Case report

Applying the WHO ICF framework to communication assessment and goal setting in Huntington’s Disease: A case discussion

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ABSTRACT

Purpose: Huntington's Disease (HD) is a fatal, hereditary neurodegenerative disorder that is characterized by a triad of motor, cognitive and psychiatric symptoms that impact on both communicative effectiveness and the treatment techniques used to maximize communicative participation. The purpose of this article is to describe the application of the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) to communication assessment and goal setting for a 37 year old man with HD.

Method: Communication assessment consisted of qualitative interviews based on the ICF framework with the client and his mother, supplemented with quantitative communication assessments. Analysis and conceptualization of assessment information was completed with a modified version of the Rehabilitation Problem Solving Form (RPS-Form) (Steiner et al., 2002).

Results: While impairments in body structures and functions were evident, analysis revealed that environmental factors such as family support were both key barriers and facilitators to communicative participation.

Conclusions: This case illustrates the potential of using the ICF to conceptualize communicative functioning and disability in HD and particularly highlights the importance of consideration of personal and environmental factors in revealing contributions to activity limitations and participation restrictions. Further investigation of applications of ICF for individuals with HD is suggested.

Learning outcomes: As a result of this activity, readers will recognize the application of the WHO ICF to assessment and goal setting in a complex hereditary condition, Huntington Disease. As a result of this activity, readers will describe the use of the Rehabilitation Problem Solving Form (RPS-Form) for communication disorders. As a result of this activity, readers will identify relevant issues in comprehensive communication assessment of a fatal, degenerative neurological condition such as the advantages and challenges of clinical use of the ICF and its coding. As a result of this activity, readers will introduce life storybooks as a potential legacy item in degenerative diseases.

1. Introduction

Huntington's Disease (HD) is a hereditary, fatal neurodegenerative condition that can have a profound effect on an individual's communication. Subcortical and cortical degeneration in HD results in physical, cognitive and emotional symptoms that manifest between 35 and 40 years of age (Folstein, 1989). There is a slow progression of these symptoms over
an average of 16 years, although this can be highly variable ranging from 4 to 38 years (Folstein, 1989). Consequently, up to 88% of people with HD require residential care and virtually all people with HD need long-term medical, nursing and allied health support for themselves and their families (Nance & Sanders, 1996).

The primary communication symptoms in HD include progressive deterioration of speech and cognitive-linguistic skills (see Yorkston & Beukelman, 2007 for a detailed review). In summary, individuals may present with hyperkinetic or occasionally hypokinetic dysarthria, partially reflecting the underlying movement disorder of chorea (Darley, Aronson, & Brown, 1969). Speech intelligibility may be significantly reduced for everyday listeners (Klasner & Yorkston, 2005) and some individuals may be non-verbal in later stages of the disease (Podoll, Caspary, Lange, & Noth, 1988). Cognitive-linguistic impairments observed include deficits of problem solving and understanding complex or implied meanings (Chenery, Copland, & Murdoch, 2002; Murray & Stout, 1999). Social situations may be problematic due to difficulties following conversational rules (pragmatics) and interpreting facial expressions and tone of voice (Speedie, Brake, Folstein, Bowers, & Heilman, 1990). In later stages, individuals may exhibit primary language impairments such as reduced syntactic complexity of sentences, word finding problems as well as verbal and written comprehension difficulties (Murray, 2000; Wallesch & Fehrenbach, 1988).

The complex interplay of disease symptoms and the hereditary nature of HD increase the challenge of supporting individuals with their communicative participation and treatment options. Motor deficits such as chorea and dysphagia (Young et al., 1986), cognitive decline such as short-term memory loss and subcortical dementia (Bamford, Caine, Kido, Cox, & Shoulson, 1995) and emotional changes such as agitation, apathy, depression and aggression (Paulsen, Ready, Hamilton, Mega, & Cummings, 2001) may all impact the effectiveness of communication assessments and treatments (Klasner & Yorkston, 2001). HD is autosomal dominant and each child of an affected parent has a 50% chance of inheriting the disease. The marital and parental pressure on families often leads to significant family breakdown and a difficult upbringing for children (Keenan, Miedzybrodzka, van Teijlingen, McKee, & Simpson, 2007; Korer & Fitzsimmons, 1985). The hereditary nature of the disease and individuals’ prior experience with it may influence how they cope with life and influence how they approach assessment and treatment planning (Hunt & Walker, 1989).

Therefore, assessment and goal setting in HD can be complex due to the long-term triad of symptoms and complex social dynamics associated with the hereditary nature of the disease. To date, research into communication difficulties in HD has focused largely on communication impairments with limited use of functional tasks. The impact of speech and cognitive-linguistic impairments on an individual’s daily activities and life participation has rarely been studied in HD and to our knowledge, no communication assessments have been specifically designed for, or standardized and validated on the HD population. The challenge for clinicians is to create assessment protocols that capture the relative contribution of these disease-related factors but also integrate social and environmental factors to develop interventions aimed beyond the level of impairment to life participation.

The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) (2001) is a potential biopsychosocial framework to meet this challenge with a person-centred approach. It offers the opportunity to systematically conceptualize assessment and goal setting by considering disability and functioning at the level of body functions and structures and also the activities people undertake (the execution of a task or action) and at a societal level, the areas of life in which they participate. Critically, it also recognizes that these domains cannot be understood without consideration of contextual factors and adds these elements to the previous International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (World Health Organization, 1980). Contextual factors include the person’s environment from the physical to societal level and also personal factors such as age and gender that may affect the way they experience their health condition. In a disease with such a complex interplay of symptoms and social and familial consequences, the multidimensional biopsychosocial nature of the ICF offers an important clinical tool for speech-language pathologists working with people with HD.

