

# **Adjustment processes in chronic aphasia after stroke: Exploring multiple perspectives in the context of a community based intervention**

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## **Abstract**

### *Background*

The impact of chronic aphasia following stroke on quality of life (QOL) is widely acknowledged, with improved QOL recognised as an important outcome in aphasia recovery and supported by emerging quantitative measures. One of the key constructs recognised as contributing to QOL in other chronic conditions is psychosocial adjustment, the mechanisms of which are little understood for the person with aphasia.

### *Aims*

This study addressed adjustment processes in aphasia by exploring multiple perspectives from people engaged in the Communication Hub for Aphasia in North Tyneside (CHANT), a two year community intervention for long term aphasia. The study aimed to explore the adjustment process over time in people with aphasia using thematic analysis of personal narratives derived from a combination of sources: semi-structured interviews with reflections on experience, quantitative measures of change in QOL and self assessments of change.

### *Methods and Procedures*

Three people with mild or moderate chronic aphasia and three people without aphasia involved in CHANT were recruited (a carer, a volunteer, and a local government employee) to participate in semi-structured interviews at two to three month intervals over a 12 month

period. A total of 28 semi-structured interviews were transcribed and analysed thematically by a small team using NVivo8 software. Narrative data were interpreted within the broader context of QOL measures and self assessments of living with aphasia (Mumby and Whitworth, 2012).

#### *Outcomes and results*

Changes over time that reflected evidence of psychosocial adjustment from the multiple perspectives of the participants covered five core themes: *Intervention type, Effectiveness, Barriers, Facilitators, and QOL*. A model is proposed to encapsulate the barriers and facilitators that impacted on the process of adjustment and contributed to QOL for individuals involved in the intervention. This model is consistent with the domains from other classifications based on the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001), viewing adjustment as a progression towards 'wholeness'. The processes involved in personal (and specifically, emotional) adjustment to aphasia are explored, including three stages in rationalisation: Looking back, Looking around and Looking forward, and the process of transforming negative emotional reactions into positive outcomes.

#### *Conclusions*

The processes of adjustment in chronic aphasia are complex and vary both over time and according to individual perspectives and circumstances. This preliminary longitudinal study identified commonalities in participants engaged in long term intervention over 12 months, enabling models of adjustment to be proposed for further exploration and evaluation.

## **Background**

People with chronic aphasia following stroke clearly undergo processes of adjustment in living with this condition (see Gordon 1997, McClung, Gonzalez Rothi & Nadeau, 2010) and yet the broader studies of adjustment to stroke do not specifically address aphasia (McKevitt, Redfern, Mold & Wolfe, 2004). People with aphasia are often excluded from studies of stroke because of their communication difficulties (e.g. D'Alisa, Baudo, Mauro & Miscio, 2005; Daniel, Wolfe, Busch & McKevitt, 2009) preventing a deeper understanding of the adjustment processes with this population that would, in turn, inform longer term interventions. With aphasia evident in approximately a third of people who have a stroke (Engelter et al., 2006), this population is only likely to increase as people survive stroke more often and live longer with chronic disability (Code & Petheram, 2011). The commensurate shift in healthcare from acute care to long term recovery (UK, Care Quality Commission, 2011) will also demand a greater appreciation of the needs of people with long term conditions.

Evidence of difficulties associated with aphasia following stroke is robust. Hilari, Northcott, Roy and Marshall, (2010) found that the presence of aphasia three months post stroke increased the likelihood of high psychological distress by 8.73 times compared to when aphasia was not present. Hilari, Needle and Harrison's metanalysis (2012) also showed depression to be more frequent in people with aphasia compared with others with stroke. Reduced quality of life (QOL) has been reported in people with aphasia at six months post stroke compared to those without aphasia (Hilari, 2011), and QOL factors relating to level of independence, social relationships and the environment were shown to discriminate those with aphasia (at least 6 months post stroke) from those without aphasia (Ross & Wertz, 2003). In a study of 150 people with aphasia who had lived at home for at least three months since their stroke, Dalemans, de Witte, Beurskens, van den Heuvel and Wade (2010a) found that

aphasia severity had a unique negative effect on social participation. While these studies provide evidence of the impact of aphasia on long term recovery in terms of QOL and participation, it is unclear how people living with aphasia adjust to these particular challenges, especially in terms of longitudinal perspectives and change over time. Constructs such as QOL are primarily outcomes at a particular time, whereas adjustment concerns the process and mechanisms of change.

### ***Frameworks for understanding adjustment to aphasia***

Measures of linguistic and cognitive impairment in aphasia, while crucial within aphasia rehabilitation, frequently fail by their nature to encapsulate the broader issues related to living with aphasia, particularly when language recovery plateaus. Alternative assessments have therefore sought to investigate, in particular, QOL, drawing on such tools as the Burden of Stroke Scale (Doyle, McNeil & Hula, 2003), the aphasia-specific Stroke and Aphasia Quality of Life measure (SAQOL-39) (Hilari, Byng, Lamping & Smith, 2003) and the Assessment of Living with Aphasia (Kagan et al., 2010). In a study of 30 people with chronic aphasia (more than 12 months post stroke), Cruice, Worrall, Hickson & Murison (2003) found that communication assessments involving the domains of impairment, activity and participation (World Health Organisation, 2001) predicted the importance of psychological well-being and social health, and affirmed QOL as an important outcome measure requiring consideration in any investigation of adjustment to aphasia.

Qualitative methods are increasingly being employed in aphasia research (Damico, Simmons-Mackie, Oelschlaegers, Elman & Armstrong, 1999) to gain a more holistic view of impact of communication impairment from the perspectives of those living with aphasia. One approach increasingly being employed in this field involves the Aphasia Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008), a schematic representation of life with aphasia, drawing on the domains from the International Classification of Functioning,

Disability and Health (ICF) (World Health Organisation (WHO), 2001). Combining functioning and disability (body functions and structures, activities and participation) with contextual factors (environmental factors and personal factors), the A-FROM is designed to provide a framework for setting intervention goals and monitoring their course over time. Other frameworks have also been proposed for understanding the influences of extra-linguistic factors on outcomes for aphasia post stroke. McClung et al. (2010), for example, provided a clinician checklist based on ‘ambient factors’, such as ‘spirituality’, ‘leisure activities’ and ‘communication partners’, although the authors conceded that few of these factors, identified by speech-language pathologists as potential factors influencing language recovery, had been adequately studied. Code (2001) reported a multilevel model for considering recovery in aphasia, including emotional and psychosocial factors, but this has yet to be systematically supported by research evidence. Despite the recent attention to psychosocial factors in recovery, the need remains for a greater understanding of how people with aphasia adjust to impairment (‘coping with aphasia’, Hermann (1997) or ‘living with aphasia’, Kagan et al. (2008)). Whilst some of the factors in long term adjustment are accessible using quantitative measures (e.g. of QOL, depression), mixed methodologies are required to inform an understanding of the underlying adjustment processes.

### ***Insights from qualitative psychosocial studies of aphasia***

Qualitative studies attempting to conceptualise QOL for people with aphasia have highlighted the complexity of this construct, offering some key insights into factors that may be involved in adjustment. Cruice, Hill, Worrall and Hickson (2010) conducted structured interviews with 30 people with chronic aphasia, identifying ten factors to be considered in rehabilitation. The core factors in QOL, from the perspective of people with aphasia, included *activities, verbal communication, people and body functioning*, while other influences involved *health, stroke, mobility, home, independence and positive personal outlook*. These core factors contributed to

QOL both negatively and positively. Within the ICF (WHO, 2001) framework, however, while negative and positive aspects are identified for each of the domains of body function and structures, activities and participation, and barriers and facilitators identified within the environment, positive and negative aspects are termed 'not applicable' for the domain related to personal factors. Given Cruice et al.'s (2010) identification of positive personal outlook as an influential factor, and the importance of positive feelings identified by Ross and Wertz (2003), this suggests that personal factors may, as yet, be underexplored within the ICF framework.

