

Research Report

Patients' experiences of disruptions associated with post-stroke dysarthria

Sylvia Dickson[†], Rosaline S. Barbour[‡], Marian Brady[†],
Alexander M. Clark[§] and Gillian Paton[¶]

[†]Nursing, Midwifery and Allied Health Professions Research Unit, Glasgow Caledonian University, Glasgow, UK

[‡]School of Nursing and Midwifery, University of Dundee, Dundee, UK

[§]Faculty of Nursing, University of Alberta, Edmonton, AB, Canada

[¶]Department of Speech and Language Therapy, Royal Alexandra Hospital, Paisley, Glasgow, UK

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Abstract

Background: Post-stroke dysarthria rehabilitation should consider social participation for people with dysarthria, but before this approach can be adopted, an understanding of the psychosocial impact of dysarthria is required. Despite the prevalence of dysarthria as a result of stroke, there is a paucity of research into this communication disorder, particularly studies that address the experiences of individuals. The available literature focuses mainly on the perceptions of others or includes groups of mixed aetiologies.

Aims: To investigate the beliefs and experiences of people with dysarthria as a result of stroke in relation to their speech disorder, and to explore the perceived physical, personal and psychosocial impacts of living with dysarthria.

Methods & Procedures: Participants for this qualitative study were recruited from twelve hospitals in Scotland that served both rural and urban populations and afforded opportunity for comparison. Semi-structured, in-depth interviews were carried out over a 12-month period with 24 individuals with varying severity of dysarthria following stroke. The interviews were orthographically transcribed and coded using the NVivo package, which also facilitated identification of patterns using the constant comparative method.

Outcomes & Results: The results of the study indicate that the effects of dysarthria following stroke extend beyond the physiological characteristics of the impairment. In turn, the resulting communication difficulties lead to changes in self-identity, relationships, social and emotional disruptions, and feelings of

Address correspondence to: Sylvia Dickson, Nursing, Midwifery and Allied Health Professions Research Unit, Glasgow Caledonian University, Glasgow, UK; e-mail: sylvia.dickson@gcal.ac.uk

stigmatization or perceived stigmatization. The impact of dysarthria was found to be disproportionate to the physiological severity, with participants continually striving to get their speech back to 'normal'.

Conclusions & Implications: The findings provide insight into the psychosocial impact of dysarthria following stroke. Speech and language therapy interventions need to go beyond the speech impairment to address and promote psychosocial well being, reduce the likelihood of feelings of stigmatization and changes in self-identity, irrespective of the severity of dysarthria.

Keywords: Stroke, dysarthria, rehabilitation, psychosocial, severity.

What this paper adds

What is already known on this subject?

There is a paucity of research into dysarthria following stroke, particularly studies that address the experiences of individuals.

What this study adds

The effects of stroke-related dysarthria extend beyond the physiological resulting in communication-related difficulties, which in turn lead to changes in self-identity, relationships, social and emotional disruptions, and feelings of stigmatization or perceived stigmatization. The impact of dysarthria can be disproportionate to the physiological severity. Many individuals with dysarthria following stroke continually strive to get their speech back to 'normal'.

Introduction

Function, disability and health

'Dysarthria' is the collective term for a group of related speech disorders that are characterized by slurred, poorly articulated speech, as a consequence of weakness, incoordination, or paralysis of the speech muscles caused by damage to the central or peripheral nervous system. Articulation, loudness, pitch, respiration, rhythm and rate of speech can be affected in isolation or combination. While dysarthria can have a number of aetiologies including degenerative, infectious or traumatic causes, stroke-related dysarthria is vascular in origin resulting from a unilateral or bilateral lesion. It is largely associated with spastic and unilateral upper motor neuron dysarthria, and to a lesser extent some other subtypes (e.g. flaccid) (Kent *et al.* 1998). The prevalence of dysarthria post-stroke has been conservatively reported to be between 20 and 30% (Warlow *et al.* 2000).

The World Health Organization's (WHO) Classification of Functioning, Disability and Health (ICF) encompassed manifestations of health conditions as the result of complex interactions of the person with the physical, social and psychological environment (World Health Organisation (WHO) 2001). Employing this framework to evaluate the existing dysarthria literature highlights that the activity (executive on a task) and participation (involvement in life situations) elements of the disorder have received limited attention with literature and research focusing mainly on the pathology (disease and diagnosis) and associated impairments (symptoms and signs).

Pathology/impairment focused research

Various evaluations of the effectiveness of behavioural interventions to maximize the perceptual characteristics (intelligibility) of people with dysarthria have been reported (Gentil 1993), but few have rigorously evaluated these techniques. Considerable variability in the population type, study design and focus of treatment makes comparisons difficult (Sellars *et al.* 2005). An extensive randomized controlled trial to assess the effectiveness of speech and language therapy for individuals with post-stroke communication difficulties including dysarthria is currently on-going (ACT NoW Study 2006).

