

Section 1

Background to Stroke and Stroke Services

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Chapter 1

Experiences and Effects of Stroke and Its Aftermath

Prosperity doth best discover vice, but adversity doth best discover virtue.
Francis Bacon (1625/2009)

Experiences and effects of stroke: the survivor's perspective

Stroke is a life-changing condition for survivors and those around them. In addition to the many and varied physical symptoms, such as reduced mobility, difficulty in controlling basic body functions and impaired speech, it also has a profound psychological impact. The effect of stroke on lives is clearly illustrated in the conclusions of a review of 39 studies of life after stroke (Bays, 2001a). Studies conducted in most nations found quality of life following stroke declined markedly, and it was consistently lower than that experienced by healthy adults. Stroke survivors were less able to engage in everyday activities and in social activities and were more depressed than healthy adults of similar age and background. These three things were also strongly associated with their self-reported quality of life. We are fortunate to be able to achieve a detailed insight into how life is affected by stroke through the accounts of stroke survivors who retain, or regain, the ability to communicate and are able to recount their experiences. The accounts of about 1000 survivors, from childhood to over 90 years of age, have been collected and analysed in research articles (Table 1.1), and several have produced in-depth autobiographies of their stroke experiences while many others have published their stories on stroke-related websites (Table 1.2). Such accounts are inevitably retrospective, and cannot hope to capture all the complexities and nuances of moment to moment streams of experiences. In some cases, moreover, they have been written despite impaired mental processes. However, they provide

Table 1.1 Qualitative Studies of Experiences of Stroke Survivors

<i>Article</i>	<i>Number of survivors</i>	<i>Time since stroke (discharge)</i>	<i>Age</i>	<i>Method</i>
Akinsanya, Diggory, Heitz and Jones (2009)	1	First 6 hours	47	Biographic article, with professional commentary
Alaszewski, Alaszewski and Potter (2004)	31	Unknown interval after discharge	40–89	Interviews
Backe, Larsson and Fridlund (1996)	6	3 weeks	50–66	Interviews
Banks and Pearson (2003)	50	Up to 15 months after discharge	18–49	Interviews, diaries
Bays (2001b)	9	After discharge, mean 30 months since stroke	Mean 68.2	Interviews
Bendz (2003)	15	3 to 12 months	Under 65	Interviews
Burton (2000a)	6	12 months	52–81	Interviews
Chest, Heart and Stroke Scotland, Scottish Association of Health Councils (2001)	114	Unknown interval after discharge	unknown	Interviews, focus groups
Cox, Dooley, Listo and Miller (1998)	39	Less than 4 years	63–93, mean 78.5	Interviews
Davidson and Young (1985)	29	1–7 and 12–18 months after discharge	40–82	Interviews
Doolittle (1992)	13	3 days to 6 months	Unknown	Interviews
Dowswell, Lawler, Dowswell, Young, Forster and Hearn (2000)	30	13–16 months	60–94	Interviews
Eaves (2002)	8	Up to 4 months	56–79	Interviews

Ellis-Hill, Payne and Ward (2000)	8	In hospital and 12 months after discharge	56-82	Interviews
Faircloth, Boylstein, Rittman, Young and Gubrium (2004)	57	1 to 12 months after discharge	46-88	Interviews
Faircloth, Boylstein, Rittman and Gubrium (2005)	111	1 to 24 months after discharge	Mean 67	Interviews
Folden (1994)	20	Within 2 weeks and 3-4 weeks after discharge	65-78	Interviews
Gillen (2005)	63	Soon after stroke, 5-7 days after admission to rehabilitation unit	Mean 61	Interviews
Haggstrom, Axelsson and Norberg (1994)	29	Unknown	60-91	Narratives
Jones, Mandy and Partridge (2008)	10	6 weeks to 13 months	Mean 61.8	Interviews
Kaufman (1988)	64	Unspecified	Over 45	Interviews
Kirkevold (2002)	9	1 week to 12 months	40-83	Interviews
McLean, Roper-Hall, Mayer and Main (1991)	20	Unknown interval after discharge	Mean age men 69, women 78	Interviews
Morris, Payne and Lambert (2007)	10	4-18 months	45-81	Focus group
Mumma (1986)	30	Over 3 months	Middle-aged	Interviews
Murray and Harrison (2004)	10	4-20 years	38-81	Interviews
Nilsson, Jansson and Norberg (1997)	10	1 and 3 months after discharge	53-81	Interviews
O'Connell, Hanna, Penney, Pearce, Owen and Warelow (2001)	Less than 40 survivors	2 to 180 months, mean 4.5 years	Mean 58.4, 20-89	Focus groups