Other studies relevant to the process of adjustment have addressed issues such as social participation and communication access. Dalemans, De Witte, Wade and van den Heuvel (2010b) investigated social participation from the perspective of 20 people with aphasia, at least six months post stroke, using diaries and interviews and found that people, while not explicitly using the concept of social participation, talked of engagement, involvement and belonging, and, moreover, placed greater importance on the quality of social activities than the amount of activity they took part in. Simmons-Mackie et al. (2007) explored the issues associated with communicative access from the perspective of staff teams involved in aphasia rehabilitation who participated in targeted training. A thematic analysis of observations, interviews and focus groups with participating staff identified barriers and facilitators to communication and decision making with people with aphasia and the need for system change, offering indications for future interventions.

Few studies address adjustment per se, though some shed light indirectly by looking at goal setting in people with aphasia (e.g. Worrall et al., 2011), or identifying how people experience 'living successfully with aphasia' (Brown, Worrall, Davidson & Howe, 2010). Worrall et al. classified goals taken from interviews with 50 people with aphasia according to the ICF components, finding nine broad categories, with most goals being linked to *Activities*

*and Participation*, followed by *Environmental Factors, Body Functions and Structures*, and *Personal Factors*. Similarly, in an interpretive thematic approach, Brown, Worrall, Davidson and Howe (2010) explored the ‘positive adaptive processes’ in long term aphasia, and identified the four core themes of *doing things, meaningful relationships, striving for a positive way of life*, and *communication*. These studies each explored factors relating to QOL at one point in time rather than tracing the processes of adjustment.

In exploring QOL, the perceptions and needs of carers living with aphasia also need to be acknowledged (National Clinical Guidelines for Stroke, Royal College of Physicians, 2008; McKeivitt, Redfern Mold & Wolfe, 2004). Pound, Parr and Duchan (2001) used guided interviews prior to, during and six months after a six week intervention with four carers of people with aphasia and identified key issues related to social relationships, confidence and identity, charting an ‘up and down’ journey’ (p491) rather than a linear path in relation to initial goals. Specific adjustment processes were identified in a study of paid carers during the acute phase of rehabilitation, (Sundin, Norberg & Jansson, 2001) namely: ‘*calling forth responsibility through fragility*’, ‘*restoring the patient’s dignity*’ and ‘*being in a state of understanding*’; their application to other types of carers, however, and with chronic aphasia is unknown.

### ***Exploring adjustment as change over time***

To understand adjustment requires longitudinal studies of participants with chronic aphasia. However, even those studies that do follow participants over time (e.g. using multiple interviews with a single case, Barrow, 2008) have tended not to focus on the mechanisms underlying change. In one of the few longitudinal group studies looking at change in chronic aphasia and focussing on QOL issues, Van der Gaag, et al. (2005) combined quantitative and qualitative measures in investigating people attending an aphasia therapy centre over a six month period. Measures of QOL (SAQOL-39, Hilari et al. 2003) showed significant

improvement in the communication domain, though not overall. Qualitative interviews scheduled at 'baseline' indicated dominant themes around a sense of loss, and at 'follow-up' showed improvements in confidence and independence and a desire to participate, however the mechanisms involved in the changes over time were not explored in this study.

Similar positive evidence of change has been seen in other studies with some attempts to unpack some of the broader concepts. Hoen, Thelander and Worsley (1997) measured change in the psychological well-being of 35 people with chronic aphasia and their families after engaging with a six month community based intervention using a reduced version of Ryff's psychological well-being scale (Ryff, 1989). Hoen et al. found improvements in self-acceptance, purpose in life and personal growth in the people with aphasia, as well as improved autonomy and environmental mastery. Social support, in the form of social companionship and informational support, has also been shown to be positively associated with QOL in people with chronic aphasia (Hilari & Northcott, 2006). Studies of volunteering by people with aphasia (Pearl, Sage & Young, 2011) and of vocational and work activities (Hinckley, 2002; Morris, Franklin and Menger, 2011) further highlight ways in which peoples' increased social participation relates to improving life with aphasia, acknowledging 'coping' and 'changing'. In such studies, QOL and adjustment tend to be discussed together, though the former is regarded here as a state and the latter a process.

Personal adjustment has received less attention in recent literature, although Brumfitt (1993) identified that an important consequence of aphasia is losing a sense of self. Tanner and Gerstenberger (1988) proposed that the grief response (a model initially developed by Kubler-Ross (1969) for characterising bereavement) be applied to neuropathologies of speech and language, including aphasia, to account for dimensions of loss within relationships, self and the environment. Gainotti's (1997) review of emotional psychological and psychosocial problems in aphasia considered this grief model (a progression from denial, through feelings



of anger and frustration, to what Tanner and Gestenberger term 'depression' and, providing that the depression was not 'pathological', finally to acceptance). Gainotti concluded that the grief model accounted for emotional and behavioural changes in some but not all personality types. Evidence is still needed concerning whether people with aphasia progress through the proposed stages of denial, frustration, and depression to acceptance (Code Hemsley & Hermann, 1999).

Adjustment to other types of chronic disability has been reported to involve spirituality (do Rozario, 1997). In her exploration of wholeness and reconstitution in coming to terms with disability and chronic illness, Rozario (1997) identified five key factors, namely *spiritual transformation, hope, personal control, positive social supports* and *meaningful engagement in life*. McClung et al. (2010) also identified spirituality amongst their 'ambient factors' impacting on aphasia but this area of adjustment, along with other aspects of personal adjustment, has not been studied.

In summary, increased insight into the nature of QOL in people with aphasia has yet to be underpinned by an understanding of the adjustment processes occurring over time in chronic aphasia, and how people both re-engage in participation and come to terms with personal factors. The current study is an exploration of living with aphasia within the context of a two year project called CHANT (Communication Hub for Aphasia in North Tyneside), funded by a local authority in north east England as a partnership with the speech and language therapy (SLT) service and the Stroke Association to provide support to people living in the community with long-term aphasia following stroke. Mumby and Whitworth (2012) have previously described the effectiveness of the CHANT intervention in helping people to live with long term aphasia, identifying which aspects of the intervention underpinned this success, and uncovering barriers and facilitators in relation to QOL. The current study extends the investigation by exploring the processes in adjustment to aphasia over time.

## Methods

The study was carried out over a twelve-month period within the CHANT intervention (summarised below) using a systematic interpretive approach (Attride- Stirling, 2001). Thematic analysis addressed the experience of taking part in the aphasia intervention to explore the processes of adjustment over time that, as suggested by Green and Britten (1998), are not captured by the numerical measures alone. Personal narratives were derived from five semi-structured interviews per participant over a 12 month period, mapping their engagement with aspects of the intervention, and thematic (interpretive) analysis was used to explore themes arising from the data longitudinally. Quantitative measures were also taken to provide contextual information about the participants in CHANT, the nature of their aphasia, their quality of life, and change over time within domains corresponding to the ICF. The CHANT intervention included (a) direct tailored support to people with aphasia following stroke and their carers, and (b) indirect support via awareness-raising and the provision of training within the local community. The group measures are reported in depth elsewhere (Mumby & Whitworth, 2012), including a more detailed description of the CHANT intervention. The current paper explores the experience of a purposive sample of participants in the intervention, in the context of their respective measures.

### *Participants*

All people with aphasia joining CHANT (59 participants in total), were approached to take part in the broader evaluation of the intervention (Mumby & Whitworth, 2012). No participants recruited to the study were receiving additional impairment-based therapy. Purposive sampling was used to select three of these participants at the time of initial assessment to take part in semi-structured interviews to maximise diversity across the sample of personal characteristics (e.g. gender, age, occupation), potential experiences and communication needs (see parameters in Table 1). The participants were more than one year

post stroke (range 13-52 months). Aphasia severity was rated in consultation with the referring therapist using previous assessments where available. People with severe aphasia or severe hearing loss were excluded as their level of impairment may have restricted their ability to converse sufficiently within interviews. After his second interview, one person with aphasia (PWA1) died and a further participant was recruited to preserve the diversity of characteristics (PWA4) and offer his perspective in the remaining interviews. Details are also provided in Table 1 for the husband (with aphasia) of the carer who participated in the interviews (see below).

