CHAPTER 1

1 Introduction

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Why is this topic of importance?

The subjective experience of people with acquired communication impairments has been of concern to health professionals for a long time, with contributions to knowledge coming from a range of professional fields, most particularly from Speech and Language Therapy and from Clinical Psychology. This book creates the opportunity to discuss these contributions. It aims to bring together material on psychological well-being from the academic literature and to discuss how it may be applied to professional practice with people who have acquired communication impairments. It allows the perspectives of different professional groups to contribute to this area of work and creates opportunities for working across boundaries in the healthcare context.

Although it has been widely recognised in the literature that people with acquired communication impairments have intense emotions and distress about their situation, specific methods for helping have only emerged slowly. Various influencing factors have affected progress. For example, aphasic speakers may often be excluded from research into psychological well-being, if they are viewed as unable to comply with the data collection because of their linguistic difficulties. Typically, the data collection would involve a questionnaire, and the severely impaired aphasic speaker may find this too complex to respond to. This has therefore limited the research evidence. In addition, methods for analysing the psychological or emotional responses of participants with communication impairment have been unavailable until recently (Gainotti, 1997). Our understanding of emotional reactions to brain damage has had to be drawn from the non-communicatively impaired population, and this theoretical framework may not transfer well.

For people who experience a stroke, brain injury or a progressive neurological illness, the loss of communicative ability can be a shattering experience. Ordinary everyday conversations may become impossible, complex discussions are out of reach, and access to a normal social life and employment may be difficult. Although there is an abundance of material about how to describe the different types of communication impairments, the way that loss of communication relates to psychological well-being still

needs to be brought into a wider academic and professional arena. As Tanner and Gerstenberger (1988) state, 'a person's psychological status cannot be separated from the neuropathology of speech and language' (p. 84).

By far the greatest amount of research has been done into aphasia and the depressive reaction (Code and Herrmann, 2003). It is not clear why this should be, other than clinicians observe depressive reactions in aphasic speakers and are motivated to seek solutions. It does not really explain why there is so little research into anxiety impairments and acquired communication impairments, or why subjective experiences of people with progressive conditions have been so under-researched in comparison. Recently De Wit *et al*. (2008) examined over 500 participants who were post-stroke and not specifically people with acquired communication impairments. In this large multicentre study the results showed that the prevalence of anxiety was 22–25% and depression 24–30% during the first 6 months post-stroke. The authors noted that anxiety was almost as common as depression. This result may provide useful guidance for understanding the prevalence in the communicatively impaired population.

The purpose of this book is not to examine the nature and description of acquired communication impairments nor is it to focus on the social model of disability and how this challenges traditional therapeutic methods. These aspects are already addressed in other formats. This book aims to look specifically at current thinking on psychological well-being and how it may be managed in these populations. Few books look at this critical field although the needs of this population are great. It is intended that the multidisciplinary format will draw from a wide variety of sources and allow the reader a greater understanding than with a uniprofessional approach.

Types of acquired communication impairments

The main types of communication impairments that affect people with acquired aetiologies are language based or related to motor speech difficulties.

Aphasia (often termed 'dysphasia')

One of the most common causes of aphasia is stroke, but this language impairment can be seen in brain injury and cerebral tumour (Kolb and Whishaw, 2003). Acquired disordered communication, not aphasia, can be seen in other conditions such as dementia or traumatic brain injury (Royal College of Speech and Language Therapists, 2005). Aphasia is an acquired condition and occurs because of a focal lesion to the dominant hemisphere of the brain. The key symptoms focus on the impaired ability to understand spoken or written language and the impaired ability to use spoken and

written language. The symptoms will vary in degree of severity across these modalities and there may be a great amount of individual variation in how these communicative impairments present. Essentially, aphasia can show a breakdown in any of the linguistic domains: syntactic, pragmatic, morphological, lexical, semantic, phonological and orthographic. It is important to note that these domains do not function independently: associations between them can be observed in different forms and these will be individual to the patient. There may also be difficulties with non-linguistic communication, such as gesture or drawing. Diagnosis of aphasia can be complicated by the presence of other conditions that may co-occur, such as apraxia of speech (apraxia of speech occurs as a result of disturbances of motor programming of movements for speech, including selection, programming and control of movements (RCSLT, Communicating Quality, 2006).

The most important development in the understanding of aphasia has been the application of a cognitive neuropsychological framework (Shallice, 1988) for explaining language breakdown. This model permits understanding of function in cognition and language impairment. Clinically, it allows detailed assessments of language that reveal specific modules or routes between modules. This has allowed a much closer understanding of where language breaks down in the individual and therefore creates opportunities to focus on specific areas of deficit more easily. Furthermore the direction for assessment is primarily on the description of the individual profile rather than on group patterns of aphasia. This approach to understanding aphasia has been a significant direction in research, from building on original understanding (Ellis and Young, 1988) to applying the model to assessment (Kay, Coltheart and Lesser, 1992; Byng, Kay, Edmundson and Scott, 1996). Approaches to intervention have been extensively developed (Howard and Franklin, 1988; Whitworth, Webster and Howard, 2005). Using the social model of disability as a framework to understand the individual response to being an aphasic speaker has also been applied through work on the psychosocial effects (Code, 2003; Parr, 2004; van der Gaag *et al*., 2005). Research into the emotional consequences of aphasia has been reviewed in relation to rehabilitation (Code and Herrman, 2003).