While the ICF has been applied to some clinical areas in speech-language pathology (e.g., Brush, Threats, & Calkins, 2003; Ma, Worrall, & Threats, 2007), rehabilitation medicine (Steiner et al., 2002) and neurodegenerative disease excluding HD (Lomax, Brown, & Howard, 2004; Muo et al., 2005), experts in the field have conceded even recently, that it is yet to be commonly integrated into clinical and research practice (Ma, Threats, & Worrall, 2008). The literature contains articles in which the ICF is applied to hypothetical case studies (e.g., Brush et al., 2003) or more broadly in conceptualizing communication related functioning in health conditions (e.g., dementia; Byrne & Orange, 2005). Additionally, some authors have used the ICF framework and classification codes in order to describe the ICF’s application to a particular area of speech pathology (e.g., dysphagia; Threats, 2007b). However there are no reports applying the current WHO ICF framework and coding to actual clinical cases in communication disorders for HD. A case report, based on the previous classification system, however, provides some encouragement for this approach (Klasner & Yorkston, 2001). Klasner and Yorkston (2001) demonstrated some success in implementing linguistic and cognitive supplementation strategies for a man with HD living in the community to improve his conversations with his wife and his ability to complete daily tasks. They utilized impairment-based assessments and qualitative interviews with the man and his wife to formulate activity and participation-based treatment goals. Klasner and Yorkston reported the goals with broad reference to the WHO’s previous beta classification system, the ICIDH-2. It is not clear whether the ICIDH-2 was used systematically to drive the development of the content for the qualitative interviews in the assessment phase. Although the ICIDH-2 beta form did address environmental and personal factors, these were not explicitly considered in the assessment or analysis. Despite this, Klasner and Yorkston considered the use of qualitative interviews, with a focus on participation to be crucial for development of goals targeted at everyday life situations of a man with HD.

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In this article we describe the first application of the ICF to communication assessment and goal setting for a man with HD living in a residential care setting. We use a case-based approach to extend previous research (Klasner & Yorkston, 2001) by applying the ICF as a general conceptual framework and explicitly examining the contribution of environmental and personal factors on functioning and disability. We also use the ICF to systematically guide the content of qualitative interviews and examine the feasibility of its coding system for the assessment and goal setting process. Utilizing such a case-based approach, especially in rarer disease populations and newer research areas, provides a detailed examination of the translation of theoretical constructs into clinical process and provides further grounding to guide future research and clinical practice (Edwards, Dattilio, & Bromley, 2004).

2. Method

2.1. Case report

ER, a 37 year old man, was diagnosed with HD at age 26 by a neurologist in 1996. For 5–6 years prior to diagnosis he had increasing symptoms, including dropping objects, behaviour change and arm and facial chorea. ER’s father passed away at age 33 with HD. ER’s two siblings both had HD. One sibling had a juvenile onset and died aged 16 and the other sibling died in a residential care facility aged 33. ER obtained a mechanical trade qualification and prior to stopping work was employed as a petrol station attendant. ER had two children aged between 5 and 10 years from a relationship that ended in 1993. Despite his strong attempts to maintain contact with his children, he was estranged from them. He entered specialized residential care in 2002 some distance from his home and his main family contact was his mother. Medical reviews were conducted to evaluate functional communication of people with HD and two speech-language pathologists experienced in HD rated his communication effectiveness using a modified 20-item version of the Communicative Effectiveness Index (CETI) (Lomas et al., 1989) (activity and participation). ER’s mother was unable to participate in the assessment due to health reasons. The original published CETI was designed to assess functional communication of people with aphasia and was composed of visual analogue scales using the anchors ‘as able before the stroke’ and ‘not at all’ at either end of a 10 cm line. The original form was modified to allow for staff, families and clients with HD to rate communication using a simplified visually presented 5 point scale (1. Never able, 2. Rarely able, 3. Sometimes able, 4. Mostly able, 5. Always able). Additionally, items were added or modified to account for intelligibility, ability to repair conversation, comprehension of information and both starting as well as maintaining conversations. For example, the original item 10, ‘Having a conversation and changing the subject’ was divided into ‘Starting a conversation’ and ‘Continuing conversations and changing the topic’. Four items were added, including ‘Make your speech clear’, ‘Understand instructions from staff’, ‘Understand complex information’, and ‘Making yourself understood if others can’t understand you’. At the time, ER also participated in the speech-language pathology weekly resident ‘Talking Group’ (Berarducci, Power, Anderson, & Togher, 2003) and had regular mealtime dysphagia review assessments.