(Table 1 about here)

In addition to the people with aphasia, three people without aphasia representing different roles were recruited at the outset of their involvement with CHANT to take part in interviews: one carer of a person with aphasia (selected by the CHANT SLT and the referring therapist), one volunteer from the Stroke Association (recommended by the Stroke Association Communication Support Coordinator) and one Local Council employee (recommended by the Council lead for the CHANT Steering group) (see Table 2). Bias was reduced by early recruitment of the interview participants during the launch phase of the programme to ensure no prior knowledge of satisfaction and outcome.

(Table 2 about here)

### ***Interview protocol***

The rigour of the data collection was maximised by using independent interviewers using a guided protocol. Six graduate students in their final year of SLT training were recruited and trained in ‘total communication’ techniques (Byng, Swinburn & Pound, 2001) and

administering the semi-structured interview protocol (key questions from which are shown in Appendix A).

Each participant was interviewed by the same interviewer throughout the study so that interviews could build on each other. Before each interview, participants were put at their ease and given access to the content of any previous interviews (via a written transcript and brief discussion). From within about an hour of contact time, video recordings were made lasting approximately 10-15 minutes, to contain the main content of the interview for later transcription and analysis (but exclude the introductory recap and preliminary exploration, and the closing practical remarks). A choice of location was given to each participant for the interviews (e.g. home, the university, NHS premises or their workplace). Orthographic transcriptions of the recordings were made, supplemented by descriptions of gestures, facial expression and intonation contour to disambiguate the text.

### ***Thematic Analysis***

The transcriptions were analysed to derive thematic networks (Attride-Stirling, 2001) within NVivo8 software. Interview data were coded in themes related via hierarchical tree structures. The rigour of the analysis was enhanced by involving a small team of experienced analysts, including two members with no professional knowledge about aphasia who brought new insights to the reflective process. The majority of the analysis was carried out by the primary investigator who was involved in the intervention delivery as part of the necessary ‘immersion’ in the process (Simmons-Mackie & Damico, 1999), acknowledged as a potential source of bias and anchored by the team approach.

The coding of the interview transcripts was guided by the general aim of exploring the experience of the intervention with reference to aphasia, and to see whether factors emerged that had an impact on QOL in terms of barriers and facilitators. The longitudinal design enabled maximum opportunity to identify change over time concerning adjustment. Themes

were identified early in the data collection process with an emphasis on letting the themes emerge from the data rather than imposing pre-existing models.

As the interview data were built up, the data set was sent back and forth between team members to corroborate or amend the themes and thematic structure. The team members also met for group discussion and reflection on the data analysis. Once all the interviews had been imported and coding reached saturation, queries were run using the software to explore the relationship between key themes according to their sources and over time. Matrix coding queries were used to cross-map a number of themes simultaneously, and the processes and models discussed and developed.

The thematic analysis evolved from all interview data (28 interviews were completed) in the context of information about the CHANT intervention and the quantitative measures. The adjustment processes for the participants with aphasia were retraced within the analysis, once the themes had been established, to explore and capture the mechanisms within their personal narratives. Perspectives from the other participants in CHANT were also interpreted separately from those with aphasia.

## **Results**

The results reported here focus on processes of adjustment to aphasia. Quantitative measures reflecting improved QOL, self-assessment and goal attainment scores for the people with aphasia (including the husband of the carer) provide additional context and are reported in Appendix B. In reporting the thematic analysis, the variety seen in the personal narratives is discussed initially, followed by an outline of the core themes arising from the interviews, leading to an exploration of the underlying processes and novel frameworks proposed to accommodate these.

*Personal narratives*

Each participant interviewed had a different 'journey' through the CHANT intervention depending on their role, needs and choices. Participants engaged with the intervention via a sequence of activities, and the interviews captured their experience at discreet points in that journey (see Appendix C, and Appendix D for a summary for each participant with aphasia). Coherent pathways were identified for participants with aphasia, seen in (a), exploratory contact and groups progressing to targeted intervention via goals and interests (b) specifically tailored activity progressing to mainstream activity, and (c) dependency on help progressing to self-help. Each pathway could be seen to reflect adjustment, aspects of which will be explored in more detail later. People without aphasia also experienced a form of adjustment to aphasia according to their own personal situation, although the narratives were different from those with aphasia both in terms of processes and intensity. For example, the volunteer narrative revealed her increasing awareness and understanding of aphasia and, through provision of work experience, increasing self-confidence and skills. The council worker shared how she had modified her practices around aphasia, adjusting both the priority given to people with aphasia in her work her behaviour outside work. Finally, the carer focused on the impact of aphasia on her and the family, and the shift in reactions and strategies over time.

The processes underlying participant experiences throughout intervention were complex in nature, being derived in part from direct reflection by the participants, in part from observing others and shared experience, and overall from a synthesis of multiple narratives. These processes were considered to relate to adjustment rather than recovery as participants with aphasia had chronic impairments that were no longer being addressed by rehabilitation services, while participants without aphasia experienced their own adjustment from a different perspective. All participants were observers of others' adjustment. The main focus in

reporting the findings is the accounts of people with aphasia, although the thematic network was derived from all the participants.

### ***Core themes and subthemes***

Five core themes emerging from the thematic analysis structured the more detailed exploration of the experience of participants longitudinally in relation to the process of adjustment to aphasia. These included *intervention type*, *effectiveness*, *barriers*, *facilitators* and *QOL*. Mumby and Whitworth (2012) previously explored perceptions of the intervention by focusing upon *effectiveness* in terms of *intervention type*. The current paper explores the three other core themes in more depth, looking at *barriers* and *facilitators* in the context of the intervention, and relating these to the experience of living with aphasia and *QOL*. The account of adjustment processes was reached by reflecting on how the main subthemes reflect change over time, cross referencing them with coding of the core themes.

As improved QOL may be considered the primary outcome of positive adjustment to chronic aphasia, the core theme of *QOL* provided the main focus for the analysis. According to its subthemes, *QOL* is derived from *participation*, *a sense of worth*, and degree of *adjustment* (see thematic structure in Appendix E). The narratives highlighted that, in terms of *participation*, the amount of participation in activities was less crucial than the degree to which participation was achieved with a sense of worth. *Sense of worth* was an overarching theme, encapsulating subthemes that had personal, social and environmental aspects. This concept included a sense of self (knowing and being known) and a sense of purpose (where activity had personal, religious or community meaning) and was encouraged by peer support. The two themes of *participation* and *sense of worth* were integral to the consideration of *QOL* in terms of adjustment processes.

The barriers to achieving QOL fell into several distinct categories: barriers to a *sense of worth* were mainly personal, barriers to *participation* were mainly social, and barriers to

*adjustment* were multi-faceted. The underlying adjustment processes will be described below, specifically in terms of facilitators overcoming barriers and of personal and emotional adjustment.

### ***Overcoming barriers via facilitators***

Overcoming barriers emerged as one of the main processes in adjustment to aphasia. The barriers and facilitators generally aligned with particular types of intervention activity and the domains from the ICF and the A-FROM, shown in Table 3 supported by direct quotations from participants.

(Table 3 about here)

There were five main barriers to quality of life with aphasia, i.e., impairment, internal emotions, isolation, inaccessible systems and ignorance, the first four of which can be related primarily to domains in the ICF and the A-FROM, with some overlap, and the last one implicating all the domains.