Activity/participation focused research

The psychosocial impact of stroke and other stroke-related communication difficulties such as aphasia have received increased research interest over the years (Parr 2001, Hilari *et al.* 2003). People with aphasia have reported feelings of embarrassment, depression, and a loss of confidence associated with their language impairments and the associated difficulties they encountered such as returning to work and financial implications. Conversely, the impact of dysarthria after stroke on individuals' quality of life has received very little attention. A search of relevant databases (Language and Linguistic Behaviour Abstracts, Medline, Cinahl) and a recent Cochrane-based systematic review confirms this (Sellars *et al.* 2005). Recent policy documents have called for this component of dysarthria to be addressed urgently (Scottish Intercollegiate Guidelines Network (SIGN) 2002, Royal College of Speech and Language Therapists (RCSLT) 2005).

Yorkston *et al.* (1994) investigated 33 adults with dysarthria (two with stroke-related dysarthria). Perception of the type and frequency of situations was felt to be difficult as well as the perceived reactions of others by administration of a 100-item questionnaire. They found that individuals with severe dysarthria were more likely to report experiencing stigmatizing reactions such as laughing and ridiculing. The authors suggest that assessment of the degree of handicap associated with dysarthria could, therefore, possibly be made by asking questions about perceived reactions of others'. However, as comparisons were made between severity groups, it is difficult to know whether individuals with different medical aetiologies would respond differently. In addition, the use of a 100-item questionnaire might not be the most suitable method to solicit information from individuals who might have other post-stroke impairments. Co-existing visual problems, writing and comprehension difficulties could impinge on peoples' ability to complete the questionnaire accurately. In addition, the use of a questionnaire restricts participants' responses.

Walshe (2003) explored the impact of dysarthria on self-concept in 31 individuals (seven with dysarthria post-stroke). Self-concept was rated on the Head Semantic Differential scale (HISD) (Tyerman and Humphrey 1984) at the beginning of the study and again at 6 months after baseline. Participants completed the scale twice, once to rate past self (6 months before the onset of dysarthria) and another to rate present self. The majority of individuals rated their present self more negatively at baseline and 6 months later. The overall difference between past and present self-concept was statistically significant, although only one individual with post-stroke dysarthria participated in the repeat assessment at 6 months. As stated by the author, the use of the HISD scale has a number of limitations, including issues around

scoring and re-scoring past-self and limited information on the psychological well-being of the participants.

More recently, Mackenzie and Lowit (2006) investigated the effects of an individualized behavioural communication intervention on eight people with stroke-related dysarthria, as well as the impact of the disorder on the person. The impact of dysarthria was assessed through administration of the Dysarthria Impact Profile (DIP) (Walshe 2002) at the beginning and end of the intervention. The DIP consists of four sections: the effect of dysarthria on me as a person, accepting my dysarthria, how I feel others react to my speech and how dysarthria affects my communication with others. A significant group difference was only detected in the accepting my dysarthria section. This finding suggests that the impact of dysarthria declined over the treatment period. However, as acknowledged by the authors, the number of participants was small. In addition, a number of factors may have contributed to the positive change in acceptance, including sensitivity and support from therapists, better adjustment by individuals with more advanced communication skills and natural adjustment over time. Interestingly, no link between severity of dysarthria and psychosocial impact was evident.

Knowledge of the personal and psychosocial dimensions of dysarthria is important to speech and language therapists (SLTs) given the role of these professionals in fostering communication and rehabilitation after stroke. In comparison to aphasia, little work has been done on the psychosocial effects of dysarthria (e.g. Yorkston *et al.* 2001). There is therefore little current understanding of experiences of dysarthria following stroke, its wider psychosocial affects or how best to support patients and carers. Increased knowledge of these aspects specific to stroke-related dysarthria is needed to guide health care practice of SLTs and the wider multi-disciplinary team. A qualitative approach is ideally suited to elicit the views of individuals with dysarthria following stroke, but such an approach has been absent from the literature. While it remains acceptable to examine professional perspectives, these views may differ markedly from the accounts of patients and carers (Laurer *et al.* 1982). The present study reflects the commitment of qualitative research to examining the perspectives of those most likely to have understanding of the phenomena being explored.

Aims of the study

Individuals with dysarthria following stroke were approached to participate in the study to examine their beliefs and experiences in relation to the speech disorder and explore the perceived physical, personal and psychosocial impacts of living with dysarthria.

Methods

A qualitative approach utilizing semi-structured interviewing was adopted. Qualitative research encompasses a range of methodologies and approaches that can be used to examine stakeholders' views, experiences of health services and illness and complex processes (Malterud 1993). Interviews were selected as the preferred method of data collection even though it was recognized that the communication challenges experienced by participants would directly impinge on

the data collected. However, attaining the perspectives of stakeholders' first-hand is of greatest priority in qualitative research. A variety of methods, described below, were used to ensure that the transcriptions of the interviews were accurate and as complete as possible.