2.2. History of communication assessment

In early 2003, a number of assessments were administered to describe ER’s communication skills across the impairment, activity and participation domains of the ICF. The Western Aphasia Battery (WAB) (Kertesz, 1982), the Frenchay Dysarthria Assessment (Enderby, 1983), and the pragmatic protocol (Prutting & Kirschner, 1987) examined his expressive and receptive language processing (impairment level), speech intelligibility (activity and participation), as well as pragmatic skills in individual and group conversations (activity and participation). ER, six nurses working in a specialist residential care unit for people with HD and two speech-language pathologists experienced in HD rated his communication effectiveness using a modified 20-item version of the Communicative Effectiveness Index (CETI) (Lomas et al., 1989) (activity and participation). ER’s mother was unable to participate in the assessment due to health reasons. The original published CETI was designed to evaluate functional communication of people with aphasia and was composed of visual analogue scales using the anchors ‘as able before the stroke’ and ‘not at all’ at either end of a 10 cm line. The original form was modified to allow for staff, families and clients with HD to rate communication using a simplified visually presented 5 point scale (1. Never able, 2. Rarely able, 3. Sometimes able, 4. Mostly able, 5. Always able). Additionally, items were added or modified to account for intelligibility, ability to repair conversation, comprehension of information and both starting as well as maintaining conversations. For example, the original item 10, ‘Having a conversation and changing the subject’ was divided into ‘Starting a conversation’ and ‘Continuing conversations and changing the topic’. Four items were added, including ‘Make your speech clear’, ‘Understand instructions from staff’, ‘Understand complex information’, and ‘Making yourself understood if others can’t understand you’. At the time, ER also participated in the speech-language pathology weekly resident ‘Talking Group’ (Berarducci, Power, Anderson, & Togher, 2003) and had regular mealtime dysphagia review assessments.

2.3. Intervention request

A few months following the communication assessment, ER’s mother reported to the service social worker that she and ER were concerned for the loss of relationship with his children. She requested assistance to pass on information about ER to his children should they re-connect in the future. Referral to speech-language pathology occurred at the interdisciplinary case conference and speech–language pathologists investigated the intervention request further with ER and his mother using semi-structured interviews. This information was combined with findings from the recent communication assessments.

2.4. Semi-structured interviews

Similar to Klasner and Yorkston’s (2001) approach, we chose semi-structured guided interviews to examine communication-related activities and participation from ER and his mother’s perspective as the above assessments covered a more narrow context. The interview questions were structured according to the components of ICF framework to conceptualize ER’s functioning and disability, but also to explore personal and environmental factors. No formal
permission in two ways (see Fig. 1). Firstly, a specific section was added to document client and family’s opinions on function and activities/participation as well as contextual factors. For the current case, the form was modified with mediators relevant to identified target problems and allows the professional to document these under body structure/structure/function and activities and participation. The second section includes the health professional’s perspectives on The first covers patient and family perspectives of problems and disabilities in their own words under the headings of body document rehabilitation assessment and clinical problem solving in physical therapy. The original form has two sections.

<table>
<thead>
<tr>
<th>Areas considered</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opening questions</strong></td>
<td>'Tell me about what communication is like for you/and ER now?'</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> ‘Can you compare ‘in person’ versus over the phone or in letters?’</td>
</tr>
<tr>
<td></td>
<td>‘What would you like to achieve by working with speech pathology?’</td>
</tr>
<tr>
<td><strong>Functioning and disability</strong></td>
<td>'What communication situations do you most enjoy/are most frustrating?’</td>
</tr>
<tr>
<td></td>
<td>'In terms of communication, what is working well for you/you and ER? 'What is more difficult?’</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> ‘For example, reading/following sport?’</td>
</tr>
<tr>
<td></td>
<td>‘Tell me about this in relation to your life?’</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> ‘For example, being a father/son?’</td>
</tr>
<tr>
<td></td>
<td>‘What parts of your life do you find rewarding/disappointing?’</td>
</tr>
<tr>
<td><strong>Environment: barriers</strong></td>
<td>'Tell me about things that make communication/being involved in life more difficult?’</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> ‘...in relation to [equipment or technology/the environment here (at the residential facility/ people in your life/the health system and how it is set up)]?’</td>
</tr>
<tr>
<td><strong>Facilitators</strong></td>
<td>‘What things do you think help communication/being involved?’</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> as above</td>
</tr>
<tr>
<td><strong>Personal factors</strong></td>
<td>‘Looking beyond the HD, what personality and other factors do you think are important for us to know?’</td>
</tr>
<tr>
<td></td>
<td><strong>Probe:</strong> ‘Tell me about your coping strategies’</td>
</tr>
<tr>
<td><strong>Perceptions of the future</strong></td>
<td>‘Tell me about how you see your/ER’s communication over time’</td>
</tr>
<tr>
<td></td>
<td><strong>As above for Environment but with future tense</strong></td>
</tr>
<tr>
<td><strong>Client priorities</strong></td>
<td>‘With the options we have, tell me about the most important to least important for you’</td>
</tr>
</tbody>
</table>

questionnaires or scales were available for these purposes. We explored current as well as potential future communication issues for ER and his mother. The addition of future issues is consistent with an anticipatory approach to communication management in degenerative diseases where future communication decline is factored into communication management plans (Yorkston & Beukelman, 2007). The interview followed suggestions by Creswell (2003) and utilized open-ended questions based on the components of the ICF, followed by focused probes to further explore and clarify information (see Table 1 for examples). The interview also included questions on their perception of future communication issues and targeted their priorities for intervention. As ER had some difficulty understanding complex information, questions posed to him were more structured and he was given more time to respond.

2.5. Analysis and coding

Analysis and coding of the quantitative and qualitative data occurred in a number of steps and utilized a modified version of the ICF-based Rehabilitation Problem Solving Form (RPS-Form) (Steiner et al., 2002). The RPS-Form has been used to document rehabilitation assessment and clinical problem solving in physical therapy. The original form has two sections. The first covers patient and family perspectives of problems and disabilities in their own words under the headings of body structure/function and activities and participation. The second section includes the health professional’s perspectives on mediators relevant to identified target problems and allows the professional to document these under body structure/function and activities/participation as well as contextual factors. For the current case, the form was modified with permission in two ways (see Fig. 1). Firstly, a specific section was added to document client and family’s opinions on environmental and personal factors. Secondly, the modified form contains an added column for consideration of future issues to reflect the degenerative nature of HD. For our purposes, the ‘staff’ section does not strictly contain assessment observations directly made by staff alone. It may also contain information gained from the client and family through questionnaires, rating scales or interviews as well as observational assessments. The distinction made here is that both types of information are interpreted and coded by the staff member according to their perspective to create a holistic picture of functioning. This division preserves the integrity of the client’s and family’s input as much as possible in their own words, but also considers their perspective as part of the integration of data utilized and coded by staff.