(continued)

Table 1.1 (Continued)

<i>Article</i>	<i>Number of survivors</i>	<i>Time since stroke (discharge)</i>	<i>Age</i>	<i>Method</i>
Olofsson, Andersson and Carlberg (2005)	9	4 months	64–83	Interviews
Pilkington (1999)	13	Unknown interval after discharge	40–91	Interviews
Pound, Gompertz and Ebrahim (1998)	40	10 months	Mean 71	Interview
Rittman, Faircloth, Boylstein, Gubrium, Williams, Van Puybroeck and Ellis (2004)	51	1 month after discharge	46–84	Interviews
Rochette, Tribble, Desrosiers, Bravo and Bourget (2006)	10	3 weeks to 6 months	61–86	Interviews
Roding, Lindstrom, Malm and Ohman (2003)	5	Unknown interval after discharge	37–54	Interviews
Sabari, Meisler and Silver (2000)	6	8 months to 5 years	45–75	Group session
Sisson (1998)	11	1 week to 6 months	33–70	Interviews
Stone (2007)	83	Less than 2 years to over 10 years	Under 50	Internet narratives
Thomas and Parry (1996)	15	Unknown interval after discharge	45–77	Interviews

Table 1.2 Autobiographical Accounts of Stroke Survivors

<i>Author/date or website</i>	<i>Title</i>
McCrum (1998)	My year off: rediscovering life after stroke
Ripley (2006)	Surviving a stroke: recovering and adjusting to living with hypertension
Bauby (2002) (book)	The diving bell and the butterfly
Bauby and Schnable (2008) (film/DVD)	
Douglas (2002)	My stroke of luck
McCann (2006)	Stroke survivor: a personal guide to recovery
Bolte-Taylor (2008)	My stroke of insight
Stephens (2008)	Diary of a stroke
Kant (1997)	Rehabilitation following stroke: a participant perspective
Stroke Association: http://www.stroke.org.uk/information/my_story/index.html	Information/my story
NHS Tayside: http://www.heartstroketayside.org.uk	Stroke patient stories. heart & stroke information point
http://www.pilgrim.myzen.co.uk/patientvoices/naoconn.htm	Patient voices: reconnecting with life: stories of life after stroke
NHS Choices: http://www.nhs.uk/Conditions/Stroke/Pages/Jimstory.aspx?url=Pages/Realstories.aspx	Real stories: stroke
Stroke Alliance for Europe (SAFE): http://www.safestroke.org/Facts/StrokeStories/tabid/373/Default.aspx	Stories from stroke survivors, their carers and families
Different Strokes: http://www.differentstrokes.co.uk	Survivors' stories: adulthood, childhood and adolescence, achievements

an illuminating record of what survivors recall and believe to be their most salient perceptions and most significant feelings about stroke and its aftermath. McKeivitt, Redfern, Mold and Wolfe (2004) reviewed 95 qualitative studies of stroke survivors and carers and concluded that such studies highlight the human experience of stroke and enable the identification of perceived needs, reveal differences in priorities between patients and professionals and may also signpost barriers to best-quality care. In addition, stroke survivors reported that they valued reading the personal accounts of other survivors (Wachters-Kaufmann, 2000); it increased their sense of understanding and reduced their sense of isolation. Almost one half of the respondents in this study reported that they found solutions to practical and emotional problems through reading, and one third felt motivated to make contact with other survivors.

Despite the variability in the type, location and severity of strokes, and the diversity of survivors themselves, there is a surprising degree of congruence between their stories, and the similarities often transcend gender differences (Stone, 2007) and appear consistently in different ethnic groups (Faircloth, Boylstein, Rittman & Gubrium, 2005). An exception to the uniformity of experience is the influence of the age of the survivor. While there is a measure of concordance across age groups (O’Kelly, 2002), differences in the age of survivors do determine perceptions of the significance of stroke, priorities and the types of goals that are pursued (O’Connell, Hanna, Penney, Pearce, Owen & Warelow, 2001; Banks & Pearson, 2003; Bendz, 2003; Roding, Lindstrom, Malm & Ohman, 2003). Another important source of difference is whether the stroke is located in the dominant hemisphere and affects communication and logical reasoning (Bolte-Taylor, 2008) or is in the nondominant hemisphere, in which case language abilities are largely unaffected.

