

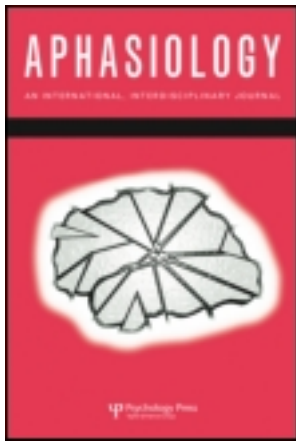
This article was downloaded by: [University of Western Ontario]

On: 31 October 2011, At: 13:06

Publisher: Psychology Press

Informa Ltd Registered in England and Wales Registered Number: 1072954

Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Aphasiology

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/paph20>

What people with aphasia want: Their goals according to the ICF

Linda Worrall^a, Sue Sherratt^b, Penny Rogers^a, Tami Howe^c,
Deborah Hersh^d, Alison Ferguson^e & Bronwyn Davidson^a

^a The University of Queensland, Brisbane, Australia

^b The University of Queensland, Brisbane, and the University of Newcastle, NSW, Australia

^c The University of Queensland, Brisbane, Australia, and the University of Canterbury, Christchurch, New Zealand

^d The University of Queensland, Brisbane, and Edith Cowan University, Perth, Australia

^e The University of Newcastle, Christchurch, New Zealand, and University of Queensland, Brisbane, Australia

Available online: 29 Nov 2010

To cite this article: Linda Worrall, Sue Sherratt, Penny Rogers, Tami Howe, Deborah Hersh, Alison Ferguson & Bronwyn Davidson (2011): What people with aphasia want: Their goals according to the ICF, *Aphasiology*, 25:3, 309-322

To link to this article: <http://dx.doi.org/10.1080/02687038.2010.508530>

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.tandfonline.com/page/terms-and-conditions>

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused

arising directly or indirectly in connection with or arising out of the use of this material.

What people with aphasia want: Their goals according to the ICF

Linda Worrall¹, Sue Sherratt², Penny Rogers¹, Tami Howe³, Deborah Hersh⁴, Alison Ferguson⁵, and Bronwyn Davidson¹

¹The University of Queensland, Brisbane, Australia

²The University of Queensland, Brisbane, and the University of Newcastle, NSW, Australia

³The University of Queensland, Brisbane, Australia, and the University of Canterbury, Christchurch, New Zealand

⁴The University of Queensland, Brisbane, and Edith Cowan University, Perth, Australia

⁵The University of Newcastle, Christchurch, New Zealand, and University of Queensland, Brisbane, Australia

Background: The goals of people with aphasia should guide service delivery. Services are increasingly influenced by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), but little is yet known about whether the goals of people with aphasia span the full spectrum of the ICF.

Aims: The purpose of this study was to describe the goals of people with aphasia and to code the goals according to the ICF.

Methods & Procedures: A qualitative descriptive research approach was used involving semi-structured in-depth interviews with 50 participants with aphasia post-stroke. Interviews were videotaped and transcribed verbatim and then analysed using qualitative content analysis. The goals of a 30% consecutive subsample were then coded using the ICF.

Outcomes & Results: Nine broad categories of goals were identified. Participants with aphasia wanted to return to their pre-stroke life and to communicate not only their basic needs but also their opinions. They also wanted information about aphasia, stroke, and available services; more speech therapy; greater autonomy; and dignity and respect. They identified the importance of engagement in social, leisure, and work activities as well as regaining their physical health. Interestingly, their goals included wanting to help others. Goals could be linked to all ICF components within the ICF, with the majority linked to Activities and Participation, followed by Environmental Factors, Body Functions and Structures, and Personal Factors.

Conclusions: People with aphasia in this study were able to articulate a wide range of goals post-stroke that encompassed all of the ICF components but had a particular focus on the Activity and Participation components.

Address correspondence to: Professor Linda Worrall, The University of Queensland, School of Health and Rehabilitation Sciences, QLD 4072, Australia. E-mail: l.worrall@uq.edu.au

We acknowledge funding from National Health & Medical Research Council (Project Grant #401532), the contribution of all participants in this study, and the UQ Aphasia Registry.

Keywords: Aphasia; Goals; Qualitative research; ICF; Health services needs and demand; Rehabilitation.

Goal setting is widely considered to be a pivotal aspect of the rehabilitative process (Bradley, Bogardus, Tinetti, & Inouye, 1999). Identifying the goals of individuals in rehabilitation allows meaningful and effective intervention to take place (McPherson & Siegert, 2007; Siegert & Taylor, 2004). Recent literature has highlighted the significance of including clients' views in rehabilitation (e.g., Barclay, 2002; Parr, Byng, Gilpin, & Ireland, 1997; Pound, Gompertz, & Shah, 1998; Simmons-Mackie & Damico, 1999), particularly in relation to goal setting, because it contributes to improved outcomes and increased quality of care (Parry, 2004; Wressle, Oberg, & Henriksson, 1999). However, Wressle et al. (1999) concluded that stroke patients do not often participate in the goal-setting process, hence there is often a mismatch of goals between the therapist and their client.