Settings and participants

Individuals with dysarthria as a result of stroke were recruited for the interviews from referrals to twelve hospital-based SLT departments across Scotland that served both rural and urban populations. SLTs identified potential participants and invited them to take part in the study. Purposive sampling was used in order to recruit interviewees. This is a well-established approach to selecting respondents for qualitative studies, where the aim is to ensure diverse coverage and to facilitate comparisons rather than aspiring to recruiting a representative sample. This approach ensured that our participants reflected a wide range of individuals with post-stroke dysarthria in terms of their dysarthria severity; level of concomitant post-stroke impairment(s); and characteristics such as their age, gender and socio-economic circumstances. Computed tomographic (CT) or magnetic resonance imaging (MRI) scans were not obtained. Ethical and Research and Development approval was obtained from each of the sites and all participants gave signed informed consent prior to participating.

Exclusion criteria included: significant cognitive impairment as measured by the Mini-Mental State questionnaire (Folstein *et al.* 1975); severe depression, which was measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983); aphasia; or residence in fully supported accommodation. Aphasia was diagnosed by the recruiting SLT and supported by completion of the Sentence Comprehension Test (listening version) (Brookshire and Nicholas 1993). A score of less than 20 on the Mini-Mental State questionnaire indicates cognitive disturbance whilst a score of 14 or more on the HADS signifies severe depression. A cut-off of more than two questions wrong was implemented for the Sentence Comprehension Test. Other concomitant impairments as a result of stroke were not an exclusion factor, although they were measured using the Barthel Index (Mahoney and Barthel 1965) in order to investigate their impact on participants' experiences with dysarthria. No upper age limit was imposed.

In total, 33 individuals agreed to participate, of whom three withdrew and two died following consent. The remaining 28 potential participants were screened against the exclusion criteria. Though no individuals were identified as having cognitive impairment or aphasia, three (two of which had severe dysarthria) were excluded on the basis they had HADS scores of 14 or greater. All participants had sufficient hearing to participate in a spoken interview.

A total of 25 individuals, who were between two and 34 months post-stroke, were interviewed in their homes. One interview recording failed and this paper draws on the remaining 24 transcripts. Both men ($n=15$) and women ($n=9$) with varying degrees of dysarthria severity (mild $n=14$; moderate $n=9$; severe $n=1$), as judged by the recruiting SLT and a senior SLT (GP), were included. There was considerable agreement between the two raters with regard to rating of severity, with only one participant being accorded a revised grading from moderate to severe. Participants had an age range of 34–86 years and a range of socio-economic

circumstances based on the Carstairs scores for Scottish postcode sectors from the 2001 census (McLoone 2004). This sample reflects the spread of people experiencing dysarthria as a result of stroke in terms of severity, the level of concomitant post-stroke impairment(s) (Mahoney and Barthel 1965) and other patient characteristics (gender, age and socio-economic circumstances) (table 1). This allowed diversity to be explored. However, recruiting individuals with severe dysarthria to the study proved to be difficult with data from only one individual with severe dysarthria included in the final results (two were excluded based on high scores on the HADS). It is possible that other individuals with severe dysarthria were not referred to the study because of other medical complications (such as aphasia). The participant with severe dysarthria used an alphabet chart to support her communicative interactions.

Data generation and analysis

Participants were interviewed in their home between February 2004 and March 2005. In-depth, semi-structured interviews were used to allow participants to raise

Table 1. Participant demographic data

Participant	Age (years)	Sex	Dysarthria severity	Barthel score	Deprivation category	Months post-stroke	Carer status
001	49	F	mild	60	5	3	none
002	50	M	moderate	100	4	6	wife
003	69	M	moderate	75	6	2	partner
004	46	M	moderate	55	7	5	partner
005	69	M	moderate	85	2	6	wife
006	66	M	mild	95	6	7	none
007	71	M	mild	75	7	9	wife
008	84	M	mild	70	4	6	wife
009	62	M	mild	85	2	5	wife
011	69	F	moderate	90	2	7	husband
012	56	M	moderate	75	2	34	wife
013	64	F	moderate	65	4	10	friend
014	73	F	severe	40	1	8	husband
016	34	F	mild	100	4	23	husband
017	73	M	moderate	95	4	15	none
019	47	M	mild	90	6	5	partner
020	76	F	mild	100	6	4	none
021	63	M	mild	100	3	2	none
022	63	F	mild	80	6	8	husband
024	75	M	mild	100	3	4	wife
025	86	F	moderate	95	7	12	none
026	62	F	mild	90	5	3	husband
027	62	M	mild	100	1	5	wife
028	56	M	mild	100	1	9	wife

F, Female; M, Male.