In the first step of the analysis, results from quantitative testing were listed in a document. Then, during the semi-structured interviews with ER (face to face) and his mother (over the phone), field notes were taken by one of the speech-language pathologists (EP). A content analysis of field notes was completed and verbally reflected back to ER and his mother. They provided feedback on whether they concurred with statements or advised of amendments to maximize validity (Creswell, 2003). The content analysis was guided by the interview format and statements were divided into the broad domains of the ICF, i.e., body structure and functions, activity and participation, environmental factors and personal factors. Statements were divided into current or future focused issues and then entered on the modified RPS-Form in the client and family sections. Information from ER’s responses to the modified CETI was also included here. Then following guidelines of
the AIHW (Australian Institute of Health & Welfare, 2003), each item was coded according to the ICF alphanumeric coding system. Body functions, body structures, activities and participation and environmental factors were classified by drawing on each ICF chapter and ‘nested’ codes within each chapter (see Appendix A for information of coding system with examples). Personal factors are not yet coded in the ICF. We chose to conceptualize ER’s functioning beyond the broad chapter headings and coded to the fourth classification level where applicable with respect to the detail of our assessment results. This detail enabled us to analyse ER’s assessment results with greater specificity for determining management goals. Utilizing the specific ICF alphanumeric coding system assisted our analysis by enabling us to manage this complex information in a structured and replicable way.

The ICF coding is neutral and so qualifiers are required to provide a meaningful understanding of an individual’s classification of functioning and disability. We contained coding of qualifiers to the level of the first qualifier, i.e., a generic qualifier that represents the extent or severity of the impairment or activity and participation difficulty for ER’s performance (World Health Organization, 2001). The first level qualifier for environmental factors consists of the extent to which an environmental factor was a barrier or facilitator (World Health Organization, 2001). This qualifier parallels more traditional clinical practice notions of severity. Coded results were then transferred to the ‘Staff’ sections of the RPS-Form.

Fig. 1. Rehabilitation Problem Solving Form (RPS-Form). © by Dr Werner Steiner, 2002. Modified by Dr Emma Power with kind permission.
2.6. Verification and reliability

For the content analysis, the original de-identified transcript was reviewed by an independent, qualified speech-language pathologist. Any disagreements on the allocation of statements to ICF components were resolved with consensus discussion. For the ICF coding, inter-coder reliability with the same independent rater was established for the ICF codes to the fourth classification level for chapter categories. While we were able to conduct reliability ratings for the coding, we felt that severity of impairment, activities and participation and extent of environmental barrier/facilitators was best determined using a consensus-based approach by two clinicians (EP, AA) who had worked face to face with ER for the assessment.

2.7. Informed consent

ER and his mother gave written informed consent for publication of the case study on forms approved by the local Human Ethics Committee. ER's mother edited components of this manuscript relating to ER's case history.

3. Results

3.1. Communication assessment findings

3.1.1. Speech functioning

On testing, ER presented with mild hyperkinetic dysarthria characterized by imprecise consonants, intermittent strained-strangled and hoarse vocal quality. Forced inspiration–expiration and reduced respiratory control was observed during speech, which may have contributed to shorter sentences and variable phrasing. He had some difficulty varying loudness (often using excessive loudness) and presented with pitch variations. Despite some motor deficits and decreased naturalness, he scored at ceiling on the word and sentence level intelligibility testing. Staff judged him to have mild-moderate intelligibility difficulties in 1:1 and group conversations and noted he needed to repeat himself. Intelligibility fluctuated with his severe truncal chorea and background noise. ER reported using some of his own speech strategies such as taking a good breath before talking to 'have enough air'.

3.1.2. Cognitive linguistic functioning

ER's WAB quotient was 86.6, classifying him with a mild aphasic impairment. Overall, he took increased time to provide answers and follow instructions on testing. His picture description consisted of simple utterances with reduced grammatical complexity. He could identify objects and follow one-and two-step commands, but had difficulty with three-part instructions. Word fluency was reduced. ER was able to read and comprehend paragraph level material well. However, his chorea appeared to contribute to difficulty writing legibly and writing more than a phrase was laborious. Spelling errors were also observed.

Observation of ER's pragmatics skills in 1:1 and group settings revealed mild-moderate difficulties across several areas. He had some limited topic selection, increased pause time, a small number of interruptions and amount of overlap, reduced quantity of output with short turns and a reliance on the communication partner to initiate and maintain topics. He varied his communicative style for sensitive, serious and humorous topics and he revised if there was a communication breakdown. He listened well to others' conversations, provided some opinions and observations and used a variety of speech acts (e.g., requests, opinions, and statements). He appeared more animated and discussed a wider range of conversational topics in the group situation compared to one to one. Intelligibility and prosodic ability were mildly impaired as stated above. Nonverbally, his body posture, arm and leg movements were distracting and more subtle gestures were distorted by facial and limb chorea. Sometimes ER required prompts and encouragement to attend the group.