Acquired dysarthria

Now commonly described in the plural, acquired dysarthrias are a group of motor speech disorders that result from damage to the neurological control systems governing the movements and integration of the muscles that control speech production. The symptoms will be directly linked to where the damage has occurred in the central or peripheral nervous system, and therefore the physical components involved in respiration, voicing, articulation or prosody can be implicated. These components also have other functions, of course, so the impact may extend beyond speech and

typically can include other, non-verbal, activities involving the vocal tract, such as chewing, swallowing or facial expression. The degree of functional limitation can vary widely, however, from a very mild paresis of the facial muscles, with similar relatively minor speech limitations, to severe limitations of speech, voice and swallowing. (For further information, see The Stroke Association's website: http://www.stroke.org.uk/information/all_about_stroke/rehabilitation/communication/dysarthria_and.html.)

Yorkston, Beukelman, Strand and Bell (1999) describe two main groupings of acquired dysarthria. The first group is caused by stroke or traumatic brain injury and is characterised by an acute onset, followed by a period of recovery, which will later become a stable, long-term level of functional limitation. The other group is described as 'progressive/degenerative'; this includes conditions such as Parkinsons's disease (see the Parkinson's Disease Society website: http://www.parkinsons.org.uk/default.aspx?page=7237) and motor neurone disease (see the website of the Motor Neurone Disease Association: http://www.mndassociation.org/), where the pattern of the dysarthria may follow a fairly typical pattern of gradual limitation that follows the progression of the other physical symptoms (Patten, 1996). A slightly different pattern occurs with multiple sclerosis (see the website of the Multiple Sclerosis Society: http://www.mssociety.org.uk/), which Yorkston, Beukelman, Strand and Bell (1999) identify as 'progression/remission', again following the pattern of the physical symptoms.

Brain injury

Camilla Herbert, in Chapter 3, describes the communicative impairments that may result from brain injury. Because of the nature of brain injury, the communicative symptoms can vary greatly (see the Headway website: http://www.headway.org.uk/). Types of aphasia may occur and symptoms of dysarthria may also be present depending on the site of the lesion. Further communicative difficulties are often seen including difficulties in the pragmatic aspect of communication, such as turn taking in conversation, maintenance of a topic in conversation, interpreting subtleties (such as the use of analogies in language, differences between sarcasm and serious statement) and keeping up with other speakers when the conversation is fast paced. There may be reductions of verbal fluency, word coherence and content aspects of language such as relevance of word choice (Royal College of Speech and Language Therapists, 2005).

Progressive forms of aphasia

Originally defined by Mesulam (2001), primary progressive aphasia (PPA) is described as gradual and progressive deterioration in various components of language function (word finding disturbances). It can proceed to impair grammatical structure and comprehension of semantics. It usually begins with mild word finding difficulties and ends in its most severe

form, with little meaningful use of language. This progression is generally considered to exist within the context of preserved other abilities such as memory, visual processing and personality, so that all difficulties within the first two years are associated with the language impairment and not other factors. There is debate within the literature about the form of other types of progressive language impairments, which present as either non-fluent aphasia or semantic dementia. There is much variation in the diagnosis and management of this condition.

What is important to note about the range of communication impairments that are acquired is that their presentation will be of an individual nature. Prior to the onset of the illness the experience of the individual is of knowing only that communication is easy and straightforward. At the onset of the illness, the capacity for easy communication is lost and it is this personal struggle with the loss of a previous skill that creates the personal difficulties for the individual. Our knowledge and understanding about the range of communication impairments grows all the time, but it is the emotional consequences of the loss of communication that must be understood more fully (Royal College of Physicians, 2005; Royal College of Speech and Language Therapists, 2005). It is likely that more understanding of this will follow in the future as the assessment and diagnostic methodologies become more sophisticated and the number of health professionals with specialist skills in these conditions increases.

Psychological well-being

Although a broad concept, the definition of psychological well-being usually includes levels of mood and mood disturbances, such as depression and anxiety. Signs and symptoms of depression include feelings of a low mood for a long period of time, feeling irritable, difficulties in concentration, tiredness, inability to derive pleasure, feeling numb, empty and hopeless, sleep disturbances, feelings of guilt and negative thoughts. Symptoms of anxiety include both psychological and physical effects. The key physical components include feelings of tightness in chest, nausea, loss of appetite, butterfly feelings in stomach, pounding heart, muscle tension and sweating. The psychological features include fearful anticipation, inability to concentrate, constant worrying, heightened alertness, sleep disturbance and a strong link with depression. Both conditions have further specific features such as bipolar depressive symptoms or severe panic disorder, but these are generally not included in relation to symptoms associated with acquired brain damage. Self-esteem or self-worth is usually considered within the broad concept of well-being, with the most important difference being that depression and anxiety have a medical diagnosis and self-esteem does not. Typically, people who are depressed will have low self-esteem, and, probably, people with high self-esteem are

unlikely to be depressed (Brumfitt and Sheeran, 1999). Further discussion of these conditions will be developed in subsequent chapters.

Factors affecting psychological well-being in the person with acquired communication impairment

In order for the authors in this book to consider the psychological effects of acquired communication impairment, it is necessary to consider contributing factors. Most authors will agree that the specific communication impairment itself will not account for the whole of the psychological impact. Other aspects will influence how the individual reacts to the loss of communication capacity. Gainotti (1997, p. 635) notes that the emotional impairments associated with becoming aphasic are complex to disentangle, and include the type of brain injury, the effects upon cognitive, communicative and motor function, the premorbid personality and behavioural factors, and the patient's own social context.