For those who have not had the experience of stroke, including carers of stroke survivors, professionals, families and volunteers alike, the personal accounts of survivors may seem fragmentary and incomplete, like a light that casts the images of figures on a wall rather than illuminating the figures themselves. The observer must interpret and extrapolate from these accounts if they are to appreciate the reality that faces the stroke survivors in ways that will enable them to reach out and make meaningful connections. For the many survivors who do not regain the ability to recount their experiences, we must rely on the uncertain metric of our own experience, lived and vicarious, to guess what they are experiencing and guide our endeavours to meet their needs and expectations. In doing so, healthcare professionals should be mindful of evidence that staff and patients have different expectations and priorities (Becker & Kaufman, 1995; Bendz, 2003; Hafsteinsdóttir & Grypdonck 1997; Morris, Payne & Lambert, 2007) as well as differing perceptions of the care provided (Luther, Lincoln & Grant, 1998). In view of this, it is unsurprising that several personal accounts are critical of aspects of care and make uncomfortable reading for healthcare professionals.

Aspects of the experience of stroke survivors

Table 1.3 provides a schematic representation of psychologically significant aspects of the journey of a typical stroke survivor, derived from the qualitative studies and biographies listed in Tables 1.1 and 1.2, and categorised into symptoms, phases and features, psychological tasks and processes and important elements. To improve continuity and flow, the following account of experiences is provided without specific references in the text for each point. Interested readers will find instances in the literature cited in Tables 1.1 and 1.2.

The first stage is the onset of symptoms which usually develop rapidly and ‘out of the blue’. Most accounts describe initial attempts to normalise symptoms, for example, as a migraine, numbness due to sleeping awkwardly on a limb, an infection or tiredness. There is frequently a sense of indifference and sometimes

Table 1.3 Psychologically Significant Aspects of Stroke Revealed by Biographies

Symptoms	Phases and features	Psychological tasks and processes	Elements	
<p>Onset and intensification</p> <p>↑↑↑↑</p> <p>Stabilize and (partially) resolve: Movement, perception, swallow, continence, pain, speech, cognition, balance, fatigue, appearance</p>	Stroke event	Normalisation, denial-acceptance	Paramedical services	
	Seeking help			
	Diagnosis	Body, not self as focus	Hospital services	
	Emergency treatment	Consent to treatment		
	Health care staff (doctors)	Connection with staff as people Accepting uncertain recovery prognosis	Resilience and adaptation versus depression and anxiety	Staff
	Hospital care (nursing and environment)	Adjustment to personal care, expectations of behaviour, routines and new surroundings		
Therapy: Arduous Effortful	Setting personal goals Fatigue	Autonomy and control versus dependence and compliance	Family and friends	
Recovery: Leaving hospital	Small gains building hope Fear of another stroke Influence of other survivors			
Residual symptoms: disabilities and deficits	Community re-integration: Restriction, constriction and loss. Integration of former life and stroke within a new life. Employment and money. Changed identity and roles. New appreciation of life, greater reflection, new learning and new goals.	Developing health-beliefs about stroke	Other Survivors	
			Community Services	

frank denial of even severe symptoms. This may be a consequence of anosagnosia due to cognitive impairments. However, some survivors cite the lack of any pain and of any visible cause as reasons for their sense of unreality and failure to acknowledge symptoms. Many expect that symptoms will be transient and see them as an unwelcome interruption to their habitual routine which they often vigorously attempt to continue. If the stroke occurs in public, then the symptoms and the reactions of others may lead to feelings of embarrassment and attempts to conceal or explain away the effects.