Within the stroke population more generally, qualitative research has recorded the human experience of stroke, identified needs as perceived by patients and their families, compared differences in priorities between patients and professionals, and determined barriers to best-quality care (McKevitt, Redfern, Mold, & Wolfe, 2004). Recent qualitative studies of patients' experiences of rehabilitation following stroke have highlighted a number of concerns and priorities, but these studies have rarely included participants with aphasia, particularly those with more severe language impairment. Recovery from physical impairments is often a priority as it may determine their return home (Bendz, 2000; Gibbon, 2004). Stroke studies have also identified a need for relevant information about stroke, its consequences, and health services at all stages of rehabilitation (Dixon, Thornton, & Young, 2007; Maclean, Pound, Wolfe, & Rudd, 2002; Mangset, Tor Erling, Forde, & Wyller, 2008; Roding, Lindstrom, Malm, & Ohman, 2003). Stroke patients have also emphasised the need for additional services, particularly to enhance their transitions across the rehabilitation continuum (Cameron, Tsoi, & Marsella, 2008). Finally, stroke patients' need for respect and dignity is related strongly to their satisfaction with rehabilitation (Mangset et al., 2008).

Goal setting with stroke patients with aphasia can be difficult: their language impairment naturally makes expressing their needs difficult, and discussing their experiences and needs can be a long and convoluted process for both the therapist and the client. This process may be compounded by cognitive capacity issues, particularly in the early stages post-stroke, although most people with aphasia should be viewed as competent partners in decision making about their needs (Kagan, 1998). Goal setting with people with aphasia may also be demanding because aphasia is a complicated and abstract concept to understand and most members of the public have not heard of the term "aphasia" (Flynn, Cumberland, & Marshall, 2009; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002) let alone understand the impact it can have on people's lives. Added to this are feelings of disempowerment when communication is impaired. Other factors that contribute to speech pathologists' difficulties in exploring the needs of people with aphasia and their families are that clients are often older and may expect to be directed in therapy rather than consulted, that the medical model setting may reinforce a culture in which speech pathologists focus on impairment, and that the professional values of the speech pathologists themselves may reinforce a belief in a curative role (Byng, Cairns, & Duchan, 2002).

Although goal setting with people with aphasia may not occur or be difficult within a busy clinical practice, it can be argued that the collated goals of a range of people with aphasia could guide aphasia rehabilitation services. In an effort to link the lived experience of aphasia to service improvements, the present study therefore aimed to uncover what people with aphasia wanted during the rehabilitation process, as well as their concerns and priorities at each stage. The goal-setting model of Bradley et al. (1999) provided the framework within which to conceptualise the expressed values and unmet needs of the participants, as well as their general and specific context-dependent goals; hence the term “goals” is used to encompass all of these concepts. Therefore the primary aim of this study was to gain an understanding of what people with aphasia want from aphasia services. While this study was Australia-based, its implications should be relevant to aphasia services in many parts of the world.

A further reason for examining the goals of people with aphasia has been the ongoing debate between impairment-based and functional approaches to aphasia rehabilitation (Martin, Thompson, & Worrall, 2008). Hillis, Worrall, and Thomson (2008) concluded that while the proponents of each approach have more in common than originally thought, where the approaches diverge is in how the proponents of each approach talk about treatment, how and what is assessed, how goals are formulated and prioritised, and what is measured to evaluate the effectiveness of therapy. Since a point of difference is about how goals are formulated and prioritised, this study gains the perspective of people with aphasia themselves so that they may contribute to the debate. To do this, the internationally recognised coding scheme of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation (WHO), 2001) was used to determine whether people with aphasia focus on impairment-based goals or whether they have goals related to the remaining components of the ICF.

METHOD

Study design

This qualitative descriptive study (Sandelowski, 2000), to gain an understanding of what people with aphasia want from aphasia services, involved semi-structured, in-depth interviews (DiCicco-Bloom & Crabtree, 2006) with 50 participants with aphasia (PWA) post-stroke. They were recruited through an aphasia registry, in addition to community contacts in three Australian cities. Supported conversation techniques (Kagan, 1998) were used to make the interviews accessible for people with aphasia.

The second stage of the study, to determine whether people with aphasia focus on impairment-based goals or whether they have goals related to the remaining components of the ICF, coded the goals of 30% of the sample according to the ICF.