Thus, even though people with acquired communication impairments share a common diagnosis, they remain individuals who have different responses to the effects of the brain damage. In terms of psychological well-being particularly, there will be differences influenced by the context in which the individual lives. These aspects deserve some recognition now, at the start of the book, to highlight their relevance.

The complexities are represented in Figure 1.1, which shows the range of factors influencing the individual's personal experience of acquired communication impairment. Broadly, these can be subdivided into internal and external factors.

Internal factors

These relate to the individual person and include the demographic profile as well as the nature of the physical condition. Further, the type of the communication impairment and particularly its impact upon the individual's life will be internal and unique to the person. There will also be variation in how a person feels and how well they can communicate their inner feelings. This may have a direct influence on accuracy of diagnosis and whether professionals offer psychological support, as the person who can communicate that they feel sad and distressed is more likely to gain support and help than the person who cannot make this clear. Thus, difficulties in communicating feelings may be part of the overall communication impairment profile or there may be specific challenges in talking about feelings that may influenced by family and cultural tradition. An individual may have grown up in a family where talking about feelings was seen as something weak or shameful, and therefore to express distress in a health context may not be part of the individual's typical behaviour. Past history of mood disturbances can also influence how likely an individual is to experience this as part of their condition, and

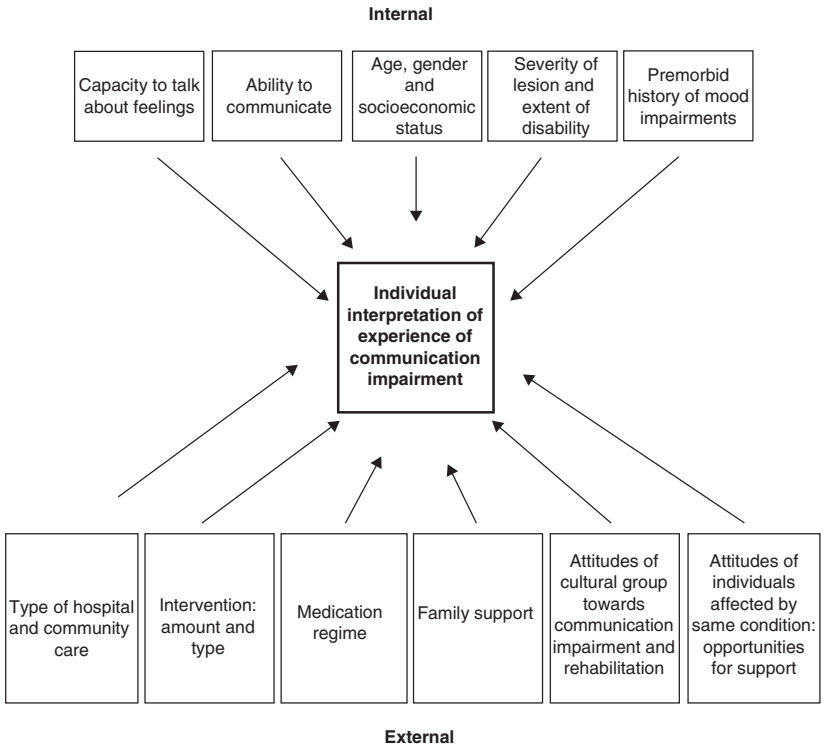

Figure 1.1 Factors influencing the individual's personal experience of acquired communication impairment.

it may be that the individual's response to the stress of communicative loss reflects how emotional responses developed at an earlier stage in the individual's life. Clearly, a tendency to mood disorder will have implications for the coping abilities of the patient after the acute illness stage, and this is discussed by Barton in Chapter 7 on interdisciplinary approaches to managing stroke. A family history of mood disorder is also a possible marker for future difficulties for the patient.

External factors

These include the features of the context in which the individual experiences the condition, and can include social and attitudinal aspects of other people who may be close to the individual, or broader aspects such as cultural understandings of disability. These factors will also include type and nature of healthcare and therapeutic interventions, which may vary in amount and when offered in relation to the time since onset of the condition. Interventions may or may not include direct work on psychological well-being. The medication regimes may also have an effect upon mood in a positive or negative way. Family support will also be relevant, where

one individual may have longstanding support from a spouse whereas another may be isolated, living alone and unable to access services easily.

Because of the variation in how the individual interprets and copes with communication impairment, the management of the individual and the support required will have to be adapted to special needs. For some individuals the environment may be the aspect that can be changed. For other individuals, attitudes of their cultural group may have the biggest impact upon their experience of coping. Significant developments in the understanding of social influences on the person with acquired communication impairments have been made in recent years, which have changed the course of intervention approaches (see the Connect website: http://www.ukconnect.org/index.aspx; Pound *et al*., 2000; Parr *et al*., 1997; Duchan and Byng, 2004; Parr, Duchan and Pound, 2004). The social model has challenged current assumptions about approaches to therapy and the increased awareness about the environment, including health professionals' own attitudes to therapy. In recent years there have been huge shifts in attitudes towards enabling patients to cope positively with acquired communication impairments and not be stigmatised. Other factors may include the experience of healthcare and rehabilitation, which may not be available easily or for long enough or be sufficiently specialised. This may be an external influence over which the individual has little control. Different approaches to healthcare may mean that the individual remains isolated from other people who have similar conditions and experiences. Volunteer services may provide these opportunities, or they may be accessed through professional health settings.