I'm typical of many patients who, when they have had a stroke, spend precious hours fighting the truth instead of fighting the illness. So I continue to deny what is happening because the truth is too stark and horrible to contemplate. (Stephens, 2008)

Eventually the survivor, or someone else, accepts the significance of the symptoms and obtains assistance. Where the person was alone at the time of the stroke there may be a delay of many hours, and efforts to obtain assistance when affected by hemiparalysis and aphasia may be protracted and traumatic. In cases where a survivor is alone and in real danger, some experience hearing helpful 'voices' commanding or urging them seek help. Hearing voices that give advice and encouragement (called auditory 'pseudo-hallucinations' because the person is aware the voices have no physical source) has also been reported by healthy, psychologically normal people in highly stressful or life-threatening situations (Spivak, Trottern, Mark, Bleich & Weizman, 1992; Brugger, Regard, Landis & Oelz, 1999), and is vividly described in Joe Simpson's book about surviving a mountaineering accident (Simpson, 1998).

But resounding like thunder from deep within my being, a commanding voice spoke clearly to me: **'If you lie down now you will never get up'**. (Bolte-Taylor, 2008)

The next phase is usually the attendance of paramedics and transfer to an accident and emergency department. The initial diagnosis of stroke is now normally completed by the paramedics at the scene, and this stage is often enveloped in a fog of confusion for the survivor, and, in those with haemorrhagic strokes, also accompanied by excruciating headache. Some survivors find it hard to accept the diagnosis of stroke.

What the hell are they talking about? A stroke! Strokes are for elderly people, with slurred speech, moving about in walkers or wheelchairs. I was only eighty; how can a stroke happen to me? (Douglas, 2002)

Survivors frequently report a sense of powerlessness and feeling extremely sleepy at this stage and resent being bombarded with questions and requests to perform neurological tests and undergo investigations; they experience diagnosis as impersonal and find it incongruous that their body, rather than their ‘self’, is the focus of others’ attentions. Where communication is affected this early experience of healthcare staff may be extremely disturbing; it may appear that staff are speaking foreign languages or in code, and this may fuel fearful thoughts about something being hidden from the survivor. Survivors may not appreciate that their speech is affected and may become angry and frustrated when staff do not understand them. Frustration about providing staff with information, while not receiving any in return is common. Once diagnosis is complete, treatment decisions must often be made rapidly.

Medical personnel swarmed about my gurney. The sharp lights and intense sounds beat upon my brain. . . . ‘Answer this, squeeze that, sign here!’ I thought, ‘How absurd! Can’t you see I’ve got a problem here?’ . . . I wanted to scream ‘leave me alone!’ but my voice had fallen silent. They couldn’t hear me because they couldn’t read my mind. (Bolte-Taylor, 2008)

Survivors’ accounts differ sharply about consent to treatment, with some reporting that they were not enabled to provide proper consent despite wishing to do so, and others feeling that being required to consent was burdensome and unrealistic and that they would have preferred staff to act in their best interests without requiring the survivor’s consent.

[T]here was one nurse I came to think of as my guardian angel, . . . with . . . a lovely smile and the most gentle manner of any nurse I’d experienced then or subsequently. . . . For her sweetness towards me in those first few dreadful hours. . . . I shall always be profoundly grateful. (McCrum, 1998)

Interactions with staff are crucial in this and subsequent stages, and the accounts are almost unanimous in identifying the personal qualities of staff as vital determinants of the survivor’s trust and confidence as well as their general sense of safety and security. One account suggested that a lesion in the left hemisphere affecting language and sequential reasoning accentuated the prominence of personal characteristics and heightened sensitivity to body language and social cues (Bolte-Taylor, 2008). However, there may be other explanations, and heightened attention to the personal qualities that define kindness, compassion and a willingness to provide care may be a common psychological response to a sudden incapacity that spurs a person to make contact with those who are motivated to provide assistance. The actual personal qualities that engender trust and confidence are rather ineffable

and writers of autobiographies of stroke struggle to elucidate them. However, being gentle and calm and genuinely interested in helping survivors, focussing on the person as well as their body, taking time and not rushing the survivor, making eye contact and using touch and other reassuring body language and creating a sense of being available for the survivor all seem to be manifestations of traits that engender an intuitive sense of trust. While the professionalism and apparent competence of staff are regarded as important, the centrality of impressions created by these personal attributes dominates almost all survivors' accounts.