Sample

Maximum variation sampling (Patton, 2002) was used in order to obtain major variations in the participants' experiences of rehabilitation services. Variation within the sample was sought for the characteristics of gender, age, time post-onset (<12 mpo; >12 mpo), and aphasia severity (Western Aphasia Battery Aphasia Quotient) (Kertesz, 1982). Individuals with other severe communication impairments (e.g.,

speech disorders such as dysarthria, cognitive impairments, hearing, or visual impairment) were excluded from the study and all participants had to be able to participate in an in-depth interview in English using speech, gesture, writing, pictures, and/or drawings. The first 15 consecutive participants recruited at one site (i.e., 30% of the total sample) constitute the subsample whose goals were coded according to the ICF.

Interviews

All interviews were conducted in the participants' homes by experienced speech pathologists trained in in-depth interviewing techniques with people with aphasia. Supported conversation techniques (Kagan, 1998) were used to facilitate the interaction. Family members were interviewed separately (their results will be reported in a separate publication), but, at the request of the participant with aphasia, were often present at the interview.

The interview schedule for the PWA included the following topics: (1) Their experiences of aphasia (e.g., *Tell me about when you first had aphasia*); (2) Their rehabilitation goals and needs (e.g., *When you first had your stroke what was important to you? What were your concerns? What did you want to work on in speech therapy? What were your goals?*); (3) Their aphasia rehabilitation and service experiences (e.g., *Did you work on these areas in speech therapy? If yes, how did you work on them? If no, what did you want to work on? Did speech therapy help?*); (4) Aphasia services they would have wanted (e.g., *What other services or things did you want at that time related to your aphasia?*). These topics were repeated for specified times after their stroke (e.g., when they first went home, when they had outpatient speech therapy, and at the time of the interview).

Analysis

All interviews were video recorded using a Sony digital video camcorder and transcribed verbatim based on the transcription conventions of Poland (2001). Qualitative content analysis (Graneheim & Lundman, 2004) was conducted to identify codes for the participants' goals and those codes with similar content were then merged into superordinate goal categories. NVivo qualitative data analysis software (QSR International Pty Ltd, 2006) and MS Word software programs were used to manage the data during analysis. Rigour was enhanced through peer checking and prolonged engagement with the participants (Mertens & McLaughlin, 2004).

The goals of the subsample were classified according to the ICF using the method proposed by Cieza and colleagues (2002, 2005). In addition to this method, six guidelines (presented in Table 1) were established to ease the process of linking items to the ICF, as well as to improve consistency between researchers prior to the reliability study taking place. To determine coding reliability, 30% of the sample was recoded 2–4 weeks after the original coding. While the intra-rater reliability (87.3% at the first level, and 81.0% at the second) met or exceeded the minimum acceptable level of 80% (Kazdin, 2003), the inter-rater reliability (65.5% at the first level of the ICF, and 57.0% at the second level) fell below this level.

TABLE 1
Coding guidelines

Rule number	Guidelines
1	Code to the level for which you have sufficient detail in the data to support your choice, rather than coding to a pre-determined level.
2	Wh: When coding, always code to the most precise ICF category.
3	Av: Avoid using the “nd” coding term (with the exception of the nd-gh, nd-ph, nd-mh, & nd-qol categories), instead, if a goal is not clear enough to be coded to an appropriate ICF category, exclude it from your coding process and note what concepts are not able to be coded.
4	If a: If a single goal contains many meaningful concepts, then code every meaningful concept to its appropriate ICF category, e.g., if wanted information from the health professional, then code information & health professional.
5	For personal factors that can also be coded within the Body Functions chapter of the ICF, code as a personal factor when applying to pre-morbid status and code within Body Functions chapter when applying to a person’s situation due to their health condition. eg. Pre-morbid confidence would be coded as a pf whereas confidence issues related to aphasia and communication post-stroke would be coded as b1226 Confidence.
6	When differentiating between the use of nd-gh (non-definable general health) and nd-ph (non-definable – physical health), use general health to describe factors pertaining to the overall condition of the person and physical health to describe consequences of a particular health condition or when relating to a particular body structure e.g., when aim is to “get better” code as nd-gh, when discussing “survival” code as nd-ph.

RESULTS

A total of 50 participants (24 males, 26 females; mean age 63.9 ± 10.8 years) with aphasia (mean duration 54.9 ± 43.6 months) were included in this study. The participants had a mean Western Aphasia Battery Aphasia Quotient (Kertesz, 1982) of 69.6 (± 24.2).