Medication

It is not the brief of this book to recommend appropriate medication for these populations, but it is worth noting current views about its use. Until recently, very little has been written about the specific use of medication in the treatment of psychological well-being in people with acquired communication impairments. The Royal College of Physicians (2005), in their published guidelines on depression following acquired brain injury, evaluate the role of antidepressants. Particular note is made of the fact that none of the existing antidepressant agents has a UK licence that specifically approves use for acquired brain injury. So that in spite of the recognition of psychological responses to acquired brain injury, very little development has taken place to enhance psychological support by medication for this group of people. Clearly, this needs to change. Apart from the obvious need to help individuals feel more psychologically stable, the potential impact upon responses to rehabilitation must not be underestimated. The individual who is depressed is potentially more likely to feel unmotivated to engage fully with rehabilitation approaches.

Direct medical advice to prescribing clinicians is, however, provided in the published report (2005), which recommends the use for depression of

agents from the main classes of relevant medications. These are broadly: selective serotonin re-uptake inhibitors (SSRIs), such as fluoxetine, citalopram and escitalopram; and other antidepressant agents, which are recommended for use as 'second line' drugs when SSRIs have not been effective. These have not been fully tested in the context of acquired brain injury. Doctors are recommended to use a specific SSRI such as citalopram or sertraline as the most relevant medication. Anderson (1997) also recommends the use of SSRIs, particularly citalopram, based on a series of studies during the first year post-stroke. Anderson recommends this drug for patients with post-stroke pathological crying. The Royal College of Physicians' (RCP's) report also notes the untested use of St John's wort and its possible use with acquired brain damage. The current guidelines state that patients must be monitored throughout any medication regime for treatment of depression. One criticism of past practice included in this publication is that antidepressants have been prescribed routinely in haste and that this may not be appropriate for all.

Consideration of further aspects

There remains some debate about whether subjective experiences of well-being are due purely to brain damage (i.e. site of lesion, severity and nature) or to secondary reactions that are emotional responses to the predicament the individual experiences. One confusing presentation in people with acute acquired communication impairments brought about by brain lesions is a set of symptoms that have been given different labels in recent times: emotional lability or post-stroke emotionalism or pathological crying (Anderson, 1997). These symptoms usually include rapid changes in mood where very strong emotions are shown such as extreme crying or laughing or even an increase in anger. The expression of these emotions may not reflect the true feelings that the individual has, but are associated instead with damage to the part of the brain that affects emotional awareness and emotional control. The presentation of the feeling is not necessarily associated with an emotionally significant thought or context. It may be the case that thoughts of close family may bring on these emotions but the behaviour may also be associated with common everyday interactions such as making arrangements about meals. Anderson (1997) reported that post-stroke pathological crying is more common than generally understood and quotes studies where 20% of patients during the first year post-stroke have shown these symptoms. In severe cases Anderson (1997) reports episodes of post-stroke pathological crying as occurring up to 100 times a day. These may be very difficult symptoms for the individual to cope with. Furthermore, potential difficulties are created for the professional in making an accurate diagnosis of true depression or pathological crying. Pathological crying or lability may be seen in other neurological conditions, such as motor neurone disease and multiple sclerosis.

Effects of psychological well-being on communication

Although primarily this discussion is about the effect of the communication impairment on well-being, there is a small literature that describes the effects of low well-being on speech characteristics. For example, there has been some research into the effect on communicative behaviours when a person is experiencing depression. In terms of depression, communication shows a reduced speech tempo, with a listless flat manner and reduced volume, stress and rhythm. There may be increased pausing. Language is described as being limited to essential communications about everyday matters. 'Depressed or low mood restricts language and renders it colourless and limited' (France, 2001, p. 76).

Auerbach and Karow (2003) discuss issues associated with assessment of mood and affect in patients with neurological disorders. They alert the reader to the factors that may influence understanding of different conditions. For example, the neurological condition may limit how well the individual can communicate feelings, and this is potentially a risk situation if the individual is severely depressed but unable to express this. Auerbach and Karow (2003) refer to four factors that can influence this situation. Firstly, the loss of functions resulting from the brain damage will create a natural response to loss that will make the individual sad and possibly depressed. Secondly, the lesion itself can affect the individual's behaviour, as in people with Parkinson's disease where changes to movement abilities may create impairments in communicating by gesture or using facial expression. Alternatively, some neurological conditions may make the individual appear as if they are distressed, as in the case of emotional lability, when in fact they do not have a mood disorder. People with some forms of neurological disease may experience limitations of cognitive function so that normal or typical expression of emotion may emerge in a more atypical form, as in ritualistic behaviours or self-harm. Finally, the role of medication must not be overlooked in this area, because medications can affect mood and behaviour. Auerbach and Karow (2003) suggest that abilities should be evaluated in order to determine whether the individual does experience legitimate emotional disturbance. They advocate that the individual ability to recognise facial and gestural expression and speech prosody should be investigated. In terms of expressive non-verbal abilities they state that the individual's capacity to use facial expression, affective speech prosody, gesture and general motor activity needs evaluation. In relation to verbal abilities, they recommend assessment of comprehension of emotional words and humour, and for expression the use of emotional language and humour should be investigated. To some extent this framework can be applied to the context of people with communication impairments, although clearly the specific difficulties in communication would need further examination. This is elaborated further by Stern, Daneshvar and Poon in Chapter 6.