Barthel score: 100=totally independent, 50–95=patient supplies over 50% of the effort, <50=patient applies less than 50% of the effort and 0=totally dependent.

Deprivation category: 1=very high deprivation, 7=very low deprivation.

Participants 010, 015 and 023 were excluded based on high HADS scores. Participant 018 recording failed.

issues of salience for them. A pilot study stage was undertaken to evaluate and inform the interview schedule. Appendix A outlines the final version of the interview topic guide. The first author conducted all the interviews and data saturation was achieved, i.e. by the last interview it was apparent that no new categories were emerging and that there was a considerable amount of repetition. The data analysis process involved a number of steps. All interviews were audio-taped and orthographically transcribed. To preserve confidentiality, pseudonyms were used to replace all identifiable names and places in the transcriptions. As a result of the participants' dysarthria the audio data were often unclear. The accuracy of the transcriptions was therefore double-checked by qualified SLTs within the research team (MB, GP), but reliability data are not available for this process.

Following transcription the interviews were imported into NVivo, a computer programme designed to manage text based qualitative data. An initial coding framework was systematically developed based on a preliminary review of the data. NVivo was used to assist analysis and to allow for revision of the coding frame and documentation of such changes. Data analysis was concurrent with data collection and the initial framework was developed after ten interviews based on the initial analysis. Patterns in the data were identified using the constant comparative method (Glaser and Strauss 1967). This initially involved reading and rereading each transcript in order to identify broad emerging themes, which were then coded. Coding is a way of gathering data on a particular topic under one heading in order to make the data manageable for analysis (Barbour and Members of Wolds Primary Care Research Network (WoReN) 2000). The next stage of analysis involved identifying the most prominent themes and any notable differences or exceptions. Sub-categories within the broad themes identified were developed through further analysis of the transcripts. The final stage of analysis involved making comparisons between gender, severity of dysarthria, age, socio-economic circumstances and the impact of co-existing post-stroke impairment(s) on participants' experiences.

Results

Four major themes were identified during the analysis. The major themes were associated with communication, normality, support and psychosocial consequences. A definition of the themes and illustrative quotes are provided in table 2.

Communication

It is not surprising that all participants in the study experienced communication difficulties at some point due to the nature of their impairment. However, two thirds of participants reported experiencing frequent, on-going communication difficulties with a range of communicative partners across a range of settings, irrespective of the severity of dysarthria. Some felt that they could no longer keep up with conversations with friends and family, including spouses, and as a result felt 'left out' and 'different'. Reports of incidents where friends, strangers and even some health care professionals communicated with them through their spouse were also common.

As a consequence of the communication difficulties experienced, participants actively modified their communication behaviour. Nearly half the participants

Table 2. Patients' experiences of disruptions associated with post-stroke dysarthria: major themes and illustrative quotes

Theme	Definition	Illustrative quote
Communication	Difficulties associated with communicating in different life situations	<p>'... like last summer we'd gone to the supermarket and a friend of mine drove the car and was speaking to us, but never spoke to me, spoke to Julie [partner] saying things like, how is he, what's he doing now, and I got quite angry and said, I'm here, can you not see me.'</p> <p>(46-year-old male with moderate dysarthria)</p> <p>'There was a point when I didn't want to answer the phone because a few people have said to me, have you been drinking? You know, and I thought no, just keep off the phone.'</p> <p>(56-year-old male with mild dysarthria)</p>
Normality	Participants desire to 'get back to normal'	<p>'If someone had told me what to expect I would have been better. It wouldn't have made me be any better, but I would have understood it better.'</p> <p>(64-year-old female with moderate dysarthria)</p> <p>'... that's seventeen weeks now and I don't think I'm one bit better today than I was two months ago. I don't seem to be, obviously people say to me you're speaking a lot better, and I say well if I'm speaking a lot better you could have fooled me. I don't feel better at all. I feel I'm just as bad as I did six weeks ago ... I'm sincerely hoping that by the time a year goes by, if I'm living, I'd expect to speak perfectly normally and if I don't I'll be really furious with myself.'</p> <p>(75-year-old male with mild dysarthria)</p> <p>'It is not what I normally sound like, that's what angers me, but, I want to sound like I used to sound like but it doesn't come.'</p> <p>(64-year-old female with moderate dysarthria)</p>
Support	Support received	<p>'I went to the therapist and they said they could only do so much, the rest was up to me.'</p> <p>(47-year-old male with mild dysarthria)</p> <p>'She [SLT] wasn't only a good therapist at teaching me; she was a good listener to me.'</p> <p>(71-year-old male with mild dysarthria)</p> <p>'(It was a bit of an idiot) of a doctor when he didn't even realise, he didn't even test for a stroke. ... Well, she [SLT] said it's too late, (I can't stop that). If the speech therapy had been introduced in the early days there would have been a chance of a possible recovery, but eh, I'm beyond recovery (and I had to accept that).'</p> <p>(73-year-old male with moderate dysarthria)</p> <p>'... they sort of pat you on the hand and say there, there dear or what a clever girl and they even do that, some hospital staff do that, you know ... it's the way that you would talk to a little child and it sort of strips you of your dignity somehow.'</p> <p>(76-year-old female with mild dysarthria)</p>

Table 2. (Continued.)