### ***Overcoming impairment (ICF: Body functions & structures/Severity of Aphasia)***

*Impairment* was the most frequent of the barriers emerging within the narratives, with the *development of strategies* being the key facilitator. Participants, all with chronic aphasia, still hoped for improvement in their aphasia and talked of ‘getting better’ despite little or no change in their aphasia severity during the intervention period (intervention was not designed to address impairment). This frequently resulted in a tension between accepting impairment and hope. Moreover, the participants identified benefits in ‘getting around’ impairment, such as setting compensatory goals in the “What Next?” groups, and practising new strategies in both ‘safe’ environments and with others with aphasia (peer support and sheltered courses).



The development of internal strategies for coming to terms with impairment will be discussed in relation to internal emotional barriers (see below). In summary, adjustment to impairment was reflected in finding and adopting compensatory activity.

***Overcoming internal emotional barriers (ICF: Personal factors)***

As raised earlier, barriers and facilitators are stated as ‘not applicable’ for personal factors within the ICF (WHO, 2001) as these are cast in terms of the environment. Analysis of the interviews, however, showed that some barriers originated from within the person rather than from the environment, forming part of the adjustment process. The narratives highlighted particular emotional reactions emerging during the post-stroke journey, both negative and positive (coded within the theme *QOL* in the subtheme of *adjustment*). According to models of grief, negative emotions are to be expected as part of the process of moving forward but, as seen in the narratives, also have the potential to limit progress if they are too dominant and act as barriers. The evidence from the narratives suggested that the adjustment processes involved an emotional shift from negative to more positive emotions, in relation to transforming the *sense of self* and *acceptance*. This shift will be explored further below under personal and emotional adjustment.

***Overcoming isolation (ICF: Relationships, activity & participation)***

Participants with aphasia expressed concern about others with aphasia being isolated, having experienced this themselves. The key facilitator was the *provision of help* in the form of personal contact through volunteer support and tailored programs of activity agreed with people with aphasia and carers to increase participation in community life. Personal involvement and relationships built up over time were viewed as the key to overcoming isolation rather than simply ‘getting out (of the house)’, and this aspect was linked with a developing *sense of self* (part of *QOL*). The importance of quality rather than quantity of

participation was stressed by the people with aphasia. The adjustment processes therefore involved supported social reintegration, with increased participation in the activities of everyday life.

***Overcoming inaccessible systems (ICF: Environmental factors)***

The barriers raised by existing systems within services (e.g. requiring people to make telephone or email contact rather than personal contact) restricted the ability of people with aphasia to access services and local facilities. Public transport was highlighted as an example where reduced access for people with aphasia often occurred (e.g. due to difficulties with numbers, timetables, completing forms, or asking for a destination), made more difficult by co-existing physical impairment or when confronted with negative attitudes of others. Facilitators were aimed at both raising awareness within organizations to bring about improved access and empowering people with aphasia to campaign for recognition and change. The adjustment processes therefore concerned increasing independence (linked with the personal processes of increasing confidence and self-determination), trying ‘new things’, and ultimately modifying environments.

***Overcoming ignorance (impact in all ICF domains)***

Ignorance about aphasia was identified as a key barrier for people with aphasia, having an impact in all domains. The process of overcoming this barrier was two-fold: (a) facilitatory activity (from within the intervention or from the participant) for *raising awareness* and (b) a subsequent positive response from those concerned, resulting in increased insight.

Information could be presented but still ignored:

PWA2: *I went into the police station and I didn't have a drink for two days right*

R: *Hm*

PWA2: *And they say's 'you're drunk'.*

R: *Ohh.*

PWA2: *And I says 'I'm not drunk' and it was a Saturday afternoon, Saturday 2 o'clock afternoon.*

R: *Hmm*

PWA2: *I says 'I'm not drunk', you know, you get people come in here at 2 o'clock in the morning [unintelligible] you know and em, I got me stroke card out and they says 'I don't care if you've had a stroke' and I got me aphasia card out as well [gestures putting card down on table].*

Raising awareness was not confined to those without aphasia (such as volunteers and staff in other organizations) but was reported as necessary for both those with aphasia and their carers. The overarching facilitator of *raising awareness* was reported to act in parallel with the other facilitators in overcoming barriers. People with aphasia valued personalised information about the condition and signposting to sources of help and resources. Equipping them with knowledge about aphasia was part of the process of empowerment (also identified as a facilitator, see Table 3).

All participants were empowered through increased awareness to make changes to their and others' behaviour. Participants with aphasia reported moving towards a greater acceptance of life with aphasia, and those without aphasia reported developing greater tolerance of aphasia in perceptions and activities ('patience', in the words of the carer). People with aphasia who initially reported dependence on the facilitators of *help and support*, later emphasized greater independence through *developing strategies* and *sharing experience*, progressing towards helping to facilitate recovery for others.

### ***A model for overcoming barriers***

A synthesis of the processes of overcoming barriers in adjustment is proposed in Figure 1 below. The barriers have been cast as the dotted lines between the domains on the A-FROM,

and as these are overcome, the domains coalesce giving rise to integration or 'wholeness' (the A-FROM in its original conception does not specify the degree of integration of domains, but acknowledges overlap rather than wholeness). Drawing on Egnew's (2005) concept of wholeness, illness (in this case, the aphasia) may be viewed as a 'threat to wholeness...and involves the physical, social, psychological and spiritual dimensions of personhood' (p259). Further, being whole again is 'to be in relationship to yourself, is to be in relationship to your body, to the culture and significant others' (p257) and is not dependent on cure or physical health.

(Figure 1 about here)

### ***Personal and emotional adjustment***

Personal factors which have the potential to become barriers in adjustment to aphasia were briefly outlined above, with reference to negative emotional reactions. A more in-depth account of personal and emotional adjustment follows, based primarily on the interview evidence from the people with aphasia.

Tanner and Gerstenberger's (1988) application of the grief model proposed that adjustment to impairment such as aphasia involved the stages of denial, frustration, and depression, progressing to acceptance. Evidence from the narratives aligned partially to this model, but showed additional processes, specifically concerning adjustment to the ongoing *loss* associated with aphasia, including restricted independence, also relating to *physical loss*. All participants talked about loss in terms of impairment but there were also descriptions of loss in personal terms.

PWA3: *Hmhm. Well you can't, it's different altogether. You know, you feel a different person altogether [gesture to self].*

Moreover, there were losses in terms of participation described by all participants, and less prominent but still present, reference to loss in terms of the wider environment. The sense of loss concerned all aspects of life. For example, when questioned about what it is like living with aphasia in her first interview, PWA3 responded: *[laugh] Start with this [gestures everything][laughs]*.

The view that aphasia adversely affects all aspects of life was reported by the participants without aphasia, a kind of ‘fragmentation’ in opposition to the movement towards ‘wholeness’ as shown in Figure 1. This fragmentation was described by PWA2 as a lack of coherence in his everyday functioning *‘I want to work, to be perfectly honest with you but I’m kind of (.)I’m just getting through the summer... Ah man, you just. I cannot’... ‘I get frustrated I cannot explain things, or worry I cannot explain things’*, and by the carer as a breakdown in relationships *‘But (-) a baby (-) a child progresses where (-) when you’ve got aphasia you go(-) it takes longer and you don’t get (-) back to where you were before’..... ‘I just get on with it’*. Some fragmentation concerned the variability and unpredictability of aphasia and the continued need to readjust, in the words of PWA4, *‘everything is changing all the time’*. The model encapsulated in Figure 1 proposes that adjustment involves resolution of such fragmentation by re-forging links between different aspects of life.

## **Emotional factors**

As well as concerning physical, personal and inter-personal loss, adjustment also involved *emotional reactions* in relation to *loss*. (These excluded those emotional changes that are the specific sequelae of stroke such as lability (Code et al. 1999), described as a separate issue by the participants with aphasia). Within the interviews, most references to negative emotional reactions concerned *fear* (direct references to *fear*, and the related themes of *worry* and *anxiety*) and *anger* (with its more extreme form, *rage*, as well as more muted *annoyance* and *frustration*). Most references to *anger* included the term ‘frustration’, the term

used in the grief model, and the theme of *fear* was very closely linked with subthemes about *uncertainty* (especially about the future) and *vulnerability*.