I'm full of an overwhelming desire to please the doctor. She is very cold, going through the routine of the examination with clinical precision, a screen behind her eyes rather like the cellophane on the display screen of a new mobile phone. . . . Why do none of the people who see me in this place treat me as if I have a brain? (Stephens, 2008)

In cases where diagnosis was initially incorrect or delayed, and treatment or investigations were perceived to be incomplete or inappropriate, survivors may experience anger at staff and continue to do so for many years. Many accounts of stroke indicate surprise at how few medical treatments were required and the infrequency of contact with medical doctors after the initial diagnosis phase. However, younger survivors in particular, may continue to have investigations to establish the cause of their early stroke for months or even years after the event.

Reports of the experiences of the direct symptoms of stroke are understandably very diverse due to variations in nature, size and location of the lesion. Hemiparesis is principally experienced through its effect on mobility and self-care capabilities. Not being able to use the toilet independently is a particular source of distress and embarrassment for most survivors. Another experience is that paralysis engenders a sense of mind–body separation highlighting the distinction between an intention to perform an act and the actual act itself. Many survivors find the lack of muscular response puzzling and difficult to accept and recount periods when they experiment with a kind of mind–body dialogue where they use concentration and the power of their mind to 'will' immobile parts of their body to respond. In some, this may evolve into a form of 'self-talk', in which the person issues mental instructions to limbs. For example, 'right arm reach out, move right, move up a bit. Now right hand grasp toothbrush. Now arm move back', and so on. Immobile limbs, particularly arms, take on special significance and may be described as 'appendages', 'flippers' and the like. Hemiparesis is also personally significant because it alters appearance, particularly through facial droop, and many survivors report being disturbed by looking at themselves in mirrors and may avoid doing so. Sensory loss and numbness are sometimes reported as

imbuing a sense of unreality, and numbness of the tongue hampers eating and risks injury through biting. Impaired swallowing causes distress through the inability to eat a normal diet and appreciate the tastes and textures of foods. Eating is also a source of pleasure and a distraction from boredom. Pain of various kinds may be experienced: headache, joint pain, muscular cramps and also neuropathic pain. All pain engenders distress, and in some cases may provoke anxiety about being moved and hamper engagement in therapy. Incontinence and constipation are often experienced as deeply humiliating and embarrassing. Visual problems such as diplopia are distressing and disorienting and, while the partial loss of visual fields may not always be noticed, its effect on functions, such as driving, makes it significant. Vertigo, which often occurs in cases of posterior stroke, is incapacitating and acutely distressing. In addition, survivors are often puzzled and frustrated by ataxia. The effects of language and speech impairments are profoundly disturbing and frustrating and have been discussed above when considering admission and diagnosis. Many survivors are fearful of cognitive impairments, and may spend hours doing memory puzzles or engaging in private mental exercises to reassure themselves. In contrast, survivors with actual profound cognitive impairments are frequently unaware and unconcerned about them. Fatigue and the need for a lot of sleep are almost universal experiences. Sleep is regarded positively as a restorative, but many reports indicate that it may interfere with schedules, plans and activities. Fatigue is seen as a barrier to therapy and return to activities of daily life and employment. If a function which is seen as vital to a person's family role or employment is affected, then a person may experience very severe sense of loss and anxiety about the future. For example, several of the accounts of stroke were written by professional writers who were extremely concerned about losing the ability to type.

The first part of my escape plan is to reclaim as much normalcy as possible: to do things I would normally do and not just sit around waiting for something to happen. . . . I must not play by the rules the stroke wants to impose on me. (Ripley, 2006)

After diagnosis and initial treatment, most survivors spend time in hospital with the expectation that the person will conform to unfamiliar routines, adopt the 'patient role' and accept personal care which is initially experienced as embarrassing and humiliating. An important psychological dimension at this stage is the person's perception of the balance between autonomy and control on the one hand and dependence and compliance on the other. Highly dependent survivors find it reassuring that they can influence the behaviour of staff even in small ways, for example by the way they greet them or make eye contact. Fear of not receiving enough care co-exists with the fear of restriction and over-protection. Imagination and fantasy are important,

especially for the very disabled, and allow survivors to transcend the present and find solace and escape.