Theme	Definition	Illustrative quote
Psychosocial consequences	Issues relating to identity, relationship, social and emotional disruptions and stigma	'Well, it wasn't my voice, because I had used tape recorders a lot before so I was used to hearing my voice and it didn't sound like me.' (63-year-old female with mild dysarthria)
		'Although I've had the stroke, but my brain, how do I explain it, I'll not accept any nonsense off of anybody and I don't want any pity off of anybody or sympathy or whatever you want to call it. I just want to be treated as a normal person.' (71-year-old male with mild dysarthria)
		'I know what bond I had with Paula. Whenever I walked into the room and whenever I talked or spoke she would silently just watch me. When Michael [husband] would do that Kyle reacted the same as Paula was with me. That took its toll on me.' (34-year-old female with mild dysarthria)
		'We had a good social life up to this happened. But, now I've only been out the house one night and that was because my daughter got engaged, so I went to her engagement party and I was ordered to go to that.' (71-year-old male with mild dysarthria)
		'... they'll [strangers] turn away, they'll talk to my wife instead of to me when I'm talking, stuff like that, you know.' (50-year-old male with moderate dysarthria)
		'... I hate myself because I can't speak right. ... People can obviously understand what I'm saying but as I said to you already, it really infuriates me that I can't speak in the same power and fire it out.' (75-year-old male with mild dysarthria)
		'I've felt depressed. Not too bad because I was improving but a couple of times I was getting to the plateau stage and I didn't seem to be improving. And that's when you start to feel depressed.' (47-year-old male with mild dysarthria)
		'You do get so frustrated when you can't get the words out. But, you also feel that small when people kind of look at you or say things like have you been drinking or, you now. It's terrible.' (56-year-old male with mild dysarthria)
		'Sometimes a stranger might think they can't talk to you ... It's the way they look, they kind of look at you. Their attitude to you.' (50-year-old male with moderate dysarthria)

reported avoiding instigating new conversations, with several reporting that when in company they did not enter into conversation or express themselves and would "just say what's necessary".

For two-thirds of participants, talking on the telephone, an activity that was barely reflected on before the stroke, was now highly problematic. Reasons for avoiding the telephone included difficulties trying to make others understand them and feeling as though they had to shout in order to communicate effectively. The fact that the other person on the phone could not see the participants' lips or facial expressions was thought to be central to the problem. Some participants also reported being uncomfortable with not knowing if they had made themselves understood and reported fears, as well as experiences where people thought they were drunk.

Normality

After recognizing that their speech had been affected by the stroke, participants sought information on how long it would be before their speech returned to 'normal'. The descriptions they gave of the SLTs' prognosis varied widely. A few participants reported a lack of information and in some cases could not recall a discussion on the nature and what to expect from the recovery process. However, nearly two-thirds believed the recovery process had been explained to them. From the comments they made it was evident that the majority of SLTs did not put a specific time scale on expected recovery, but instead provided information on possible outcomes and advice on how to reach them. In terms of likely endpoints, some participants, mainly individuals with moderate impairment, were informed that their speech would 'never' fully return to what it was before the stroke. Some were told that everybody was 'different' in terms of rate and extent of recovery, whilst others described being told that recovery would be more rapid in the early stages before reaching a plateau. Further still, many participants, mostly individuals with mild dysarthria, were informed that professional interventions were having limited impact and any further recovery was a matter of 'practice'.

Irrespective of information and advice provided, recovery was perceived by most participants as an on-going process, with the exception of six older participants (between 63 and 86 years). These older individuals attributed their stroke and resultant speech difficulties to ageing and consequently 'accepted' their level of recovery and speech capabilities. Of those participants who perceived recovery as an on-going process, some reported that others could understand them, but many believed their speech could still be improved and more therapy and practice would achieve this. However, with increasing communicative abilities, participants resumed some social and recreational roles they had previously fulfilled such as attending church or simply interacting more with people. Some participants also described progress as evidenced by increased listener comprehension and feeling less stigmatized.

Interestingly, the nature of the desired endpoint of rehabilitation varied subtly across participants. Virtually all participants made a clear distinction between being understood and the quality of their speech. From the descriptions given regarding speech and language therapy, the majority of participants appeared to be well informed about their role in the rehabilitation process and appeared to be actively carrying this out. However, the main aim of the rehabilitation process for more than half the participants (mild and moderate) was not just to improve their speech, but to get back to 'normal', with normal being described as how they spoke before the stroke.