Qualitative analysis of interview data

Nine broad categories of goals were derived from the data. The nine categories described are a reflection of the prominence of the categories both in quantitative and qualitative terms. Qualitative research does not recommend frequency counts of codes and categories, however to provide a flavour of whether themes were prominent or not, we have inserted terms like “most” participants or “some” participants to provide some context for categories. Illustrative quotes from participants are provided in italics within parentheses to encapsulate the meaning in the participants’ own words.

Categories of goals

Return to pre-stroke life. Most participants expressed their desire to be normal again and to escape their current situation and return home to the security of their old life (e.g., *Just to be normal and enjoy life*). Their main priority was to be rid of the consequences of the stroke (e.g., . . . *the most important thing was to recover from it*). For some, this dominated the early period but appeared to change as they had to accept the reality of chronic disability; for others, the goal of a return to normality persisted.

Communication. All participants with aphasia naturally spoke of the importance of recovering their communicative function. They described intense feelings of frustration, hopelessness, isolation, and depression at not being able to talk. Many stressed that the aphasia was often of higher priority to them than their physical impairments (e.g., [Aphasia] *changes your life as much as your bad leg. MORE*), which contrasted with health care systems' focus on physical recovery (e.g., *They seemed to be with legs and arms but nothing with [points to mouth]*). They spoke in a general sense about their desire for communicative function (e.g., *The main thing was to be able to talk*), as well as more specifically (e.g., *I sitted down and read. I can't read, I can't read, I can't read. Help me. I can't*). They spoke about the range of their communication needs (e.g., communication for basic needs as well as communication to express their opinions (e.g., *No. Needs, yes, but talk. . . my [points to head], I want to talk is politics and religion*). They spoke about the need for communication rehabilitation to be connected to real life (e.g., *I wanted to know things, not talk about whatever I've done in the past. . . . What's happening out in the house [gestures outside], what goes on in the world*). Participants often mentioned specific words or names they wanted to say in real life (e.g., to say her child's name; *things [words]. . . what I needed after the speech pathologist left [the ward]*). They also spoke about how communication gave them confidence.

Information. One of the most commonly reported goals was that of obtaining information. Several people reported that they were apparently not told by their therapists, particularly in the early weeks or months, of the term used to describe their communication difficulty, and if the word "aphasia" was mentioned, it was rarely explained clearly. Even if they were told, their perception was that they were not, a finding that has significant implications for clinicians. Participants wanted information about aphasia and stroke for themselves and their family (e.g., *Once you've got a name for something, it's like you've got half the problem sorted. You can chase things and you can do things. You mightn't be able to cure it and everything else but you can understand it more*). They also wanted information about their prognosis and what to expect at different stages of rehabilitation. On a practical level they needed information about aphasia and stroke to access services and to explain their difficulties to friends or people in the community. In addition, having information allowed people to start taking control and to participate in decisions about their own therapy and their own rehabilitation. Some participants also wanted more information about their therapy (e.g., *She [outpatient speech pathologist] never had a plan. . . . What are your [the therapist's] goals? Never have any. . . An hour. . . This this this this. "Time's up. You're finished" . . . [therapist] may have had goals, but I didn't see them. . . Know the goals help you relate to the subjects*).

Speech therapy and other health services. Most participants wanted speech therapy that met their needs at different stages of recovery, that was relevant to their life (e.g., *I want to read, yes, yes but there I read, but they take those away and say "Do this" [gestures writing]. I threw it away. I threw it away, because it was so silly*), that was more frequent (e.g., *If I could have spoken and did 12 hours 12 hours a day I would have been for the whole 12 hours doing the whole lot*), and that continued for longer. They wanted positive relationships and interactions with their speech therapists and other health service providers (e.g., *it was very . . . hard for me and we didn't get on so I said well . . . "I'm not going back there because it's useless"*).

Control and independence. Goals in this category included wanting to get out of an institution to their home (e.g., *Coming home from hospital. . . that was one of the main things always on my mind*), or wanting to do things by or for themselves (e.g., *using the phone, getting their driving licence back, getting back to bible study classes, learning to use the buses*). Some expressed frustration at not being a part of the decision making in their care, seeking information from sources other than health professionals. Some took on home practice as a form of taking control and continued it for years after discharge.

Dignity and respect. Many people reported a feeling of being disempowered by their aphasia. They wanted respect, stating that they were competent people, despite their communication difficulties (e.g., *Upstairs, very smart. Downstairs, crap [pointing to his head and then his mouth]; It was really important that other people know that I wasn't stupid and that I was the same person that I was before*). They sought respect by highlighting their pre-morbid skills and accomplishments or the progress they had made (e.g., *I can still, I know how to fixing a bike*).