My cocoon becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or time, set out for Tierra del Fuego or for King Midas's court. (Bauby, 2002)

Routine helps to structure days, and nights are often experienced as the worst part of each day with many survivors reporting anxiety, disturbing thoughts and problems with sleeping. Fear of recurrence of stroke and dying during sleep is often a source of distress. Weekends, when there is no therapy and few staff are available, are also regarded as bleak periods. Some survivors find rules and regulations applied in wards restrictive and oppressive, especially when there is no clear reason for them or staff flaunt them (e.g. smoking and bans on mobile phones), and survivors who inadvertently or deliberately contravene rules may come into conflict with staff. Relationships with nursing staff are crucial and, once again, personal qualities and gentleness are major determinants of survivors' reactions to staff. Being treated as an individual person with thoughts, feeling and a personality rather than as a 'body' is important, as is attention to wider human needs such helping with access to meaningful activities and personal contacts. Most survivors have 'favourite' nurses or therapists and miss them when they are away. Family members usually become indispensable at this stage, and young, previously independent, survivors may welcome their parents returning to their previous parenting role. Friends and other visitors are normally much appreciated for their company and as a link to the outside world, but survivors may sometimes feel like a captive audience, especially if visitors focus on their own concerns and not those of the survivor. Several accounts describe the automatic assumption that the survivor requires a visit from a minister of religion as inappropriate and unwelcome. However, religion is frequently a theme, and most survivors explore their orientation to spirituality or what happens after death at some stage during their recovery. Older survivors in particular may perceive religious faith as hope sustaining and their relationship to God as an important source of psychological 'connectedness' that has parallels their sense of connection with their family.

Fellow survivors emerge as important influences at this stage, visits from those who have recovered from stroke are particularly uplifting, and comparisons with other patients with greater impairments often make survivors feel fortunate and thankful. A camaraderie may develop with some fellow patients which provides mutual support and boosts morale through the realisation that the survivor is not alone. However, exposure to very ill or frail patients, and the medical and personal care procedures that they require in the ward, may be unpleasant and disturbing for less disabled survivors who see at firsthand how the human body can deteriorate and the undignified and sometimes painful measures that may be

required to support life. Similarly, survivors may be upset by patients who exhibit confused or aggressive behaviour, and there are many reports of broken sleep caused by patients who repeatedly call out, and of intrusive behaviour by confused patients. Survivors may also feel compassionate towards other patients and can experience a strong urge to help them with self-care, such as with getting to the toilet or feeding, especially if staff are too busy to do these things and a helpless patient becomes distressed. At a later stage in their recovery, many survivors also make contact with the experiences of others through reading autobiographies of stroke survivors, and this is usually a very helpful and positive experience.

Therapy is perceived as vital and as the 'route back to normal life'. Participation in therapy satisfies an urge to become actively engaged in something that improves functioning and promotes recovery, and the achievement of therapy goals is a major source of hope. However, survivors generally find it arduous and demanding and fatigue is frequently a barrier to full engagement. Many survivors develop strong and usually very positive relationships with their therapists. However, relationships are not always harmonious and therapists are sometimes seen as overly demanding or inconsiderate of the survivor's needs. Some therapy tasks are perceived as childish, and their relevance to recovery is not appreciated. Survivors set themselves personal goals and targets for their recovery, such as walking or getting to the toilet unaided, and there may be frustration and anger with therapists if the therapist's and survivor's goals are not concordant. Survivors may become despairing if they do not achieve goals, and this can result in avoidance of therapy. Most reports of this stage emphasise how important it is that therapists maintain hope and are not overly pessimistic about achieving personally significant goals. Some survivors feel a need to take the initiative and fill the time between professional rehabilitation sessions by developing their own rehabilitation routines and exercises.

The perception of recovery begins as symptoms stabilise and begin to diminish. Even tiny gains, such as the movement of a finger, can have immense personal significance. Indeed, many severely affected survivors focus on areas in which tiny but progressive improvements occur and derive hope and encouragement from any change, however small. The written accounts of survivors clearly describe how important functions continue to recover for ten years or more, and several are keen to dispel the professional 'myth' that most of recovery takes place over the first six to eight weeks. Hope for recovery may be bolstered by recollections of recovery from previous illness or injuries, and by recalling and employing strategies and approaches that were helpful in the past. Survivors may start to re-engage in activities at this stage, including reading, watching television or keeping a diary. Some may begin to look forward to the future and start to make plans for their return to home, work and life after the stroke. This may provide a welcome respite from a bleak and restricting present. The accounts of survivors differ in the extent to which they regard restitution of their former life as the primary goal of recovery, or whether they seek a new and changed life that

integrates their stroke experience into a new lifestyle. The opportunity provided by time in hospital to reflect and plan is usually viewed as a very beneficial experience, and many survivors regard it as one positive outcome of their stroke. New perspectives engendered by the stroke may enable them to see their previous lives in a new light. Some survivors start to make far-reaching plans for change and a profound separation of 'old life and old self' from 'new life and new self' begins to emerge.