Gravell and France (1991) use the analogy of a vicious circle where poor communication leads to depression, and depression makes the individual less good at talking, which then can lead to a further reduction in mood. The individual may lose communicative abilities through acquired brain damage and may experience distress at this loss. Distress leading to depression can result in communicative changes. Thus the patient may have communicative difficulties due to aphasia and secondary communicative difficulties due to depression. This may be of importance to the practitioner in terms of differential diagnosis.

Personal descriptions

There are many personal descriptions of acquired communication impairments in the literature (Moss, 1972; Newborn, 1997; Mackay, 2003). Individuals with acquired communication impairments are confronted by their changed communication abilities in almost every interaction they have with others. In his exploration into the social construction of aphasia, Mackay (2003, p. 825) describes the person with aphasia who 'lives surrounded by aphasia in every part of her/his life'.

Professionals involved with people with communication impairments are always concerned about how the individual responds to the changes in communication ability. What is often unclear is whether certain feelings are common to all or whether these feelings differ between individuals. Does everybody feel the same? Do feelings change over time? How do you come to understand yourself as a person with an acquired communication impairment? Personal accounts are essential to the knowledge base as it is only with the reports of subjective experience that professionals and the general public can gain a good understanding of the implications of loss of communicative abilities. There are now many personal accounts that reflect the feelings of the individual with acquired communication impairment, and the historical accounts discussed earlier highlight the variations in how people respond to this situation.

Brumfitt (1989) reports the personal experiences of a university lecturer who became aphasic, with a commentary on his struggle to adapt to his changed circumstances. The patient reported his distress on realising his academic skills were now much more limited and how this affected all aspects of his life. In a comment that revealed his inner struggle he said: 'it's so hard trying to become a person again' (Brumfitt, 1989, p. 5). One question posed by this report is about the specific effect on the identity of people with language loss compared with those who experience brain damage with no impact on language. Is the struggle to make sense of the situation more problematic with a language impairment? Intuitively it seems that this must be so. Individuals need language and potentially, inner language, to be able to make sense of their situation, and so with limited language abilities the adjustment to change is more challenging.

Identity

The recognition of loss of identity during the recovery stages has been frequently reported in other health conditions. Bury (1991) describes the 'biographical disruption' that occurs at the onset of chronic illness where the known identity and context experienced by the individual is lost. Charmaz (1995) has focussed on the changes to identity in people with chronic illness, and described the interaction between bodily changes and identity. As individuals adapt, either to a recovery process or a set of bodily changes that are deteriorations in capacity; the sense of who they are has to move with that process. Goals and aspirations become adjusted to what is possible, but the process of being able to adapt and cope with the changed self can be very painful. There has been some debate in the academic literature on stroke, about whether the individual creates a new sense of self because of the disruption; or whether the individual views the effects of the stroke as separate to the pre- and post-stroke sense of self which, remains a coherent thread (Faircloth *et al*., 2004). Parr *et al*. (1997) refer to this loss of identity in aphasia, where the onset of aphasia disrupts the continuous life course of the individual. Furthermore, the interaction between the experience of the communication impairment and society's reaction to it has been recognised through the work of various authors (Jordan and Kaiser, 1996).

Personal experiences

Some examples of personal experiences are included here. They reveal the personal struggle to cope with the unexpected development of an acquired communication impairment.

Aphasia

M qualified as a doctor in 1978, having been a successful medical student. She had a special interest in dermatology, and worked in the local hospital clinics as well as being a partner in a city centre general practice. In 1994 she was diagnosed with a space-occupying lesion (origin undetermined) and underwent neurosurgery. She was left with a degree of aphasia. In Box 1.1 she recalls her early experiences after the surgery.

Box 1.1 M's early experiences after neurosurgery

'You didn't know whether anything was going to come out . . . you knew you were thinking but whether you were going to be able to express yourself . . . and it was case of the words were there but they didn't seem to be in any order and they didn't seem to be stored

properly. It was as if somebody had gone into the library and thrown all the books in the air.'
'And the number of cups of hospital coffee I ended up with because I said yes rather than no. The number of people I confused and said good morning to; you know any greeting would have come out. Not particularly 'good morning' it could have been 'bye bye'. The words were there but I couldn't guarantee what I was getting.'

M was able to describe her experiences in relation to well-being in a vivid way. Initially the interviewer asked her about whether healthcare staff acknowledged her feelings and offered her guidance or medication.

> M: 'No . . . I think I was seen as someone who had had a traumatic episode in my health and I ought to feel that I was lucky to be alive and to be thankful'.

Box 1.2 contains her further comments on the loss of her well-being.

Box 1.2 Further insights from M into her loss of well-being

'Very very upset. Words had always been top priority to me . . . er I suppose one would say it was depression it was the big black hole you thought you were never going to get out of . . . I was very tired and even now if I work with words I'm much more tired than if I do physical work. And it was I suppose part of the nature of the beast . . . there's no point in crying because it doesn't do anything apart from give you a red nose but em there was the feeling it would have been better to just die rather than have the hassle of trying to fight back.'
'It feels it and er it's I suppose more then anything else it is the fact . . . I was there, I was willing, I wanted to get better, there wasn't any point at staying at the level I was at. I either had to top myself in my mindset . . . or I had to get better . . . '
'There are some times when to express your extreme despair you just want to howl you can quite see why the women keen ('to lament the dead', Irish Gaelic term, *Collins English Dictionary*) after a bereavement . . . there are just no words how despairing you are and I think that is the worst aspect that nobody actually acknowledges that that is where you are starting from and that's where you are going back to if things go wrong.'
'It's at times just so difficult to try and explain how demoralised you feel'.