Social, leisure, and work. It was very common for people to have social goals, including to be able to converse with family, chat with friends, read a night time story to the grandchildren, and feel comfortable in a crowd (e.g., *It's communication with other people. . . in the sense that. . . just to be talking to a neighbour*). Social goals were characteristic of later stages of recovery (i.e., once people were home), but were also featured throughout their rehabilitation. Social ease and acceptance were very important goals. People with aphasia were upset by boredom and isolation. Younger people with aphasia were particularly aware of the loss of work and career and often held deep, strong desires to return to some employment. These people often became volunteers if they could not achieve their work goals.

Altruism and contribution to society. A few people spoke of goals related to improving the lives of others, including other people with aphasia (e.g., *I was a mentor. . . to people who had just had strokes. . . and that's the sort of thing I'd like to do*). Some participants devoted time to helping speech pathology students by being available for clinical placements, some volunteered in groups, and some wanted to increase people's awareness of aphasia.

Physical function and health. For many interviewees, physical recovery and general health goals were closely woven into the success of other kinds of goals. Hence, although the interview focused on goals related to aphasia, participants spoke of their goals on a broader sense. Many knew it was their physical improvements that would determine whether or not they could manage at home, and this often dominated rehabilitation. Once home, people's goals often included physical health, going for walks, keeping fit, going to the gym, and managing their weight, diabetes, or epilepsy (e.g., *To get . . . the use of my hands and legs back*).

ICF coding of goals

This study also aimed to determine how the goals were coded across the levels of the ICF. As demonstrated in Table 2, their goals were linked to the full biopsychosocial spectrum, although Activity and Participation goals figured most prominently.

Participants also spoke broadly about general non-specific physical health or general health goals; because the ICF covers this entire domain, these goals were coded as “non-definable goals of physical health and general health”. Some goals required the combination of two codes (as listed in Table 2) in order to accurately reflect their meaning.

TABLE 2
Goals of people with aphasia linked to ICF coding

<i>ICF Code</i>	<i>Category title</i>
<i>b</i>	<i>Body structures and functions</i>
b144	Memory functions
b152	Emotional functions
b1644	Insight
b220	Sensations associated with the eye and adjoining structures
b28010	Pain in head and neck
b320	Articulation functions
b4200	Increased blood pressure
b440	Respiration functions
b5105	Swallowing
b730	Muscle power functions
b7603	Supportive functions of arm or leg
s7501	Structure of lower leg
<i>d</i>	<i>Activities and participation</i>
d1	Learning and applying knowledge
d110	Watching
d115	Listening
d135	Rehearsing
d140	Learning to read
d145	Learning to write
d155	Acquiring skills
d166	Reading
d170	Writing
d210	Undertaking a task
d3	Communication
d310	Receiving – spoken messages
d3152	Receiving – drawings and photographs
d325	Receiving – written messages
d330	Speaking
d335	Producing nonverbal messages
d3350	Producing body language
d350	Conversation
d3600	Using telecommunication devices
d4	Mobility
d4103	Sitting
d445	Hand and arm use
d4500	Walking short distances
d450	Walking
d465	Moving around using equipment
d4750	Driving human-powered transportation
d4751	Driving motorised vehicles
d4702	Using public motorised transportation
d510	Washing oneself
d550	Eating
d570	Looking after one's health

(Continued)

TABLE 2
(Continued)

<i>ICF Code</i>	<i>Category title</i>
d5701	Managing diet and fitness
d6200	Shopping
d630	Preparing meals
d6600	Assisting others with self-care
d7	Interpersonal interactions and relationships
d730	Relating with strangers
d7500	Informal relationships with friends
d7502	Informal relationships with acquaintances
d760	Family relationships
d8	Major life areas
d830	Higher education
d850	Remunerative employment
d855	Non-remunerative employment
d860	Basic economic transactions
d865	Complex economic transactions
d870	Economic self-sufficiency
d9100	Informal associations
d920	Recreation and leisure
d9200	Play
d9201	Sports
d9202	Arts and culture
d9204	Hobbies
d9205	Socialising
<i>Environmental factors</i>	
<i>e1</i>	<i>Products and technology</i>
e1100	Food
e1150	General products and technology for personal use in daily living
e1200	General products and technology for personal indoor and outdoor mobility and transportation
e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation
e125	Products and technology for communication
e1250	General products and technology for communication
e1251	Assistive products and technology for communication
e130	Products and technology for education
e155	Design, construction and building products and technology of buildings for private use
e2200	Plants
e2500	Sound intensity
e3	Support and relationships
e310	Immediate family
e315	Extended family
e320	Friends
e325	Acquaintances, peers, colleagues, neighbours, and community members
e330	People in positions of authority
e340	Personal care providers and personal assistants
e345	Strangers
e355	Health professionals
e4	Attitudes
e555	Associations and organisational services, systems, and policies
e5550	Associations and organisational services

