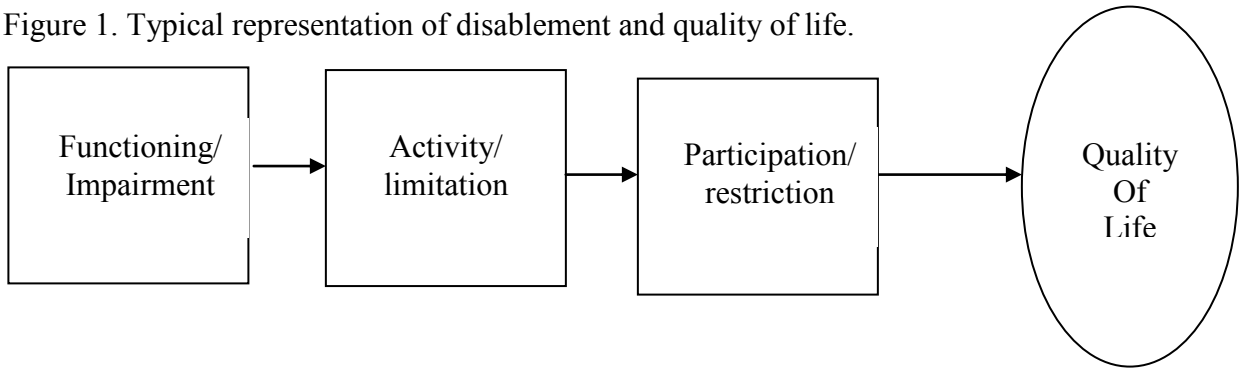
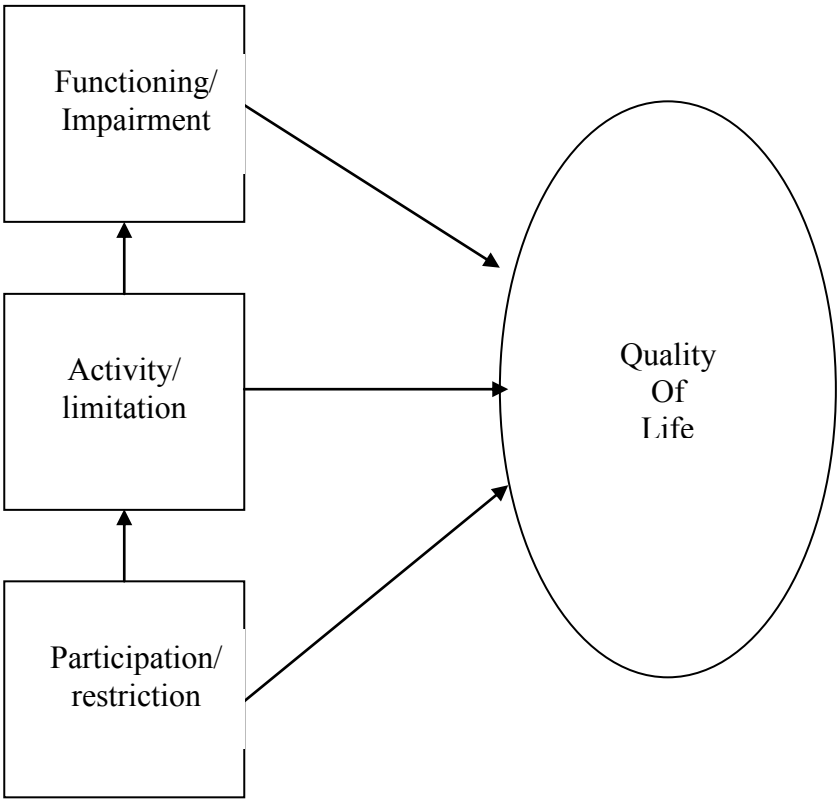
Figure 2. Alternative representation of disablement and quality of life.