With regard to communicative effectiveness, ER rated himself as 'Mostly able' (8/20) and 'Always able' (7/20) to participate in the modified CETI items, with an average rating of 4.0/5. He identified that he was 'Rarely able' or 'Sometimes able' to 'Continue conversations and follow the topic', 'Be part of a fast conversation with other people talking' and 'Understand complex information'. ER's ratings were consistent with speech-language pathologists (n = 2, average rating 4.2) and nursing ratings (n = 6, average rating 4.1), indicating some consistency in perception. However, staff rated his ability to 'Describe things in detail' and 'Start conversations with others' lower ('Rarely/Sometimes able') compared to ER ('Mostly'). Staff reported that ER met most of his basic communicative needs without significant help.

3.2. Semi-structured interviews and ICF coding

The combined coded interview and assessment data are represented on the modified RPS-Form in Fig. 2a and b. Due to the density of responses and issues, the tables are divided into functioning and disability and then contextual factors separately, although it is acknowledged these components are inter-related. Inter-rater reliability agreement for the ICF coding was 93%.

3.2.1. Functioning and disability

ER presented with mild-moderate impairments in speech functions (b310.1, b330.1, b320.1, b760.2, b440.2). He also had impairments in higher level cognitive functions (b164.2). Many of his primary language functions (mental functions of
language) were intact. However, he had some mildly reduced syntactic complexity and auditory comprehension impairment (b167.1). His written expression was poor and laborious (b16711.3). His chorea contributed to difficulty controlling voluntary limb/trunkal/facial movements (b760.3) and he had some apathy (b1301.2). ER's insight into his communication abilities appeared only mildly reduced (b1644.1) and was considered a relative strength in his functioning.

ER's activity and participation related strengths included good reported ability to understand nursing commands (d310.0) with an intact ability to communicate immediate needs (d2). The most important activity limitation/participation restriction prioritized by ER was his complete inability to interact and converse with his children (d350.4) and an inability perform the role of father and be involved in their lives (d7600.4). He and his mother expressed strong concerns about their lack of involvement and relationship with his children at the time and into the future (ER: 'I can't see my kids or be their dad', and 'they won't understand me later when I get worse'). They acknowledged that they had exhausted options for this relationship and were looking to alternative ways of communicating in the future. Other limitations and restrictions identified by ER and his mother as most important included decreased speech intelligibility, particularly on the phone with his mother (d330.1-2), reduced initiation (d3500.2) and maintenance of conversations with other residents and his mother

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**Fig. 2.** (a) Rehabilitation Problem Solving Form (RPS-Form) for functioning and disability completed based on ER's qualitative and quantitative assessment data. © by Dr Werner Steiner, 2002. Modified by Dr Emma Power with kind permission. (b) Rehabilitation Problem Solving Form (RPS-Form) for contextual factors completed based on ER's qualitative and quantitative assessment data. © by Dr Werner Steiner, 2002. Modified by Dr Emma Power with kind permission.
3.2.2. Contextual factors

Examining contextual factors allowed us to explore perceived contributors to participation functioning and disability. ER’s mother and speech-language pathologists identified that a lack of specialized facilities close to their home (e580.3) resulted in fewer communication opportunities and quality time together as ER’s mother could not frequently visit in person. She also identified that she understood that his speech was ‘a little hard to understand’ and she needed to take more responsibility for the conversation. However, ER’s mother considered the background noise near the nurse’s station as the main difficulty in phone conversations with him (e350.1) as it meant she had to listen harder and ask him to repeat more. Despite some speech and language impairments, ER’s communication functioning appeared potentially sufficient to communicate with his children. His reduced activities and participation in relation to his children was identified by staff and the family as being due to a complete barrier of family estrangement (coded as support and attitudes e310.4; e410.4) rather than impairments of speech and language functions or personal factors (e.g., not desiring contact with them). Speech-
language pathologists, staff and the family all reported that in the future, they were very concerned that his speech and language decline would contribute as a major Barrier to communicating with his children. ER, his mother and speech-language pathologists considered the 'Talking Group' as a Facilitator (e355 + 2) but he missed these opportunities if not invited to come. ER and his mother reported that they felt the best way to maintain ER's speech and language skills was to 'keep talking' (ER), and 'if you don't use it you'll lose it... well lose it faster anyway, because he will probably lose it eventually' (mother). ER, speech-language pathologists and nursing staff also considered his mother as a significant facilitator as both a support (e310 + 3) and an advocate for him (e410 + 4) and her family over the years. ER's mother and staff identified his dog as a facilitator for conversational stimulus and enjoyment (d350 + 2) and this topic was utilized in art therapy and the 'Talking Group'.

ER and his mother strongly emphasized personal factors in the interview. ER's mother reported that it was important people knew his longstanding communicative style was as 'not a man of many words' but he 'enjoyed company and always got along with people'. They both reported that their long experience with HD made them feel somewhat prepared for coping with his future decline, which they saw as inevitable (ER: 'I know what will happen, I've seen it all over the years', and his mother 'We know what we're in for, it is going to get worse. You're never fully prepared but from all our experience we are and we'll manage as we go'). They reported that this experience meant they understood the proactive nature of what they were requesting (mother: 'Because we know what will happen is why we need to do it now, before his speech gets worse'). Additionally, ER had previously helped to construct his sibling's communication book and had positive feelings towards communication books. ER stated he was not afraid of dying, but instead was afraid he would not be able to say goodbye to his children and tell them he loved them.