There were minimal explicit references to *denial*, possibly due to the participants in the study not being in early stages of adjustment to aphasia, although it was still present. Interestingly, *denial* (involving restricted awareness, or choosing to ignore issues) continued to evolve alongside the other emotional reactions within participants during the course of the study. The earlier interviews and the participant reflections about their own or other's recovery sequence also provided illustrations of *denial* as it related to fear or anger. For example, *denial* was manifested as disengagement, withdrawal or avoidance as a means of coping with the fear of social contact (e.g. PWA3 was very reticent to go to groups) or coping with the loss of skills by avoiding situations requiring these (e.g. PWA2 initially identified multiple reasons for not using written language). *Denial* was also manifested as over-preoccupation, rigidity or misdirected activity (which may be aligned with anger) to avoid positive adjustment, observed by the participants in others who refused to modify their own behaviour.

Reducing *denial* was linked with the subtheme of *raising awareness* (see above, overcoming barriers). The interviews suggested that in the process of adjustment to aphasia, the participants progressed from the negative emotional states and reactions (primarily *fear* and *anger*), to more positive ones (themes of *humour*, *expressing relief*, *motivation* and *determination* being well developed). The progression included a variety of positive outcomes (themes of *increased independence*, *enjoyment*, *hope*, *looking to the future and aspirations*, *openness and understanding (of others)*, *finding a sense of worth*, and *crusade*) coinciding with increasing *acceptance*. Unlike the grief model, there was no specific reference to depression in the interviews as a precursor to acceptance.

The narratives from the people with aphasia showed shifting emotional emphases, starting from negative reactions such as *fear* and *anger*. For example, looking specifically at *fear* (and *anxiety*), PWA3's thematic sequence may be summarised as follows (shown with the corresponding interview number containing references in brackets) with expressions of fear throughout but more positive emotional reactions increasingly voiced:

*Fear* (1-4) → *Tearfulness* (1) → *Verbalization & rationalization* (2,3) → *Enjoyment, Hope & Increased independence* (3,4)

Initially, PWA3 was openly tearful when discussing how the aphasia had stopped her being active: PWA3: (-) *Well just everything really (-) [big sigh, teary]. I find it difficult to meet people.* She emphasized verbalizing her fear and anxiety (Interview 2 and 3), particularly about communication and going out, and later rationalized some of her problems in terms of normal ageing. She was proud about her achievements in the Art exhibition (Interview 3: '*a little bit heaven*'), and hopeful at being '*a little bit better*' (Interview 3) and '*a long time yet... each time a bit more*' (Interview 4). In the final interview, she reported a little more positive but found it hard to maintain this positivity because of repeated setbacks related to ill health, having the potential to lead her back into fear and anxiety. This type of sequence was borne out in other participants. For example, PWA2 revealed his fears changing (from aversion to the telephone, to fear of social contacts, to fear of large gatherings) and resolving as evidenced in the following stages in successive interviews:

*Fear* (1,2) → *Verbalization, Increased independence* (2,3) → *Enjoyment, Looking to the future* (4, 5)

The theme of *anger* (or *frustration*) was also traced in the participants over time. For example, in PWA2 the emphasis followed the following sequence:

*Frustration* (1,2) → *Humour* (3) → *Channelling drives/Attribution of blame* (4) → *Crusade* (4)

Frustration for PWA2 concerned his inability to work as a head chef, difficulty getting words out (Interview 1), and at fatigue after talking (Interview 2). By Interview 3, he was using humour to divert some of his frustration, and by Interview 4 he was showing greater interest in the experiences of others, diverting some of his anger into concern for what was happening to others with aphasia, blaming ignorance from communication partners (*'I could have killed her'* (Interview 4) and being determined to set things right, the theme of *crusade* being found alongside references to *acceptance* and *self worth*.

The progression towards positive emotions and outcomes aligned with the 'positive personal outlook' identified by Cruice et al. (2010),

PWA2: *Em, I've got to be positive...and just move on, do you know what I mean? It's like er, I've always been a positive person but I've got to be more positive.*

Positive outcomes included the development of a sense of *crusade* in some participants (PWA1, PWA4 and, latterly, PWA2 helping to campaign about aphasia and help others).

Conversely, the concern for others with aphasia expressed by PWA3 could be traced to her own experience of fearfulness and the hope that future intervention services would prevent others from becoming isolated, rather than becoming an active campaigner herself. Positive outcomes also included increased *sense of worth* (found through volunteering, for example, see 'participation', Appendix E).



Two key processes underlying the progression within personal adjustment were reflection and rationalisation and are elaborated below.

***Reflection: Looking back, Looking around and Looking forward***

The analysis revealed three stages in thinking about living with aphasia: Looking back, Looking around and Looking forward. These three stages interwove two important subthemes within the adjustment process related to *coming to terms* and *growth* and their subthemes (see Appendix E). ‘Looking back’ comprised reminiscence and reflection including reassessments of past life, remembering the recovery sequence in relation to the length of time since the stroke, and in relation to loss. ‘Looking around’ was linked with the provision of peer support, ascertaining impairment levels by comparison with others, and reflection on what constitutes normal ageing. The subtheme of *transition* referred to a shift in behaviour observed as ongoing at the time of the interview. ‘Looking forward’ involved personal growth, demonstrated in *independence* and *confidence*, and specifically in *new things*, such as *broadening horizons* and *looking to the future*.

***Rationalisation and finding meaning***

The narratives highlighted rationalisation (i.e. consciously thinking things through, including verbalisation to make sense of life) as another key process in personal adjustment. The interviews endorsed the value of the “What Next?” intervention groups, offering a visual framework and structure for reflections by supporting participants in their verbalisation of ideas. Being able to express and discuss fear and anger (to professionals but also to others in a similar situation) was identified as part of the shift towards taking control and reaching positive outcomes. Moreover, the task of ‘Looking back, around and forward’ was facilitated by an integrated consideration of all aspects of life (as provided in the A-FROM), and to

envisage these aspects together when looking forward was part of re-forging links between the different aspects of self and re-working of self-image.

A final aspect of the adjustment process was a search for meaning, including asking the reason for the loss, asking ‘Why?’. In its most rudimentary form, this was represented in the attribution of blame, observed in all the participants with aphasia (but also found amongst those without aphasia) (see Table 4).

(Table 4 about here)

Verbalisation played a part in moving on from the attribution of blame, by reasoning ‘it happened because’, and the two main strands of this within the narratives were (a) to help others or change things and (b) to prevent others going through the same pain. Through ‘finding meaning’, both of these strands were associated with being better able to accept living with aphasia. By the nature of aphasia, verbal rationalisation is particularly challenging but constituted an important part of adjustment, in which peer support encouraged shared vulnerability and experiences, and a sense of worth. Participants referred to the resolution of *blame, guilt and shame as acceptance*.

## **Discussion**

This study sought to explore the adjustment processes underlying QOL for people with chronic aphasia, taking a longitudinal perspective. The account of adjustment was based on an analysis of the processes involved in overcoming barriers to quality of life using the domains from the ICF (as set out in the A-FROM), including the emergence of corresponding facilitators, and of those processes involved in personal adjustment. Specific processes involved in personal adjustment were explored with respect to the emotional reactions

exemplified in the narratives. As the themes and underlying processes were generated from the particular intervention experience of CHANT, and from a small sample of participants, the models remain exploratory and untested elsewhere. Moreover, whether similar processes are experienced by people who are and are not participating in intervention requires investigation. The resonance of some of the findings with the existing literature is nonetheless encouraging. The account of overcoming barriers, emphasizing *raising awareness*, aligns well with the findings of Simmons-Mackie et al. (2007) concerning communication access. The transparent alignment of the barriers with the domains on the A-FROM provides support for the usefulness of the A-FROM framework and its derivation from the ICF, reinforced by the emergence of the barriers from the interview data rather than from pre-existing categories. This support is underpinned by the natural extension of the framework to provide a model for accounting for adjustment processes.