The aphasia had a major impact on M's everyday life in relation to her career and social life. Her comments about this are in Box 1.3.

Box 1.3 How aphasia impacted M's career and social life

'I had a bit of a paralysis but I have sorted it out over time. But I can cope. The ability to read had gone as well. There is no enjoyment in watching TV if you can't make out the nuances or anything else. And when I wanted to write a letter of thank you to the nursing staff and I wanted to spell the word 'whilst' . . . I had 14 different attempts and not one of them was the right one. My mother kept them. Basically once she had shown me it . . . yes it was obvious, but even now, if I try if there's something that you need to sound out phonetically . . . I don't understand why. It's almost as if the connection isn't there.'

'I had to retire because basically I hadn't got the health to go back in because they needed me back in two years and it was a city centre practice . . . a lot of hands on and so I was retired.

'Sometimes I've paid to go to the theatre and I can't make out what's going on the stage and you're hesitant to say anything as to whether they're not being very clear with the diction or whether it's your filters which have gone and so you find yourself very diffident about criticising anything which might be bad in case it's your competence . . . enjoy it or understand it. I used to have a couple of foreign languages but they've gone completely.'

'Also if there is a lot of outside noise and even on a good day if I was trying to have this conversation with you and there was someone with a loud voice here then there's no way I can hear myself think. So that is major problem now . . . if there are other noises then the concentration isn't good enough to shut them out'.

M was asked to describe other people's attitudes towards her since becoming an aphasic speaker. Her reflection of this (Box 1.4) includes concerns that professionals failed to see the extent of her personal loss. Her extensive abilities as a doctor with a very good education could be overlooked because of the way aphasia was interpreted by health professionals. It is too easy to use a benchmark of whether the individual can make basic requests and manage routine daily activities without due regard for the individual variations in how people live their lives. Those people who rely heavily on high-level language skills will face many challenges when coping with an acquired communication impairment because of the difficulties in accessing their premorbid status.

Box 1.4 M's frustrations with the attitudes of others

'To be told I ought to be thankful that I'd got speech at whatever level . . . I couldn't read philosophy . . . I had before and I wanted to again . . . I wanted to make sense out of it and in the early days it's so difficult. I think it was the fact that I was being patronised . . . you know

it puts you back very much to the childlike model where you feel like kicking their shin!'
'I was made to feel that I was being selfish in that I was wanting more, that I ought to be glad that I was as good as I was and that a lot of people were worse than that. And when I pointed out that a lot of people weren't as bright as me in the first instance it was when I got some really quizzical looks . . . why because you have had a medical catastrophe . . . why shouldn't you be striving to be what you were before? That is very patronising.'
'Most of us would settle for 75–80%, but so often the indication was well you've got 25% of what you were . . . think yourself lucky. One of the first times I actually found a torrent of words which was wonderful . . . didn't come out with a lot of sense but the feeling was when somebody told me I ought to consider myself 'lucky'. I started off swearing, which I didn't tend to do much before and asked her why she thought I was xxxxing well lucky when it was the most unlucky thing that ever happened. And she was shocked! Really quite badly shocked . . . well if it makes her think twice about saying the same to someone else . . . it's just as well.'

Help for coping with the effects will come from a variety of sources within the individual's own environment. In Box 1.5, M describes some examples of this, with evidence that friends in an entirely informal way, thought of ways to help. Professional contacts provided a different sort of support, and finally M developed solutions on her own through the walking and reliance on her own company.

Box 1.5 M's sources of help and support

'A lot of the post operative care came from very good friends who encouraged me to do the quick crossword of the *Guardian* as therapy and now I usually miss about 2 clues whereas when I first started I would only get about 2 clues.'
'I've been very fortunate in that I had the support of colleagues and have had one catastrophe when I tried to do one workshop but for the last 2 years I've been president of a European Society and so have had to give presentations . . . so talk about having safety nets and backups . . . it's all written out, someone else can read it if I can't, I explain what's the problem at the start . . . so that I have the confidence to try and do it.'
'Basically it's the silent disability and nobody realises. On a bad day you go for a walk. You don't find people . . . you go and do something that doesn't need words . . . of any sort. I went for long walks. The dog has never been fitter!'

Factors which were recalled as helpful to her sense of well-being are reported in Box 1.6.

Box 1.6 M's route to recovering her well-being

'I had some very good friends in the hypnosis society and they were doing some very good courses in neurolinguistic programming (a type of hypnosis) and that has been very helpful.'
Interviewer: Can you say in any way how that did help you? What did it do?
'It gave framework I think. I think that's where it helped most. The Speech and Language Therapist said that . . . when I'd been away for one of the weekends . . . it was almost as if I'd gone up a gear, I was finding words more easily, it was almost as if they were teaching me how to reopen blocked roads . . . certainly I feel that if you are looking at the metaphor of roads I feel I'm on the country lane rather than being able to go on the motorways.'