3.3. Communication intervention goals

Once the RPS-Form was completed and discussed by both of the speech-language pathologists, the findings were discussed with ER and his mother. From this discussion ER and his mother decided on three main goals and interventions that would assist with achieving their goals. The goals focused on their priority areas of d3 communication and d7 interactions/relationships:

 Goal 1: Despite adequate communication skills, ER is currently unable to communicate with his children (e310.4; e410.4). ER, and his mother will collaborate with speech-language pathologists to produce a legacy life story book and DVD (environmental product, e125) that will maintain his capacity to: (i) tell his children about himself and his love for them (d350) and (ii) fulfill the role of father (d7600) when his communication declines or he passes away. 

 Goal 2: ER and his mother wish to maintain their relationship with phone conversations that are less effortful (d6701/d330). A mobile phone for ER (environmental product/technology, e1250) would enable conversations in quieter areas (e2501) to reduce background noise and maximize ER's intelligibility (d330).

 Goal 3: ER and his mother believe that he should continue to maintain and practise his conversations with other residents in his home (d9205). Staff will continue to encourage and invite ER to the weekly 'Talking Group' (e355). The strategy of personal invitation from nursing staff/student speech-language pathologists (e355, e340) will help ER to overcome initiation and apathy difficulties to participate in this group.

4. Discussion

This report describes the application of the ICF to communication assessment and goal setting for a man with HD and his mother. Analysis of data from formal assessments and qualitative interviews revealed that ER had mild-moderate communication impairments in body structures and functions and he, his mother and staff were concerned for any future communication deterioration. The most significant barrier to participation in important life areas for ER was not his communicative impairments, but environmental factors such as family attitude and reduced support that arose from his family breakdown. The following section will divide discussion of ER's case into three areas; the goals established by ER and his mother, how the ICF framework contributed to the assessment and goal setting process and important issues for clinical application of the ICF.

4.1. Goals established collaboratively with ER and his mother

Three goals were developed focused on supporting participation in communication activities with ER's children, his mother and fellow residents. The goals provide further support for recent findings that family wish to see increased social communication participation for their loved ones with HD (Hartelius, Jonsson, Rickeberg, & Laakso, 2010).

ER's most important goal was to tell his children about himself, his love for them and to be involved in the role of father, despite his estrangement from them. Creation of a life story book and DVD was chosen by ER and speech-language pathologists as the most effective way to achieve this goal. Life story work may take the form of a book or recorded narrative that documents a person's life history (Shadden, Hagstrom, & Koski, 2008). This approach has been used in a variety of contexts for different purposes including a reminiscence tool for people with dementia (Moos & Bjorn, 2006), preservation or development of post stroke identity in aphasia (Pound, Parr, Lindsay, & Woolf, 2000) and as a legacy item for people with
terminal illness (Rosenbaum et al., 2006). People with terminal illness and their families who engaged in life story work have reported increased social interaction and reduced caregiver stress compared to families who received supportive telephone conversations from researchers (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008). Despite being years away from a traditional palliative stage, the essential component of this goal for ER was production of a legacy item that he himself would make using his relatively intact speech abilities. ER and his mother acknowledged the uncertainty that his children would eventually see the book and DVD due to their estrangement. However, both ER and his mother reported that constructing the items would bring them significant peace of mind in telling his children he loved them and fulfilling the role of father. The speech-language pathologists had been using a life story intervention program with many HD clients. However, this was the first time that the requested focus of a client’s book was specifically as a legacy item. It is also the first study to raise the issue of life story books as legacy items for people with communication difficulties in HD. Life story work may be an important aspect of a communication intervention plan for a person with HD. However, unlike other more rapidly progressing terminal conditions, life story work in HD needs to be considered well before a palliative stage is reached and before communication declines if the person with HD is to construct his own life story and message to loved ones.

The family’s second goal focused on reducing conversational effort on the phone due to background noise. Noisy environments are significant barriers to participation for people with communication difficulties (Howe, 2008). It was unlikely that we could change the actual physical environment of the nurses’ station to reduce noise. However, modification of the communication technology with a cordless phone was considered feasible. Fortuitously, a short time after ER’s assessment, the residential care facility upgraded fixed line phones to cordless ward phones. This provided more communication-friendly locations not only for ER, but also for other residents with a variety of communication difficulties (e.g., hearing loss). System level environmental changes may be effective ways to minimize communication barriers for a larger proportion of the population in a particular environment (Howe, 2008).

ER’s third goal was to continue to attend the weekly ‘Talking Group’ as part of his total interdisciplinary care plan program. As many of the residents engaged in daily TV viewing and newspaper reading, the group provides a supported opportunity for residents to discuss events of the week and raise awareness of topics of interest within the group that could be discussed further outside the group. Both ER and his mother emphasized the importance of the group as a positive, enjoyable experience socializing with fellow residents (Berarducci et al., 2003). This also supports research that found that families of people with HD view social communication-opportunities for people with HD as critically important to participation (Hartelius et al., 2010). ER’s case demonstrates this may be even more crucial for residents with reduced contact with family and friends.

ER and his mother also wanted ER to ‘keep talking’ and considered that the ‘Talking Group’ would assist with maintaining his communication skills. His mother’s use of the phrase ‘use it or lose it’ is supported by a key principle of neuroplasticity (Kleim & Jones, 2008) where neuronal networks that are not engaged in a specific task over time, may degrade. Encouraging ER to continue to communicate in the group may support some maintenance of his communication skills over time. Studies with HD rodent models (R6/2 mouse) have suggested that even minimal environmental enrichment may slow disease progression (Hockly et al., 2002). The notion of neuroplasticity and environmental enrichment associated with communication over time in HD deserves further exploration.