Support

Nearly all participants viewed SLTs as the professional group who contributed most productively to improvements in speech and support. Moreover, comments from some participants suggested the role of the SLT went beyond treatment of their communication impairment to provide support on a more personal level. Many SLTs also provided participants with a contact telephone number should they have any problems in between visits or post-discharge.

A number of participants (all of which had a deprivation category of between five and seven indicating low deprivation) reported feeling 'stupid' when doing the exercises provided by the SLTs. This was generally associated with the kind of activities they had to do such as speaking in front of a mirror and repeating articulation exercises described as 'how now brown cow' or 'the rain in Spain falls mainly on the plains'. However, participants recognized that the exercises aimed to improve intelligibility of their speech. Improvements were generally attributed to the use of particular techniques, such as pronouncing problematic sounds and words and the provision of advice on how to make their speech clearer, such as taking deep breaths, slowing their speech down and staying relaxed. Personal attitudes associated with improvements included taking the initiative to improve their speech, being determined and practising. Whilst overall, the input of SLTs was valued, some participants expressed how they would have liked, in addition to receiving more speech and language therapy, the opportunity for the SLT to visit them at home.

In contrast to SLTs, other members of the health care team in both hospital and primary care sectors were viewed as providing limited support. Two participants described late diagnosis of stroke by their doctor (which in turn delayed treatment for their speech), whilst others reported experiences of hospital staff treating them as 'a child'.

Psychosocial consequences of dysarthria

Reduced communication skills as a consequence of dysarthria following stroke can extend beyond the physiological to cause changes in self-identity, relationships, social and emotional disruptions and feelings of stigmatization or perceived stigmatization.

Changes in self-identity

For more than half the participants dysarthria resulted in negative changes in self-identity. Communication difficulties experienced resulted in some individuals feeling 'different'. Participants' and others' perceptions of the speech difficulties were consistently framed around the concept of 'normality' with dysarthria being seen as 'abnormal'. Some participants felt they were now treated differently and experienced discomfort at being accorded sympathy and wanted to be treated 'normal'. There was the potential for this special treatment to have a detrimental effect on the individual's ability to communicate effectively, leading to feelings of embarrassment. In addition, many participants described changes in how their voice sounded which also had a negative impact on self-identity.

Relationship-based disruptions

Communicative disability had wide implications not only inherently for an individual's communicative interactions, but also their personal relationships. Disruption within family relationships was a particularly prominent theme for the two participants who had young children. One participant felt she had not bonded with her youngest child as a direct result of her speech difficulties. She also believed his speech was underdeveloped as a consequence of her reduced communicative

interactions with him. The other participant with young children decided he did not want to see them until his speech was intelligible as he did not want to embarrass them.

Although participants generally spoke about the relationship-based disruptions experienced as a direct result of dysarthria, a few discussed how dysarthria had had a positive impact on their familial relationships. For example, one participant reported that their dysarthria had brought the family closer together, while another (who frequently worked away from home prior to his stroke) reported having a changed, more appreciative outlook on life.

A number of participants described how their spouse would speak for them on their behalf. For some, this was viewed positively, particularly when interacting with strangers. But other participants believed this had a detrimental effect on their ability to communicate and caused tension between couples.

Social disruptions

Dysarthria also had considerable social implications, with more than two thirds of participants experiencing social disruptions. Difficulty keeping up with conversations and making themselves understood resulted in a number of participants actively avoiding specific situations such as social gatherings. This can, in turn, compound social isolation. The one participant with severe dysarthria described limitations on her activity and participation in terms of her inability to make friends.

For many, dysarthria had an impact on everyday social tasks. Speaking to people in shops or by telephone were problematic for many participants, with two thirds reporting avoidance of these situations. Some participants developed innovative strategies for minimizing such difficulties; one individual reported using the self-service desk when shopping to avoid spoken interactions.

Many participants described feeling different and wanting to be treated as 'normal'. However, since many actively avoided situations and changed their social behaviours it could be argued that, to some extent, the participants' social isolation was self-imposed. Nevertheless, examples of other people socially isolating the person with dysarthria and making them feel different were also evident.

Emotional disruptions

The communication difficulties experienced by participants also had associated emotional implications, with nearly all participants reporting emotional disruptions. These emotions could generally be classified as ongoing emotions (general reactions to dysarthria) or situational emotions (emotions that were experienced as a consequence of social situations). Based on the reports given by participants with mild dysarthria, the emotional impact appeared to be disproportionate to the physiological severity of dysarthria.

Ongoing emotions reported were associated with how participants felt about being unintelligible and included feeling 'helpless' and 'scared'. Though individuals with severe depression were excluded, some participants described depression and a lack of confidence as a direct result of dysarthria. Some were generally angry or annoyed that their speech had been affected, or with how their speech had been affected. One participant, who had mild dysarthria, reported to 'hate' himself

because he felt he could not speak properly. Other participants reported getting upset as a result of having to repeat themselves.