Summary

M has built on her abilities throughout this long time of recovery and has created a successful professional life for herself in a different direction. She has been able to increase her knowledge and move forwards, working at international level in a branch of psychological medicine. However, in looking back at her experiences she reported that the support she gained from the healthcare system was limited, in her view. She has been struggling to cope with the loss of her significant skills as a doctor for a long time. M summarised her experience as: 'It's like trying to find your way in a cloud.'

Acquired dysarthria

In looking at the impact of acquired dysarthria on the self concept, Walshe (2003) showed that for 31 participants, the dysarthria had a negative impact upon on the self concept and that this did not change over time. Unlike aphasia, acquired dysarthria represents a different challenge for the individual. For these people their reduced intelligibility may affect the success of their communication with others and they may face prejudice from listeners who perceive their speech as 'slow' or even as someone who is 'drunk'. Yorkston, Beukelman, Strand and Bell (2001) examined the subjective experiences of people with multiple sclerosis who have associated dysarthria. As part of the analysis of in-depth interviews, one of the emergent main themes was 'communicating is unpredictable'. Part of this theme referred to individuals'

perceptions about being treated differently because of their speech. One participant recalled a difficult interaction with a store manager. She described the manager thus: 'she just looked like I was driving her nuts, like I was really frustrating her and bothering her' (Yorkston, Beukelman, Strand and Bell, 1999, p. 134). Over time these difficult experiences may influence how the individual develops an understanding of self and identity.

John is 75 years old and worked before retirement as a pharmacist. He had a left cerebrovascular accident (CVA) in 2003 and was left with significant difficulties with dysarthria. He was able to write about his experiences and these are presented below. In Box 1.7 he describes the early stages of his experience.

Box 1.7 John recalls the immediate aftermath of his stroke

'I cannot remember much after this but I was told that I had suffered a mild stroke. I had another stroke a few days later and lost my ability to walk, swallow and speak. I was finally diagnosed with temporal arteritis and moved to another hospital. Thus began a five month period of tests, assessment and treatment of which I have very little memory. I can remember that I often felt marginalised and lonely when mywife wasn't there—most others didn't bother speaking to me when they realised that I couldn't carry on a conversation.'
'I accepted my lack of speech as part of my illness and thought that I would either die or be completely better in a short time.'

John has made useful observations of his communication successes and factors that affect the success, as recorded in Box 1.8.

Box 1.8 John's observations on communication

'Older friends, probably because they cannot hear so well, often have difficulty with what I am saying whereas our young grandchildren, although they all live abroad and don't see us very often, can carry on a perfectly normal conversation with me—perhaps this is because they are competently bilingual although other young people also manage to understand me.'
'One thing that really annoys me is when someone pretends to understand what I am saying. I can tell immediately when that is the case.'

He was also able to reflect on his recovery, as he describes in Box 1.9.

Box 1.9 John's first steps to recovery

'When I first started making sounds and began to speak again I thought I sounded stupid so I didn't say anything that wasn't absolutely necessary. Now I am getting more confidence and speak more but it sometimes tires me if I speak for a long time. I still find it hard to say certain words but when I get stuck I can use the sign alphabet with Julia but not many others know it. Otherwise I try another word or spell it out letter by letter.'

'My son made me a large board showing big letters of the alphabet and a few useful words which I could point to but using it was a slow process. Very gradually I became able to mouth odd words then make vague sounds of speech.'

'The gift of the ability to speak and be understood is taken for granted by almost everybody. It is only valued when it is taken away. Even a simple monosyllabic phrase like ''Hi, how are you?'' opens a new world of communication. It is a long hard road to recovery but it is well worth the effort in the end.'

The experiences of being a carer

Although this book is focused almost exclusively on the patient experience, it is important to note the role of the carer, which will be critical to outcome. Often the experiences of people who care for individuals with acquired communication impairments are overlooked. Managing to care for an individual who has a significant acquired communication impairment as well as low mood associated with this, is extremely challenging. The carer, particularly if he or she is the spouse or long-term partner, may go through a period of shock and anxiety while waiting to see if the individual will survive the stroke or brain injury. Then they have to cope with the information that their partner may survive but with a substantial degree of disability. Healthcare services rely on carers having the personal capacity to provide this sort of support. However, the literature shows that this is not easy. Personal accounts of coping (Hale, 2002) report on the difficulties in adjusting to the disability and the strength needed to manage over time. Pound, Parr and Duchan (2001) interviewed four women whose husbands had aphasia and their views were analysed in order to develop professionals' understanding about how to develop the content of a support course for spouses in the same situation. The interviews revealed that there were individual differences between the four women in terms of how they responded to their husband's aphasia. A range of problems emerged across the four interviews, which focused on the main themes of:

- difficulties in coping with changed and difficult behaviours on the part of the husband;
- coping with the effects of a partnership that was premorbidly difficult;
- balancing the demands and needs of other family members;

- managing time to take care of self, domestic activities and work;
- dealing with other people's responses to the husband's aphasia;
- negative feelings of uncertainty and despair. (Pound, Parr and Duchan, 2001)

Professional healthcare services such as Clinical Psychology and Speech and Language Therapy have developed in a variety of settings in different countries and the approaches to interventions for well-being may vary. Attention to the individual and carers feelings and emotional well-being may be prioritised in some working contexts and less so in others. This may be because of attitudinal factors but may also be related to resourcing issues and the limited number of health professionals who work in this specialised area.