(Continued)

TABLE 2
(Continued)

<i>ICF Code</i>	<i>Category title</i>
e575	General social support services, systems and policies
e580	Health services, systems and policies
<i>pf</i>	<i>Personal factors</i>
nd – ph	Not definable – physical health
nd – gh	Not definable – general health
d166 & d330	Reading and speaking
d6200 & e140	Shopping, and products and technology for culture, recreation, and sport
d920 & e325	Recreation and leisure, and acquaintances, peers, colleagues, neighbours, and community members
e130 & e3	Products and technology for education, and communication
e130 & e580	Products and technology for education, and health services, systems, and policies

DISCUSSION AND CONCLUSIONS

Categories of goals

In summary, the rehabilitation experiences of participants with aphasia described nine broad categories of goals post-stroke. The priorities of return to pre-stroke life, communication, and physical function and health might be expected in the aftermath of stroke but the broader life goals in the areas of social life, work, and leisure, as well as altruism are not so well recognised in rehabilitation. The need for information about aphasia and stroke was also emphasised by participants in this study. These findings mirror those from the UK (Byng, Pound, & Hewitt, 2004) in that, while many participants spoke positively about the services they received, many spoke negatively about their experiences of health services, including speech pathology services. These results show similarities to studies of the experiences of stroke patients; however, with subtle yet important differences. Similar findings to stroke studies include the priorities of physical recovery, information, dignity and respect, and additional rehabilitation. Not unexpectedly, participants with aphasia also spoke of their communication priorities but, possibly due to the effect of aphasia on relationships, social, leisure, and work goals were also a major objective. The subtle differences in the narratives of people with aphasia in this study compared to the findings when stroke participants were interviewed reflect the widespread impact of a communication disability on relationships in particular and their consequent effect on social, leisure, and work goals.

The effect of aphasia on relationships was also shown by the importance of having positive relationships with speech therapists and their other health service providers. Impaired communication acts as a filter between the participant with aphasia and health professionals, blocking or hindering them from obtaining or accessing appropriate information and services. Therefore, during stroke rehabilitation, those patients with aphasia may be additionally disadvantaged and disempowered. A comparison of the rehabilitation experiences between aphasic and non-aphasic stroke patients may clarify this issue further. These findings encourage services to place the relationship between service provider and user at the centre of treatment.

ICF coding of goals

This study showed that the goals of people with aphasia link to levels across the ICF spectrum. Their goals could be related to all ICF components, with the majority linked to Activities and Participation, followed by Environmental Factors, Body Functions and Structures, and Personal Factors. More of their goals therefore focused on daily activities, community participation, and environmental factors than on body structures or functions. This suggests that the ICF coding system can capture all of the goals for people with aphasia. These results also add weight to Geyh et al. (2004) who have developed an ICF core set for stroke. Codes at the first and second level of classification identified in our study comprised 83.9% of Geyh et al.'s ICF core set for stroke. However, the results contrast to those of speech pathologists in subacute rehabilitation who targeted primarily levels of impairment and activity limitations with few explicit goals aimed at the level of participation (Leach, Cornwell, Fleming, & Haines, 2010).

Inter-coder reliability at the first and second levels of the ICF did not reach an acceptable level (Kazdin, 2003), suggesting that different clinicians are likely to code goals to the ICF in different ways. This may relate to how familiar the coder is with the context of the goal. The first coder transcribed the interviews, identified and then coded the goals; as such, their level of familiarity with the context was high. In contrast, the second coder was unfamiliar with the text and may not have had a thorough understanding of the context in which the goals were described, consequently coding them differently. Both coders referred to the ICF book, but were not officially trained in ICF coding as this training has not yet been made available, hence official ICF coding training may also assist with inter-rater reliability. The degree of mismatch occurred mostly in three chapters of Environmental Factors—health services, systems, and policies (e580), associations and organisations, services, systems, and policies (e355) and acquaintances, peers, colleagues, neighbours, and community members (e325). This may point to some ambiguity within these chapters. Also in general, goals were more reliability linked at the first level of the ICF rather than the more detailed second level. Accuracy of clinical coding may also be improved once the “Procedural Manual and Guide for the Standardized Use of the ICF: A Manual for Health Professionals” (see Threats, 2008) becomes available. In contrast, intra-coder reliability at level one and level two exceeded the acceptable level, indicating that linking of goals to the ICF can be achieved reliably by one coder over time.