The work of McClung et al. (2010) included ‘spirituality’ as an ambient factor relevant to aphasia rehabilitation, a dimension reinforced by the current study which considered adjustment to aphasia as moving towards ‘wholeness’, and reported a ‘sense of worth’ as intrinsic to QOL, which suggests that spirituality may involve more than one domain. Healthy normal ageing depends on spiritual as well as physical and psychosocial wellbeing (MacKinlay, 2001), with normal ageing involving increased vulnerability and a recognised shift from ‘doing’ to ‘being’ or, in the terms of the current study, a shift from participation per se to a sense of worth, and a focus on quality rather than just quantity of activity. These findings align with Dalemans et al.’s (2010b) assertion that participation in itself is not enough, but it needs to be meaningful in terms of personal goals and societal roles. Isolation is also an issue in the normal ageing process, and the role of reminiscence in ageing is widely acknowledged, themes that readily emerged from the narratives. The additional challenges associated with adjusting to life with aphasia appear, therefore, to

concern the accentuation of barriers, and possible acceleration of normal shifts whilst living with an acute sense of loss associated with impairment.

The exploration of personal adjustment in the narratives has been considered in the light of Gainotti's work into emotional, psychological and psychosocial problems in aphasia (Gainotti, 1997). As existing research does not provide evidence for the expected course and timescale of reactions to loss in aphasia, the current study offers novel preliminary insights into aspects of the emotional reactions evident in people with chronic aphasia. Interestingly, while the study provides evidence of denial, frustration and anger, the emotional shifts leading towards increasing acceptance did not all fall into the category of 'depression' (as within the grief model), although some elements of depression were represented (e.g. Gainotti included anxiety and guilt). Previous models have also not suggested how people make the shift from depression to acceptance; the current study therefore offers the first preliminary suggestions for how some people progress towards acceptance in terms of emotional shifts and also the shared pathways within the intervention. Given the small number of interview participants, it is not clear how generalisable these shifts and pathways are. Further, none of the interview participants with aphasia in the study had treatment for depression, either in the past or present, and only one member of the larger cohort was known to be diagnosed with depression. Although an association of aphasia with depression has already been acknowledged, it is equally important in seeking positive outcomes to understand the emotional adjustments taking place in those who do not have depression.

The assertion from the narratives that loss was experienced in relation to all aspects of life is consistent with Tanner and Gerstenberger's (1988) 'dimensions of loss', and the dimensions they identify may be equated to the domains from the A-FROM (loss of person: relationships/participation; loss of self: personal factors; loss of object: environmental factors). In addition, the findings about the process of re-forging links between the different

aspects of self and re-working self image are consistent with the assertions of Brumfitt (1993) regarding the importance of regaining the sense of self. Further, the current study offers complementary findings to those documented by Christenson (1997) from one person's experience of the sense of self in aphasia.

Particular challenges faced by people adjusting to aphasia clearly extend beyond the linguistic impairment. From the account of underlying processes drawn from the narratives, the ability to reflect and rationalise is strongly implicated, likely due to the role verbalisation can play in clarifying and crystallising thoughts and ideas. This underpins the need to provide specific support for Looking back, Looking around and Looking forward in the rationalisation process, and helping people to self evaluate the different domains for living with aphasia.

In reflecting on any impact of the methodology on findings, the process of taking part in the interviews may have enhanced participants' tendency to reflect and rationalise, and the council worker commented '*...and after having done the interview the last time, I went away, and you think about what you've said, and you think, e, I think as you're going round your ordinary life, over the next few days, it hits you again*'. The narratives also showed, however, that increased reflection arose from taking part in the group and individual discussions for people with aphasia in the intervention.

While the use of multiple perspectives in generating the narratives provided a rich source of data, this also comes with caveats. There were discrepancies, for example, between the perspective of the carer and those of people with aphasia about positive outcomes in the adjustment process, underpinning the need to look specifically at carer perspectives about adjustment in future studies. The people with aphasia described the value of tailored intervention whereas the carer was concerned that it '*gets him out of the house*' (see also '*expectations of outcomes*' in Mumby and Whitworth, 2012), giving greater prominence to the social benefits of the programme. Such discrepancies are also reported elsewhere

(Gillespie, Murphy & Place, 2010; Cruice, Worrall Hickson & Murison, 2005). Studies specifically examining the experiences of carers (e.g. Pound Parr & Duchan, 2001) are needed to shed light on the processes carers might adopt in adjusting to aphasia.

In a final caveat, the current study is not considered to represent the experience of people with severe aphasia who were excluded from the narratives (although the carer's husband had severe aphasia, along with others in the broader study). Hilari et al. (2009) reported lower QOL scores in those with severe aphasia compared with others with aphasia, and their experience of adjustment may not align with the models that account for the current data.

### **Conclusions**

The thematic analysis of narratives derived from the longitudinal study within the CHANT intervention has shed light on mechanisms of adjustment in chronic aphasia, enabling different models and frameworks to be proposed that map the experiences of people with aphasia with intervention pathways and processes. Conclusions about adjustment to aphasia in general should be cautious as the models being proposed require corroboration from a larger sample of participants, and within further settings and intervention contexts. However, building on recent explorations of what constitutes QOL in long term aphasia, this study draws on multiple perspectives over time to examine the processes of adjustment and establish the bases for designing effective long term interventions.

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**Table 1. Characteristics of interview participants with aphasia (including details of the person whose carer took part).**

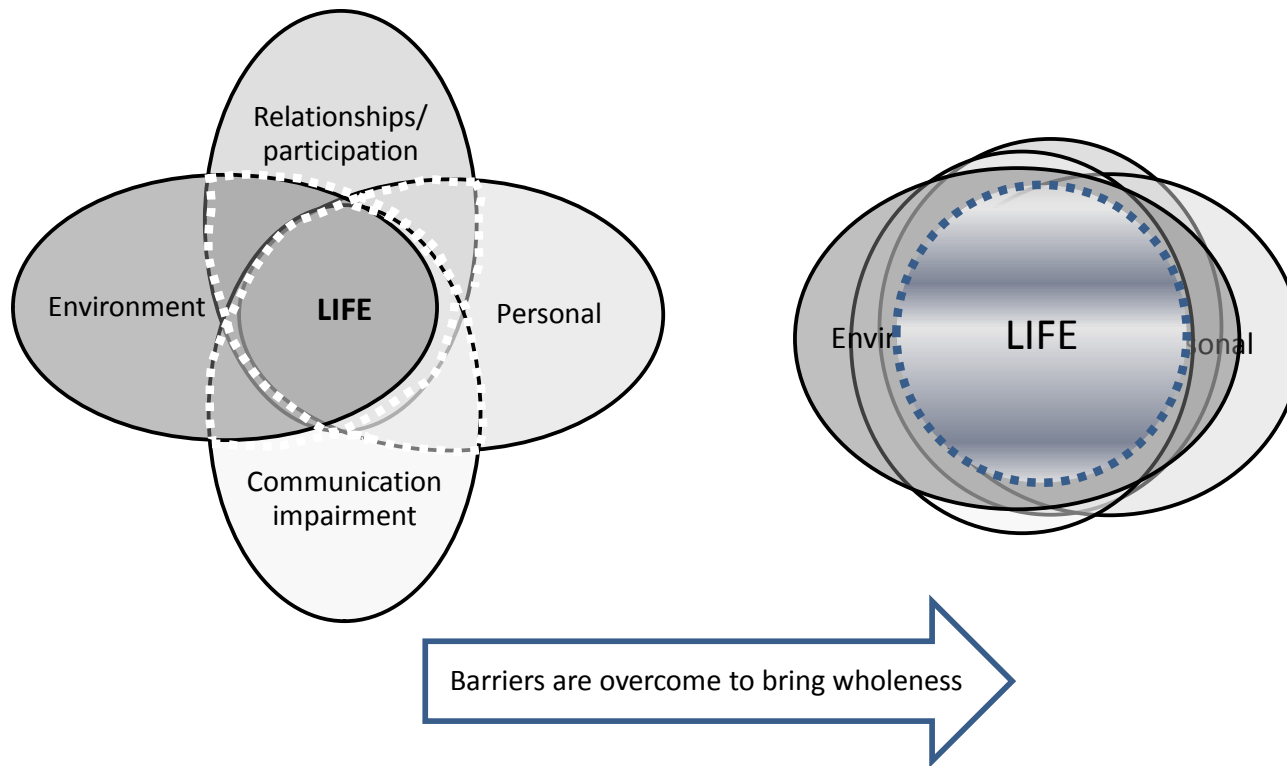
	<b>PWA1</b>	<b>PWA2</b>	<b>PWA3</b>	<b>PWA4</b>	<i>Husband of carer</i>
<b>Gender</b>	Male	Male	Female	Male	<i>Male</i>
<b>Work status</b>	Retired	Unemployed	Retired	Retired	<i>Unemployed</i>
<b>Occupation</b>	Solicitor	Chef	Teacher	IT consultant	<i>Manual worker</i>
<b>Age in years</b>	70	40	76	68	<i>57</i>
<b>Months post stroke</b>	13	29	26	27	<i>52</i>
<b>Receptive aphasia severity</b>	Mild	Moderate	Moderate	Mild	<i>Moderate</i>
<b>Expressive aphasia severity</b>	Mild	Mild	Moderate	Mild	<i>Severe</i>
<b>Additional concerns</b>	Mild dysarthria; mild right-sided	Severe hemianopia; short term memory problems	Hemianopia; right-sided hemiparesis	Mild right-sided hemiparesis now resolved	<i>Hemianopia; right-sided hemiparesis</i>