4.2. How the ICF framework contributed to the assessment and goal setting process

Assessment and goal setting in HD can be challenging. Although few communication assessments are designed or validated for people with HD, the ICF enabled more targeted, holistic assessment with available tests and qualitative interviews. Utilizing the ICF ensured we gave consideration to each ICF domain regardless of the specific assessments used, which may change depending on client level of functioning or clinician preference. The interviews provided unique information about activity and participation areas important to ER and support the claim (Klasner & Yorkston, 2001) that qualitative interviewing is a valuable method for determining participation-based intervention goals in HD.

Another important aspect of our evaluation was that the ICF encouraged more positive emphasis on functioning as well as disability and communication facilitators (Byrne & Orange, 2005). ER presented with communication impairments that were consistent with the HD literature. However, the modified CETI and structured interview explored his strengths. These revealed retained communication skills and insight that was important to acknowledge and document. Although insight can often be impaired in HD (Deckel & Morrison, 1996; Hoth et al., 2007), ER’s relatively intact insight was a crucial feature in engaging with clinicians and developing highly anticipatory treatment goals. The interviews also focused on ‘What can help?’ (through Facilitators or a reduction in Barriers), which encouraged ER and his mother to actively contribute to his communication goals and treatment options.

Most importantly, this case highlights the importance of specific examination of environmental and personal contributors to communication-based limitations and restrictions. Explicit consideration of barriers (and facilitators) in ER’s environment revealed that the strongest barriers to his participation was not his communication impairment but instead attitudes and levels of support from some of his family. Strained family relationships may be particularly present in some HD families (Keenan et al., 2007; Korer & Fitzsimmons, 1985) and may result in decreased communicative opportunities for the person with HD (Hartelius, Jonsson, Rickeberg, & Laakso, 2009). Although our previous assessment approach may have revealed this issue for ER, the ICF framework increased the weighting of environmental and personal factors as potential
some evidence suggests that a carer's coping style in HD often involves avoidance which makes future planning difficult. They had declined to talk about the future, it enabled staff to consider what anticipatory planning could be enacted. While Steiner et al. (2002) also allowed us to represent ER and his mother’s views on how they might engage with future treatment planning, or if they had declined to talk about the future, it enabled staff to consider what anticipatory planning could be enacted. While some evidence suggests that a carer’s coping style in HD often involves avoidance which makes future planning difficult (Lowit & van Teijlingen, 2005), ER’s case demonstrates this should not be a universal assumption. In relation to the ICF personal factors, ER’s case reinforces that while personal factors are mostly considered separate to the person’s disease/condition (Threats, 2007a), in HD and other hereditary diseases, the disease may still impact an individual’s personality. For ER, he described the disease as being ever present in his upbringing. Without him even demonstrating symptoms, HD impacted strongly on his personal coping style and attitudes due to the experience of living with his father and two siblings who had HD. Although not yet formally coded in the ICF, exploring and documenting personal factors allows for a greater understanding of the whole person.

Overall, the integration of the ICF framework and coding into our assessment and goal setting process enabled a more systematic and holistic examination of important areas. These were activities and participation for ER and his mother, the degree to which body function impairments and environmental factors contributed to limitations and restrictions, the personal expertise possessed by ER and his mother and the strategies that were key to developing his goals. An assessment that focused at the impairment and even activity level alone may not have resulted in the goals established by this ICF-based process.

4.3. Important issues for clinical applications of the ICF

Through this case study, we also identified some important issues in the implementation of an ICF-based approach to assessment and goal setting. The first issue related to the large scope and complexity of the ICF. Although we gradually increased our familiarity with the ICF, at first we found it to be overwhelming. Our experience reflects a common criticism from rehabilitation medicine (Stucki, Ewert, & Cieza, 2003) and speech-language pathology (Threats & Worrall, 2004), that the ICF is unwieldy in its original form. However, the strength of the ICF is the systematic consideration of a wide range of domains and this is particularly relevant for complex diseases such as HD. To assist clinical implementation, smaller core sets that limit classifications to specific conditions or contexts are in development for chronic conditions such as stroke (Cieza et al., 2004) and neurological conditions in post acute settings (Stier-Jarmer et al., 2005). While some neurodegenerative disease sets are in progress such as Multiple Sclerosis, none have been developed for HD.

The use of the modified RPS-Form (Steiner et al., 2002) was a resource that assisted with conceptualization of the major ICF components from multiple viewpoints. In the present study we used the form primarily as a systematic representation of multiple viewpoints of ER’s functioning and contextual factors. It enabled us to draw together our assessment findings in one document for the purposes of clinical problem solving in a way we had not done previously. Due to the density of information, we did not represent proposed causal mediators on the form with arrows as proposed by Steiner et al. (2002). Additionally, the ICF itself does not assist with prioritization of potential areas for intervention. Instead, we asked ER and his mother to confirm their key priorities and then discussed the range of facilitators and barriers identified by ER, his mother and staff. We then documented our conclusions separately into the goals identified above. Potentially, we could have also represented these specific findings on the form, or on three separate forms for each goal. Clinicians may find the form a helpful resource to mediate various stages of the assessment and goal-setting process in conjunction with clients and staff. The addition of the two time frames of ‘current’ and ‘future’ may be beneficial for speech-language pathologists working with people with degenerative disease and also people with chronic conditions such as dysarthria or aphasia, where future aspirations and concerns can be documented.