The finding that people with aphasia have goals across the ICF spectrum confirms that the full spectrum of ICF components is important to people with aphasia. The preponderance of Activity and Participation level goals reflects the importance of everyday life activities and reinforces that people with aphasia do see these as a high priority. Hence, aphasia rehabilitation services that fail to target these (either directly or indirectly) are failing to address the major life priorities of clients. While individual participants had unique profiles of goals that would need to be accommodated in aphasia rehabilitation, services also need to be planned around the major components of the ICF. For example, environment factors, such as friendship, were mentioned by participants as goals. What services do speech pathologists provide to help people with aphasia maintain old friendships and develop new friendships throughout the continuum of care? Social isolation, anxiety, and depression are major sequelae of aphasia and have such an impact on wellbeing (Cruice, Worrall, Hickson, & Murison, 2003; Thomas & Lincoln, 2008). Therefore effective services to prevent such consequences (for example, friendship or social network programmes) may be one of the

most important contributions to achieving meaningful outcomes. The environmental coding (e3 – Support and Relationships) reinforces the importance of relationships to people with aphasia, with health professionals and health providers as well as with family, friends, and acquaintances. Aphasia services providers are therefore encouraged to consider the goals of people with aphasia described here and consider how they are responding to what people with aphasia want. Future publications from this large database will report on the goals of people with aphasia according to prominent parameters (time post onset, severity of aphasia, living situation, etc).

All participants in this study were able to articulate meaningful goals, given appropriate conversational support. Hence the goal-setting process described by Turner-Stokes (2009) and conceptualised by Scobbie, Wyke, and Dixon (2009) can be used with people with aphasia, but aphasia-friendly modifications (Aleligay, Worrall, & Rose, 2008; Howe, Worrall, & Hickson, 2005) may need to be routinely offered to these patients. As noted by Wade (2009), setting goals with patients and monitoring their achievement is a core practice in rehabilitation. When the medium of goal setting (communication) is impaired this practice becomes more difficult, hence occurs less frequently, and subsequently increases dissatisfaction with services. This cycle of marginalisation may be broken with strong relationship-centred, aphasia-friendly goal setting.

Manuscript received 2 March 2010

Manuscript accepted 12 July 2010

First published online 29 November 2010

REFERENCES

- Aleligay, A., Worrall, L. E., & Rose, T. A. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*, 22(4), 383–407.
- Barclay, L. (2002). Exploring the factors that influence the goal setting process for occupational therapy intervention with an individual with spinal cord injury. *Australian Occupational Therapy Journal*, 49, 3–13.
- Bendz, M. (2000). Rules of relevance after a stroke. *Social Science & Medicine*, 51(5), 713–723.
- Bradley, E. H., Bogardus, S. T. J., Tinetti, M. E., & Inouye, S. K. (1999). Goal-setting in clinical medicine. *Social Science and Medicine*, 49, 267–278.
- Byng, S., Cairns, D., & Duchan, J. (2002). Values in practice and practising values. *Journal of Communication Disorders*, 35, 89–106.
- Byng, S., Pound, C., & Hewitt, A. (2004). *Living with severe aphasia: The experience of communication impairment after stroke*. Brighton, UK: Pavilion Publishing (Brighton) Ltd.
- Cameron, J. I., Tsoi, C., & Marsella, A. (2008). Optimizing stroke systems of care by enhancing transitions across care environments. *Stroke*, 39(9), 2637–2643.
- Cieza, A., Brockow, T., Ewert, T., Amman, E., Kollerits, B., Chatterji, S., et al. (2002). Linking health-status measurements to the International Classification of Functioning, Disability and Health. *Journal of Rehabilitation Medicine*, 34(5), 205–210.
- Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., UstUn, B., & Stucki, G. (2005). ICF linking rules: An update based on lessons learned. *Journal of Rehabilitation Medicine*, 37(4), 212–218.
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, 17(4), 333–353.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40, 314–321.
- Dixon, G., Thornton, E. W., & Young, C. A. (2007). Perceptions of self-efficacy and rehabilitation among neurologically disabled adults. *Clinical Rehabilitation*, 21(3), 230–240.
- Flynn, L., Cumberland, A., & Marshall, J. (2009). Public knowledge about aphasia: A survey with comparative data. *Aphasiology*, 23(3), 393–401.

- Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., et al. (2004). ICF Core Sets for stroke. *Journal of Rehabilitation Medicine*, 36(4 suppl 44), 135–141.
- Gibbon, B. (2004). Service user involvement: Key contributors, goal setting and discharge home. *Journal of the Australasian Nurses' Rehabilitation Association*, 7(2), 8–12.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.
- Hillis, A. E., Worrall, L., & Thompson, C. K. (2008). The state of impairment- and consequences-based approaches to treatment for aphasia: Final commentary. In N. Martin, C. K. Thompson, & L. Worrall (Eds.), *Aphasia rehabilitation: The impairment and its consequences* (pp. 261–269). San Diego, CA: Plural Publishing Inc.
- Howe, T. J., Worrall, L., & Hickson, L. (2005). *The accessibility of community environments for adults with aphasia*. Paper presented at the Clinical Aphasiology Conference, Sanibel Island, FL.
- Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, 12(9), 816–830.
- Kazdin, A. E. (2003). *Research design in clinical psychology*. Boston: Allyn & Bacon.
- Kertesz, A. (1982). *Western Aphasia Battery*. New York: Grune & Stratton.
- Leach, E., Cornwell, P., Fleming, J., & Haines, T. (2010). Patient-centred goal setting in a sub-acute rehabilitation setting. *Disability and Rehabilitation*, 32(2), 159–172.
- Macleane, N., Pound, P., Wolfe, C., & Rudd, A. (2002). The concept of patient motivation: A qualitative analysis of stroke professionals' attitudes. *Stroke*, 33(2), 444–448.
- Mangset, M., Tor Erling, D., Forde, R., & Wyller, T. B. (2008). 'We're just sick people, nothing else': Factors contributing to elderly stroke patients' satisfaction with rehabilitation. *Clinical Rehabilitation*, 22(9), 825–835.
- Martin, N., Thompson, C., & Worrall, L. (Eds.). (2008). *Aphasia rehabilitation: The impairment and its consequences*. San Diego, CA: Plural Publishing.
- McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: A systematic review. *Stroke*, 35(6), 1499–1505.
- McPherson, K. M., & Siegert, R. J. (2007). Person-centred rehabilitation: Rhetoric or reality? *Disability & Rehabilitation*, 29(20), 1551–1554.
- Mertens, D. M., & McLaughlin, J. (2004). *Research and evaluation methods in special education*. Thousand Oaks, CA: Corwin Press.
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with loss of language after stroke*. Buckingham, UK: Open University Press.
- Parry, R. H. (2004). Communication during goal-setting in physiotherapy treatment sessions. *Clinical Rehabilitation*, 18, 668–682.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. St Paul, MN: Sage Publications, Inc.
- Poland, B. (2001). Transcription quality. In J. G. J. Holstein (Ed.), *Handbook of interview research: Context and method* (pp. 629–649). London: Sage Publications.
- Pound, P., Gompertz, P., & Shah, E. (1998). A patient-centred study of the consequences of stroke. *Clinical Rehabilitation*, 12, 255–264.
- QSR International Pty Ltd. (2006). *NVivo qualitative data analysis software (Version 7)*. Doncaster, Vic, Australia: QSR International Pty Ltd.
- Roding, J., Lindstrom, B., Malm, J., & Ohman, A. (2003). Frustrated and invisible: Younger stroke patients' experiences of the rehabilitation process. *Disability & Rehabilitation*, 25(15), 867.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340.
- Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation*, 23(4), 321–333.
- Siegert, R., & Taylor, W. (2004). Theoretical aspects of goal-setting and motivation in rehabilitation. *Disability & Rehabilitation*, 26(1), 1–8.
- Simmons-Mackie, N., Code, C., Armstrong, E., Stiegler, L., & Elman, R. J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, 16(8), 837–848.
- Simmons-Mackie, N., & Damico, J. S. (1999). Social role negotiation in aphasia therapy: Competence, incompetence, and conflict. In D. Kovarsky, J. Duchan, & M. Maxwell (Eds.), *Constructing (in)competence: Disabling evaluations in clinical and social interaction* (pp. 313–341). Mahwah, NJ: Lawrence Erlbaum Associates Inc.
- Thomas, S. A., & Lincoln, N. B. (2008). Predictors of emotional distress after stroke. *Stroke*, 39(4), 1240–1245.

- Threats, T. (2008). Use of the ICF for clinical practice in speech-language pathology, *International Journal of Speech-Language Pathology*, 10(1), 50–60.
- Turner-Stokes, L. (2009). Goal attainment scaling (GAS) in rehabilitation: A practical guide. *Clinical Rehabilitation*, 23(4), 362–370.
- Wade, D. (2009). Goal setting in rehabilitation: An overview of what, why and how. *Clinical Rehabilitation*, 23(4), 291–295.
- World Health Organisation (WHO). (2001). *International classification of functioning, disability and health (ICF)*. Geneva, Switzerland: World Health Organisation.
- World Health Organisation (WHO). (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: World Health Organisation.
- Wressle, E., Oberg, B., & Henriksson, C. (1999). The rehabilitation process for the geriatric stroke patient: An exploratory study of goal setting and interventions. *Disability and Rehabilitation*, 21(2), 80–87.