	hemiparesis				
<b>Co-morbidity</b>	Heart problems	Epilepsy	Arthritis, cancer in remission	Heart problems	<i>Nil known</i>
<b>Family</b>	Lives with his wife who has arthritis. Children and grandchildren.	Married, no children. Wife is his carer.	Lives with her husband who is her carer. Children include one with special needs.	Married, no children. Lives with his wife, with a high degree of independence.	<i>Married, with children and grandchildren nearby</i>
<b>Mobility</b>	Walks with stick	Walks but unsteady	Walks short distances	Walks unaided	<i>Walks short distances with stick</i>
<b>Transport</b>	Car driver	Public transport with escort	Taxi	Car driver	<i>Taxi</i>

**Table 2. Characteristics of interview participants without aphasia**

	<b>Carer</b>	<b>Volunteer</b>	<b>Council worker</b>
<b>Gender</b>	Female	Female	Female
<b>Age band in years</b>	<60	<40	<50
<b>Work status</b>	Main wage-earner	Job seeker	Employed full time
<b>Occupation</b>	Catering assistant	Hairdresser	Adult learning advisor
<b>Transport</b>	Taxi/Public transport	Public transport	Car driver
<b>Family</b>	(see details for husband)	Married with children	N/A
<b>Additional factors</b>	Babysits for grandchildren	Attending literacy classes	N/A

**Figure 1: Conceptualising barriers being overcome in terms of the ICF domains: an adaptation of the A-FROM (Kagan et al., 2008)**





**Table 3. Processes in adjustment: Barriers and facilitators through intervention type, within ICF domains**

<b>MAIN DOMAIN</b>	<b>BARRIER</b>	<b>FACILITATOR</b>	<b>INTERVENTION TYPE</b>	<b>PROCESSES</b>	<b>Related examples from the interviews</b>
<b>Communication Impairment (ICF: Body functions and structures)</b>	Impairment	Development of strategies	“What Next?” groups  Courses (One-to-one)	Trial and adoption of compensatory activity	<i>Carer: I haven't seen him talk to anyone with aphasia before like him (-) erh (--) and it was nice to see him having like (--) he was helping (--) his friend was getting stuck and he was helping him or he would get stuck and his friend was helping</i>
<b>Personal factors (ICF: Personal factors)</b>	Internal emotional barriers	Sharing experience  Verbalisation	One-to-one Peer support Supported activity	Emotional shift Transformation of self Self-determination Increasing confidence	<i>PWA3: I don't upset myself I think, because I (-) slowly from, starting, nothing at all [unintelligible] back [unintelligible] then, slowly back to myself, bit more but not</i>
<b>Relationships/ Participation</b>	Isolation	Provision of help	Graded return to activity	Social reintegration & alternative	<i>PWA1: well they're-they're-they're explaining (-) all (-) things you can (.) get you know like e you're-your libraries and things like that and about eh</i>

<b>(ICF: Activity and participation)</b>			Volunteer support Signposting	networks Increasing participation	<i>cram-pran (--) c er transport 'n that you know all that type of thing you know^ and er the-they're help I mean I've got a er-er-er computer and I'm-I'm-I'm still l-learning you know I mean. I haven't got a clue really but th-they help me in there [laughs]</i>
<b>Environment (ICF: Environmental factors)</b>	Inaccessible Systems	Raising awareness  Empowerment	Communication access training Volunteering Planning group and self-help	Changing environments Increasing independence Doing 'new things'	Council worker: <i>Well hopefully if I came across somebody with aphasia now I would at least have some idea of how to approach them....and hopefully make them feel eh comfortable.....stuff like that and just try let them communicate in the way that they are best able....and try and find out the preferred method</i>
<b>All domains of A-FROM (ICF: relating to all domains)</b>	Ignorance	Raising awareness	One day events Training One-to-one Group peer support (Planning group)	Developing insight Acceptance/ Tolerance Empowerment	PWA4: <i>Mainly peop- people's lack, of (-) erm, you know not recognising that people have, something wrong with them.....Em, I look well enough in you know [gestures towards self, top to bottom]....But there is still something wrong</i>

**Table 4. Examples of attribution of blame**

	Emotional reaction	Outcome with example	Attribution	Emotional shift	Rationale
<b>Directed out</b>	Anger at other things/people	Aggression <i>Carer: 'He just lashes out: it's pure frustration'</i>	It's x's fault	Blame	I didn't deserve it
	Fear of other things/people	Defensiveness PWA2: <i>'I never pick up the phone to strangers'</i>	It's not my fault		
<b>Directe</b>	Anger at self	Frustration PWA1:	It's my fault		

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		<i>'me wife I-I must I- I must be a pain on her'</i>			
	Fear of being hurt	Vulnerability PWA3: <i>'I don't know if people can understand really what's happening at all'</i>	I'm not in control	Guilt, shame	I did deserve it

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## **Appendix A: Interview questions**

*What sort of contact do you have with CHANT at the moment?*

*What led up to this?*

*What does aphasia mean to you?*

*Could you tell me how you think aphasia affects everyday life?*

*What helps communication when someone has aphasia?*

*What are the main barriers to communication in your opinion?*

*Do you think being involved in CHANT makes any difference? How?*

*Have your ideas changed over time?*

*Is there anything else you'd like to mention?*

**Appendix B. Measures of change over time for the participants with aphasia**

f= fully achieved; p= partially achieved; t=still thinking about it; n=not achieved. (N/A) = not fully reassessed

Percentage shows proportion of goals that were fully or partially achieved according to self-review 4-6 months after setting them.

Pre-post time lag for SAQOL was 9-12 months & for self assessment was 4-6 months. (PWA1 only completed reassessment of goals).