Our second issue was providing efficient, user-friendly access to the ICF framework and coding to establish collaborative treatment goals for ER and his mother. This is an essential ethical underpinning of the ICF (Threats, 2006) and mandated in Annex 6 of the ICF. We discussed contents of the RPS-Form with both ER and his mother and simplified ICF concepts and language to maximize access their access to the ICF. While both ER and his mother engaged in discussion regarding the general findings and interviews, they declined to participate in detailed discussion of the framework and coding. A number of other factors may have contributed to their level of engagement and access to the ICF. These include the inherent complexity of the ICF, our own developing knowledge of its language, ER’s language impairments and his mother’s geographical distance to the unit. Further consolidation of our ICF knowledge will assist with development of user-friendly client resources to support discussion of the ICF framework and coding in response to varying levels of engagement and interest.

The third issue was the complexity of the ICF coding system. Initially, the orientation to the codes and the implementation of coding was time-consuming. However, our coding became more efficient as our familiarity with the system improved. We achieved excellent levels of inter-rater reliability within chapters to the fourth level of coding between the independent contributors to ER’s disability and functioning. Additionally, the ICF coding more explicitly documented not only the presence of these factors but their relative degree of impact on activities and participation. This ensured the balance of impacts on ER’s communication was represented across impairment and contextual domains. However, the communicative impairment was relevant. ER, his mother and staff considered it a crucial future communication challenge as the disease progressed and his mild-moderate communication impairment was viewed as one of ER’s current strengths.

Although not yet formally coded in the ICF, exploring and documenting personal factors allows for a greater understanding of the whole person.
The ICF uses an alphanumeric coding system in which letters b, s, d and e denote body functions, body structures, activities and participation and environmental factors, respectively. Personal factors are not currently coded in the present version of the ICF. The letters are followed by a numeric code that starts with a chapter number (one digit), followed by a second level (two digits), and third and forth levels (one digit for each) allowing for increasing specification. Codes are neutral and require qualifiers to provide meaning. Generic qualifiers represent the extent or severity of the problem for impairment of structure or function, and activity limitations/participation restrictions for the person’s current functioning. This is represented with a decimal point after the category code with a score from $0 = \text{no problem}$, $1 = \text{mild problem}$, $2 = \text{moderate problem}$, $3 = \text{severe problem}$, $4 = \text{complete problem}$. Environmental factors can be coded as barriers or facilitators using the same 0–4 scale as above. Facilitators are noted with a ‘?’ sign and barriers are noted simply after a decimal point ‘.’ (Table 2).

Acknowledgements

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Appendix A. Outline of the ICF alphanumeric coding system

The ICF uses an alphanumeric coding system in which letters b, s, d and e denote body functions, body structures, activities and participation and environmental factors, respectively. Personal factors are not currently coded in the present version of the ICF. The letters are followed by a numeric code that starts with a chapter number (one digit), followed by a second level (two digit), and third and forth levels (one digit for each) allowing for increasing specification. Codes are neutral and require qualifiers to provide meaning. Generic qualifiers represent the extent or severity of the problem for impairment of structure or function, and activity limitations/participation restrictions for the person’s current functioning. This is represented with a decimal point after the category code with a score from $0 = \text{no problem}$, $1 = \text{mild problem}$, $2 = \text{moderate problem}$, $3 = \text{severe problem}$, $4 = \text{complete problem}$. Environmental factors can be coded as barriers or facilitators using the same 0–4 scale as above. Facilitators are noted with a ‘+’ sign and barriers are noted simply after a decimal point ‘.’ (Table 2).
<table>
<thead>
<tr>
<th>Example</th>
<th>ICF component</th>
<th>Letter</th>
<th>Level 1 (chapter level)</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
<th>Severity qualifier (0–4)</th>
<th>Final code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild difficulty understanding spoken language</td>
<td>Body functions</td>
<td>b</td>
<td>b1 mental functions of language</td>
<td>b167 mental functions of language</td>
<td>b1670 reception of spoken language</td>
<td>b16700.1</td>
<td>1</td>
<td>b16700.1</td>
</tr>
<tr>
<td>Moderate damage to parietal lobe of brain</td>
<td>Body structures</td>
<td>s</td>
<td>s1 structure of nervous system</td>
<td>s10 structure of brain</td>
<td>s1002 parietal lobe</td>
<td>s1002.2</td>
<td>2</td>
<td>s1002.2</td>
</tr>
<tr>
<td>Severe breakdown of child–parent relationship</td>
<td>Activities and participation</td>
<td>d</td>
<td>d7 interpersonal interactions and relationships</td>
<td>d7601 child-parent relationships</td>
<td>d7601.43</td>
<td>3</td>
<td>d7601.43</td>
<td></td>
</tr>
<tr>
<td>Absence of support of friends</td>
<td>Environmental factors</td>
<td>e</td>
<td>e3 support and relationships</td>
<td>e320 friends</td>
<td>e320.4</td>
<td>4</td>
<td>e320.4</td>
<td></td>
</tr>
</tbody>
</table>

Note: For activity and participation domains, the ICF provides a single domain list that may be applied differently by the user. In this study we used the same domains for both activity limitation and participation restrictions rather than attempting to designate some domains as activities and others as participation (Australian Institute of Health and Welfare, 2003).
Appendix B. Continuing education

1. In Huntington Disease physical, cognitive and psychiatric symptoms all may impact on the communication impairment.
   a. True
   b. False

2. In the current case, background noise was seen by ER’s mother as a greater barrier to understanding his speech on the phone, than ER’s own dysarthria.
   a. True
   b. False

3. In this study, the two independent raters achieved less than 80% agreement on the categorization of the ICF domains.
   a. True
   b. False

4. For ER, communication impairment was determined as the most important contributing factor to his participation restrictions.
   a. True
   b. False

5. The neuroplasticity principle of ‘use it or lose it’ was advanced by ER’s mother as a strategy to minimise communication decline.
   a. True
   b. False

References