There are many associations that help people with acquired communication impairments and their families. Some of these are privately funded organisations, some are organised through the NHS, and some are set up by individuals with aphasia who run web pages and conferences to help support people with acquired communication impairments and their families. Connect, the communication disability network (www.ukconnect.org), has developed a wide range of innovative approaches to helping aphasic speakers and their families. The recent publication *Caring and Coping* (Connect, 2008) provides guidance for people with aphasia and their family and friends. The Nottingham Speech and Language Therapy Service runs a special clinic to help aphasic speakers and their families (see 'Beyond words—a counselling service for clients with communication disability'; http://www.tin.nhs.uk/events-calendar/inspiring-success-2006/finalists/counselling-service).
Also web pages set up by aphasic speakers are providing a lot of help for individuals and their families (Aphasia Now; http://www.aphasianow.org/) and have created opportunities for people to link together and gain support. Holland (2007) provides extensive advice to professionals about how to counsel people with acquired communication impairments, and the families of such people. The chapter on how to counsel families containing a patient with a progressive disease provides an excellent source for professionals.

Julia is John's wife. They met at university and she also worked as a pharmacist. She provided some comments on her experiences during John's illness and recovery. In Box 1.10 she describes her memory of the early stages.

Box 1.10 Julia's reactions to her husband's stroke

'When John had a stroke and was taken to hospital I was in a state of complete shock. Although he had not felt well for a few weeks he had covered it up and pretended it was nothing particularly serious.'
'We have no relatives in Britain but as soon as John was taken to hospital our daughter caught the first available flight from Cyprus and

before she went back our son drove from Luxembourg. They and their families have been, and continue to be, a tremendous support to both John and me. Most days I speak to them on the phone to let them know how John is getting on.'
'When John was first in hospital his walking got worse, he started choking on food and after ten days, whilst having a short service with the hospital chaplain, his voice just faded away. He never made another sound for over three months; he couldn't mouth words, in fact he couldn't even move muscles to smile for a few weeks.'

Julia made a series of useful observations on her experience of John's communication, as recorded in Box 1.11.

Box 1.11 Communicating with John — beginning again

'John gradually became more alert to his surroundings and started mouthing words. After three months in hospital, when I was leaving one evening, I bent over to kiss him and he whispered ''Night, night''. I was so excited I could have shouted the news from the rooftops. That was the beginning but he often couldn't make any noise at all although on other occasions he managed odd words in a gruff voice.'
'At first most of John's words were difficult to make out, which was very frustrating for both of us—for John that he could not make me understand and for me because I felt guilty that I couldn't understand and I really wanted to help him. Even now, if John suddenly changes the subject, I occasionally have difficulty in following what he is saying and have to enquire as to what we are talking about.'

Julia noted John's improvement and gave an example of how things had changed since the beginning of his illness, recounted in Box 1.12.

Box 1.12 Perseverance and progress

'I don't like going out without John unless a friend can sit with him. Once, however, I had to pop out for about half an hour and leave John on his own so I left the phone at his side in case he needed to get in touch with me urgently. When I got back a friend had rung and John had answered the phone for the first time in four years. I was really thrilled to learn from the friend that she had been able to carry on a normal conversation with John and could understand everything he had said. I'm so proud of John for his perseverance and progress with his speech.'

Over time the views of people who live with someone who has an acquired communication impairment develop and mature, and here with Julia it is possible to see how her care and support for her husband has been a positive influence on how they have both coped.

What do these personal views tell us?

Although the experiences of each person are different and reflect the variable ways the communication impairment has impacted on them, there are also some commonalities. The confusion and uncertainty at the time of the acute illness are common to all, along with the shared anxiety about the future. There is a shared desire to get better and to improve, which the communicatively impaired speakers quoted here refer to by using the image of a 'long hard road' and a 'country lane instead of a motorway'. This image of moving along some sort of route fits with the general health narrative of a recovery trajectory, where the individual experiences an acute illness and then struggles towards improvement. All three refer to the significant changes that have occurred: the loss of employment and professional role, the social limitations and the ways in which the individual has had to learn to cope in society. In order to avoid struggling with speech there is a tendency not to speak, or to give up when factors affect the capacity to understand such as effects background noise. There are the reported difficulties when trying to understand each other and the need to develop strategies to manage this. The difficulties in understanding are based not just on the communication of the message from one person to another, but in the way other people fail to understand the impact on the speaker of losing speech. Both speakers refer to annoyance and even anger when people pretend to understand them, or at worst make assumptions about how they should be feeling ('I think it was the fact that I was being patronised'). There is positive recognition of change and improvement, as marked by success in speech being understood by a listener, or achieving the level of giving a public presentation, or being able to leave John and let him answer the telephone successfully. There is, finally, a shared complexity of experience: the communication impairment seeps into all aspects of individuals' lives ands shapes their future.

Conclusion

This introductory discussion has aimed to highlight the key aspects of the conditions, along with examples of personal experience and discussion of important factors.

One of the most important aspects to emerge from this chapter is the complexity of the conditions described. When there is a communication impairment along with a physical condition a huge range of factors become relevant and important to clinical management. Inevitably this means that the assessment of the condition and decisions about intervention will involve a variety of health professionals. The benefit from this is that the patient is seen from a wide variety of perspectives, so that the sharing of knowledge between professionals will result in a better outcome for the patient. It is hoped that the considerations brought out in the introduction along with the detailed discussions in subsequent chapters provide a direction and focus for the health professionals of the future.

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