As well as looking forwards, survivors have time to reflect on the causes of their stroke, and some come to view it as a kind of punishment for their past lives and become assailed with regret and remorse. Another common area for remembrance and reflection are the illnesses and deaths of parents and other loved ones. The survivor may draw parallels with their own current predicament, and feel that they achieve greater insight into how their relatives felt and behaved when they were ill. Although depression may occur at any stage after stroke, the period after the initial shock, when survivors have time to take stock and reflect, is often the occasion for clinical depression, in which both body and the mind are affected, or an existential crisis that affects mental equilibrium, adjustment and relationships but has few physical effects. Survivors report difficulty with the regulation of their emotions and many are labile and have angry outbursts which they subsequently regret, often targeted at those they love and depend upon. Surprisingly some see lability as a positive change and feel they have 'rediscovered' a lost ability to express feelings. Survivors' perceptions of their capacity to be resilient and adaptable in facing the challenges that confront them are important in determining the degree of depression, despair and anxiety that they experience.

But I didn't want to see anybody. I didn't want anyone to see me. . . . I lay like that, in the darkness, almost comatose, my head stuffed in the pillow for a long time. Sometimes, my wife, sons, friends came in to see me, but I didn't see them. I didn't hear them. Sometimes, I didn't know whether it was day or night. It seemed as though I was in a black cave far down below the surface of the earth. (Douglas, 2002)

During recovery, survivors begin to consolidate what they have learned about stroke into an internal model of the condition. This often reflects the common-sense model of illness described by Leventhal, Diefenbach and Leventhal (1992) in which the dimensions of identity, timeline, consequences, cause and cure/control are central. This set of beliefs displaces older beliefs based upon vicarious experiences of the strokes of relatives and friends. Survivors often supplement information imparted by staff with reading leaflets or books about stroke. What they find is not always comforting, particularly statistics about recurrent stroke, its link with dementia and the side effects of treatments. Fear of recurrence of stroke often surfaces at this time, as does the effect of the trauma of the stroke

itself, and many survivors report a sense of anxiety, especially about going home, if that is where they had the stroke and the event was traumatic or they struggled to summon help.

Unfortunately it at this time I came across a newspaper headline, which stated that strokes double the risk of Alzheimer's disease. This was a difficult thought to deal with. . . . The next thing I discovered was that recurrent strokes are frequent . . . the fear of a second, and worse stroke, was very potent. (McCann, 2006)

The milestone of going home or to a placement is reached during this stage, and occurs increasingly sooner in the stroke care pathway due to early discharge policies. Leaving hospital frequently becomes an important goal, even an obsession that drives up motivation to engage in rehabilitation activities. Some survivors describe their discharge from hospital as a welcome 'escape' from what they perceived to be an alien and unsympathetic world. Unfortunately, reports of difficulties in the planning of the transition from hospital to home are frequent. Pringle, Hendry and McLafferty (2008) reviewed 28 studies of experiences soon after discharge and highlighted the importance of the profound personal and social changes that occur following stroke. Personal accounts often describe how returning home is initially experienced as liberating, but this is followed by a realisation of the impact of residual disabilities, and the extent to which former activities are inaccessible and must be curtailed: a person may 'discover' their disabilities through comparison with their former capabilities in the same home environment. Impaired movement, communication, memory and sensation may limit self-care, leisure and social activities. The impact of these disabilities may be accentuated by the reduction or termination of input from professional care staff and a home environment which is less adapted to support people with disabilities than the hospital setting. When they occur, restricted mobility and the inability to drive are serious losses and may provoke a sense of imprisonment. Walking may be limited by fear of falling, and, if and when walking recovers, it is perceived as a major marker of recovery, as is the resumption of driving. A proportion of survivors also endure episodes of confusion and disorientation.