Participants reported feeling embarrassed, angry, frustrated, upset and stupid in the face of others' reactions to them, which included family, friends and health care professionals. Interactions with strangers evoked a particularly strong emotional reaction.

Stigmatization/perceived stigmatization

Two thirds of participants raised issues relating to stigmatization as a direct result of their dysarthria. People with whom the stroke survivors came into contact had the potential, or were perceived to have the potential, to make moral judgements or inferences about them. This suggests that the participants viewed the ability to speak intelligibly and at a reasonable speed not solely as an objective task or skill, but as a behaviour that was key to the making of social judgements by others (Williams 1999).

Although participants reported experiencing communication difficulties with friends and family, communication difficulties with strangers appeared to be even less acceptable and associated more frequently with stigmatization. Reports of stigmatization were as common, and the impact as great, for participants with mild dysarthria as it was for those with moderate, irrespective of age, gender and socio-economic circumstances.

Impact of co-existing post-stroke impairment(s) on the experiences of the speech disorder

More than two-thirds of participants had some degree of associated physical disability as a result of the stroke (Barthel score of between 50 and 95, supplying at least 50% of the effort with the activities of daily living). These concomitant physical problems generally had an impact on the individual's independence. Participants reported difficulties completing the housework, shopping or using public transport independently. For some, not being able to drive following stroke was an important factor.

The impact of co-existing stroke-related impairment(s) varied. Current physical problems were more problematic for some than speech difficulties. For example, difficulty writing, not being able to drive and not being able to stand for long periods of time were perceived by some as barriers to returning to work. However, for other participants, speech difficulties were seen as the main obstacle to returning to work. Interestingly, the physical difficulties experienced were not coupled with the same feelings of frustration, anger, embarrassment or marginalization that were generally associated with the speech impairment. This suggests that, overall, dysarthria had a greater effect on individuals than did physical difficulties.

Discussion

Summary of the main findings

Participants' experienced significant and ongoing disruption to psychosocial well-being and self-image, irrespective of the severity of dysarthria, age, gender, socio-economic circumstances or perceived recovery. Restrictions in performing everyday

tasks (particularly communication on the telephone and with strangers) and feelings of stigmatization in a variety of social situations were common. The ability to speak in a range of ‘normal’ ways was a prominent theme throughout the interviews with speech generally being viewed as a behaviour prone to defining social judgements by other people (Williams 1999).

Impact of the severity of dysarthria on the experience of the speech disorder

Unsurprisingly, participants in this study experienced communication difficulties. What is notable, however, is the impact of these difficulties was equally significant for mildly affected patients as it was for those with moderate impairment. Participants consistently identified problems with their speech as a major consequence of their stroke, even where their dysarthria was perceptually considered mild. No distinct differences in experiences were seen between those with mild and moderate dysarthria with participants in both groups experiencing changes in self-identity, relationships, social and emotional disruptions and feelings of stigmatization or perceived stigmatization.

Implications for SLT clinical practice

Brumfitt (2006) highlighted that SLTs consider psychosocial aspects of aphasia to be either important or very important to the overall management of their clients. These findings reflect the attitudes of the SLTs, and study participants, who attended a dissemination day as part of their involvement in the present dysarthria study and also recognized the importance of addressing the psychosocial impact of dysarthria. Therapy should account for, evaluate and address psychosocial issues with activity and participation elements of dysarthria being considered when developing therapy goals. Different ways of providing this care involving utilizing various members of the speech therapy team and/or patient–carer dyads and self-support groups should be explored. In addition, it is important that SLTs are aware that the impact of dysarthria on the individual can be disproportionate to the physiological severity. Whilst participants perceived their speech as improving, achieving ‘normality’ remained an elusive goal and failure to meet this goal was associated with disappointment and frustration. Goal setting during rehabilitation should therefore address the issue of aiming for ‘normality’. SLTs should promote the concept, particularly with individuals with mild impairment, that whilst their voice may sound different to how they spoke prior to the stroke, their speech is (or with rehabilitation, may be) intelligible to others. Over the long term, community or web-based virtual therapy and support services, such as used for aphasia (e.g. Speakability), may be an efficient and effective means to allow individuals with dysarthria and their carers to share experiences of rehabilitation and generate conceptions of ‘normality’ that are not defined by other people.

Overall, SLTs were seen by participants as having contributed most usefully to improvements in speech and providing support. However, many participants reported wanting their therapy sessions to continue over a longer period of time and have the opportunity for the SLT to visit them at home. Many of the SLTs provided participants with a contact telephone number should they have any problems in between visits or post-discharge. However, as discussed earlier, the fact that talking

on the telephone was now problematic for many of the participants suggests this may not be the most appropriate way of providing further support.