		PWA1		PWA2		PWA3		PWA4		Husband of carer	
		pre	post	pre	post	pre	post	pre	post	pre	post
<b>SAQOL-39</b>	<b>Physical</b>	2.65	(N/A)	3.76	3.28	3.35	3.94	4.53	4.88	2.76	3.24
	<b>Communication</b>	3.57	(N/A)	3.14	3.43	2.71	3.43	3.86	4.43	2.86	2.86
	<b>Psychosocial</b>	2.64	(N/A)	2.09	2.82	2.45	3.36	4	4.45	3.09	2.64
	<b>Energy</b>	2.5	(N/A)	3	3.5	3	3.5	4.23	4.25	3.75	4.25
	<b>SAQOL overall</b>	2.79	(N/A)	3.1	3.28	2.95	3.64	4.23	4.62	2.97	3.1
<b>A-FROM based self assessment</b>	<b>Impairment</b>	5	(N/A)(p)	6	7 (p)	5	5 (n)	7	7 (p)	2	5 (p)
	<b>Personal</b>	8	(N/A)(f)	5	8 (p)	4	4 (f)	8	8 (p)	5	5 (f)
	<b>Relationship participation</b>	6	(N/A)(f)	8	8 (f)	6	7 (p)	7	8 (p)	7	7 (p)
	<b>Environment</b>	5	(N/A)(f)	4	5 (p)	5	7 (p)	8	9 (p)	8	6 (f)
	<b>Overall score</b>	24	(N/A)	23	28	20	23	30	32	22	23
	<b>% goals partially or fully achieved</b>		100%		100%		67%		100%		100%



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	Expert trainers		[2]		[3,5]	5	[3]			5	[2,3]				
Mainstream course	Adult Learning					6	[4,5]	4	[3]				[4]	6	[3,4]
	Other e.g. Libraries									5	[3-5]				
Bridging to others	Support e.g. Job coaches					6	-			-		5	[5]		
Stroke group	Existing generic support group	3	[2]	3	[4]		[2,3]	3	-	4	[1,3,5]	2	[2]		
Stroke event	Partnering local stroke services					6	-	5	-						
Volunteering	Activity in volunteer role			4	[3-5]							2	[2-5]		
CHANT planning	Campaign group of people with aphasia	4	[2]	5	[3]					5	[3-5]	5	[5]		



## **Appendix D. Summary of narratives with reference to participant journeys through the intervention: perspectives from people with aphasia**

### **PWA1**

PWA1 was a retired professional with mild aphasia and was involved in CHANT from the outset via the contact with existing Expert trainers within the SLT service. He took part in the focus groups that shaped the design of the service and was initially self-deprecating about his communication, but gained confidence and a sense of crusade, trying to ‘put right’ some of his own hurtful experiences by helping others with aphasia. PWA1 became acutely ill with cancer and died before his reassessments were complete (interview 2 was the last interview). Despite this, Appendix C shows that he took part in many of the activities being offered within CHANT, moving from the ‘What Next?’ groups to tailored courses and taking part in one day events, and the Planning group. He did review his goals before he died, and had fully achieved three out of four of them despite his illness (see Appendix B). He particularly valued peer support, the social aspects, and the campaigning role of CHANT, as well as being aware of carer strain and their need for support. Up until his death, he was keen to continue his campaigning about aphasia and asked that his paintings from Art and Aphasia still be included for exhibition.

### **PWA2**

PWA2 was relatively young (aged 40 at first contact) in comparison to the other participants in CHANT (mean 69 years, range 37-92). He was an unemployed chef who had moved into the area since his stroke, having experienced a lack of understanding of his aphasia where he and his wife lived before (from experiences with support services, the general public and the police). His mild expressive aphasia and moderate receptive aphasia were compounded by epilepsy, short

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term memory problems, and severe hemianopia, and he described difficulty integrating into his surroundings and accessing help. Initially he feared a recurrence of isolation and misunderstanding. Appendix C shows how he first accessed information at a one day event and then became involved in a 'What Next?' group, before progressing through CHANT computer courses, training as an Expert trainer and then accessing more mainstream training. He needed courses to be delivered at his pace and valued the scope within CHANT to repeat learning until he was confident. He valued one to one support, and getting to know other people locally with aphasia, so that he could understand more fully how it affected people and adjust to life with aphasia. He expressed increasing awareness and confidence, aided by peer support within CHANT. As he moved through CHANT, he became able to look to the future in terms of volunteering and work. His quality of life as measured by the SAQOL-39 did improve over the year (see Appendix B), in particular his 'psychosocial adjustment', despite ongoing problems with mobility and his epilepsy. He made gains in his self assessment scores and at least partially achieved all of his goals.

### **PWA3**

PWA3 was initially very unsure about taking part in CHANT due to her reluctance to go outside the home and low self esteem. Having worked as a special needs teacher, she was acutely aware of her impairment and felt upset by her social isolation. After several home visits aimed at individual goal-setting, she agreed to attend the Art and Aphasia course with her husband present initially and, after gaining confidence through contact with others with aphasia (peer support) and one to one volunteer attention within the course, she then accessed a one day event with her husband. Over the year, she made gains in all aspects of quality of life measured by the SAQOL-

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39 (see Appendix B), despite having ongoing health problems (arthritis and cancer in remission) and talking of the difficulties of normal ageing. She did not persevere with her initial goal related to impairment (writing skills) but achieved or partially achieved the goals in other domains. Her narrative highlighted the value of CHANT as people understood and accepted her with aphasia, a position she felt her family and close friends have struggled to achieve. She stressed the need to extend resources for other isolated people. She recounted the barriers that she had had to face, (particularly in communication and confidence), the strategies that helped, and the sense of achievement and self worth developed through participation in the Art group and exhibition.

#### **PWA4**

PWA4 was a retired professional with mild aphasia and had participated as an Expert trainer within the local speech and language therapy service (similar to PWA1). On the surface he appeared to have made a relatively good recovery, but nevertheless his interviews revealed that as he took part in CHANT and was encouraged to reflect on his life through discussions in the individual assessment and groups, he was aware of further adjustment taking place and being facilitated. Over the year his quality of life as measured by the SAQOL-39 did improve, to the highest level overall of all the interviewees (4.62 out of a maximum of 5, see Appendix B) and he at least partially achieved all his goals. He only recorded slight improvement, however, on self assessment as he retained an expectation of more progress in the future in all the domains within the A-FROM.

He took part in a ‘What Next?’ group, and then chose to volunteer to help others in subsequent groups. He became both active in the Planning group and in mentoring further Expert trainers, and also acted as an ambassador for aphasia in the one day events and helped to steward

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at the Art and Aphasia Exhibition. Peer support and social contacts were very important to him, and by acting as a volunteer helper within CHANT (and elsewhere) he felt empowered. This fulfilled a desire to 'put something back' but also formed part of the ongoing adjustment and resolution of his self image. Like PWA1 he had a sense of 'crusade' in including others with stroke within intervention, and making sure aphasia was publicized. He identified the appropriateness of various CHANT activities according to peoples' needs and interests, and voiced strong opinions about the point of view of people with aphasia and the of general public, though not about any specific needs of carers. He strongly voiced a perception that the local authority and health service needed to continue and extend the service provided by CHANT due to the degree of isolation felt by people with aphasia and their inability to access services due to communication disability.

**Appendix E. Subthemes within *Quality of Life (QOL)***

<b>Quality of Life</b>	<b>Sense of worth</b>	Sense of self			
		Life experience			
		Goals	Crusade		
		Aspirations			
	<b>Participation</b>	Types of Participation	Work		
			Volunteering		
		Leisure activities			
	Amount of activity				
		Social networks	Professionals		
			Friends		
		Family			
	Everyday life	Social aspects			
		Effects on everyday life			
<b>Adjustment</b>	Loss	Physical loss			
	Emotional reactions	Positive reactions		Humour, enjoyment, relief, motivation	
Negative reactions				Anger, fear, denial and rigidity	

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		Growth	New things	Broadening horizons Looking to the future
			Independence	
			Confidence	
		Coming to terms	Transition	
			Reminiscence and reflection	Normal ageing Comparison with others Past life Recovery sequence Time post stroke
			Rationalisation	
			Peer support	
			Acceptance	