The individuals that participated in the study were between two and 34 months post-stroke. No distinct differences in experiences were evident on the basis of time post-onset, indicating that the psychosocial impact of dysarthria following stroke can be long-term. The need for a longer-term approach to the rehabilitation of stroke patients has become increasingly recognized in the literature. The knowledge that individuals with stroke-related dysarthria can experience long-term psychosocial problems should therefore be taken into account by SLTs at discharge and in the delivery of longer-term support. Psychosocial issues could, for example, be addressed during an additional discharge consultation with a member of the SLT team 6 months after completion of the initial intervention.

Research into the impact of dysarthria on the individual has received little attention. We found the level of impairment to be disproportionate to the level of handicap, with the impact being equally significant for mildly affected individuals as it was for those with moderate impairment. This finding further strengthens the RCSLT's (2005) view that it is important to elicit from the individual their understanding of dysarthria and what *they* consider the impact of dysarthria is, irrespective of physiological severity.

Carers

There is evidence that caring for an individual post-stroke has an impact on carers' emotional health, leisure activities and family relationships, but the specific challenge of caring for an individual with stroke related dysarthria has not been explored. As part of this study we had hoped to conduct focus groups or, if more convenient, one to one interviews with carers to explore the impact of dysarthria on them. However, only three carers consented and one-to-one interviews were used instead. Interestingly, the carers interviewed primarily talked about the impact of dysarthria on the individual, which in each case was their spouse, before the impact on them. This, together with the reluctance of other carers to participate, may testify to the challenges of caring for someone with dysarthria and the guilt associated with raising their own concerns. More large scale research focusing on carers of people with stroke-related dysarthria is needed to gain a greater understanding of their experiences and needs.

Conclusion

Treatment of the pathology and impairment elements of dysarthria are important and should not be dismissed. However, there should be a balance in rehabilitation programmes to consider fully the psychosocial impact of dysarthria following stroke on individuals. The apparent mismatch between the physiological severity of dysarthria and the perceived effect on individuals' lives highlights the potential impact of unwitting exclusion from appropriate treatment of individuals with mild speech difficulties. Speech and language therapy interventions might need to go beyond the speech impairment to address and promote psychosocial well being and reduce the likelihood of feelings of stigmatization and changes in self-identity, irrespective of the severity of dysarthria. Reasons for the lack of linkage between

severity of speech disorder and psychosocial impact should be examined further. A quantitative investigation of the relationship between severity and psychosocial impact may generate insights into determining factors.

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Appendix A: Interview topic guide

Introduction

When did you have your stroke? What have things been like since then? What could you/can you not do?

Stroke context

Severity of stroke? Why? Have things changed over time?

When does it affect you more or less?

Anxiety Emotions Tiredness Other

Recovery process?

Dysarthria

How speech was affected?

Can you make your speech better?

Controllability Self Efficacy

Why speech was affected by the stroke?

Situations where people have had difficulty understanding?

Social Recreational Occupational Friends

How do you know that they are having difficulty understanding you?

How did you feel when this happened?

Self worth Emotions Esteem Experiences

Social situations

Social situations found most difficult because of your speech?

What makes these situations difficult? What do they have in common?

What makes these kinds of situations easier to deal with?

How do you avoid being in these kinds of situations?

Psychological reactions and isolation

Is it usual for you to feel like this (i.e. as isolated or down ...)? Have you ever felt like this before your stroke?

Reasons for feeling this way? How much is the speech part of it?

Who have you talked to about your feelings? What did they do for you?

Do you still feel as (down)? What made the difference? What will make the difference?

How can health professionals help?

Impact

How has your speech difficulties affected your life?

Domestic Occupational Recreational Psychosocial Interaction with family?

Less opportunity to talk now? Why/how can this change?

Management

What have you done to make your speech better?

Exercises Slow down Avoidance

What have others contributed to this? What support has been helpful/unhelpful? Information/advice received?

Carers Family GPs SLTs Other

Treatment received for speech?

How could other people have helped you more?

Support Advice Information Exercises

How did you find talking to health professionals about your speech?

Responsiveness Listening Understanding

Who is the most appropriate person to help people with such speech difficulties? What do they do?

Help seeking Interface Consultations

Communicating with friends/family/health professionals? Changes over time?

Life goals associated with speech?

Employer and occupational issues (if applicable)

How will job be affected?

Informing employer of stroke and speech difficulties? What you could and could not do? What was said about the speech difficulties?

Difficulties and ways forward discussed?

Employers' reaction and concerns? How concerns were addressed?

Adjustments made since returning to work?

Own business/self-employed (if applicable)

Difficulties that would affect how you could do your job?

Who did you discuss your situation with? (bank, family ...) Issues discussed? What were their reactions to you? How did they help or hinder things?

What things did you do to keep your livelihood going?

Is there anything related to what we talked about you would like to add?