Survivors often report being abruptly abandoned by services once they return home, and wish that therapy had continued over a longer period. Many note that care staffs' and therapists' visits to home are frequently delayed and curtailed, and they are liable to be distracted by phone calls. This is sometimes described as a feeling of being 'dumped' by support services following discharge. One gap in our knowledge of survivors' experiences after discharge is an autobiographical account by someone discharged to a care home. Bauby's (2002) book about being cared for in a naval hospital provides some insights, but he suffered from locked-in syndrome which is an unusual and extremely severe condition. One response to the reduction in professional input may be the development of

exercise and mind training routines. These may involve basic tasks such as walking in a straight line and catching or squeezing a ball, or more sophisticated activities like playing computer games or doing crosswords. Survivors may make resolutions about exercising to stay fit and adopting healthier diets and lifestyles. Progress is often variable, with good days and setbacks. Survivors report being elated when they make new achievements, but experiencing episodes of depression and gloom when they seem to be making no progress. In younger people this recovery phase is often when the investigations into the causes of their stroke take place. This may require them to attend hospitals and to endure tiring or painful examinations and procedures. There may be fear of reoccurrence and frustration with professionals if a cause cannot be found and treated.

At first, it was a massive relief to be home again, a milestone in my slow return to the world I'd lost, but then depression began to set in. I became more and more obsessed with my disabilities, and more and more frustrated. (McCrum, 1998)

After some time at home most survivors begin to experience the effects of their stroke on their social world, valued roles and sense of identity. The social circle often contracts to close family and friends. Relationships with family members often change as a result of dependency and the need to accept assistance from them. Changed emotions and emotional expression and communication impairments also affect family relationships. Survivors normally seem to come to terms with accepting assistance and generally express appreciation towards caregivers. Many report that relationships become closer and more meaningful as a result of dependency, and in some cases a sense of reciprocity develops in which the survivor develops an appreciation of their own contribution to the well-being and fulfilment of their carers. However, a sense of being burdensome to relatives is also common, and a significant proportion of survivors experience marital breakdown which contributes to disruption and distress. Survivors may not be able to perform accustomed roles, such as that of breadwinner, or tasks, such as housework or cooking, that defined their former roles. They may be unable to attend meetings and events that were important sources of social contact and role identity. Younger survivors in particular may feel that their gender identity and capacity to form romantic attachments is diminished. Misinterpretation of disabilities as drunkenness or mental handicap and being reprimanded or 'talked down to' can cause distress and may induce avoidance of public places and social withdrawal that accentuates isolation. However, many survivors make contact with stroke groups and stroke clubs at this stage and derive major benefits in terms of emotional support and practical help. Survivors and their carers may continue to feel the sense of professional abandonment that began with the cessation of intensive rehabilitation therapy following discharge from hospital, and it is common to experience difficulty in locating and accessing

needed services. Financial provision for the future emerges as a concern and returning to work is a theme for those employed at the time of their stroke. Some dread the first contact with former colleagues and feel shame about their disabilities. There may be concerns about how colleagues and managers will view the survivor, and about changes that have occurred at work since their absence. Attitudes towards returning to work differ markedly; some survivors view re-engagement as impossible and undesirable, and the stroke as an opportunity to invest energy in leisure activities or to make employment changes, while others long to return to their former job and find that not being able to work is a significant and enduring loss. When a person does return to work, or work-related activities, it is usually viewed as a major achievement and a milestone in their recovery. Many survivors find it deeply rewarding to substitute or supplement work by helping other survivors in various ways; by visiting them, writing letters, writing and disseminating their own stories or by joining support groups and stroke clubs.

My stroke taught me so much, and for all that it stole, it gave me even more. In the process of healing, my life has changed for the better. Now I want to share what I have learned. (Douglas, 2002)

Survivors may find that the stroke prompts them to make provision for their families in the form of wills or gifts, and also to plan for possible future incapacity by making advance directives and donating powers of attorney. Some survivors adopt alternative medicine, such as acupuncture, reflexology or herbal remedies, and generally report that it is beneficial. There are also personal accounts of engaging in psychotherapy and of its role in achieving a better understanding the reasons for depression and anxiety. Therapy may also help to put the survivor's previous life and the effects of stroke into perspective. However, timing is crucial, and reports suggest that psychotherapy with a focus on general adjustment is most useful after returning home when the full implications of the stroke are clear. There are also many accounts of coping strategies that have been found to be helpful in dispelling depressive feelings and improving adjustment. These include looking on the bright side, drawing comparisons with more disabled individuals and feeling grateful, helping others, taking responsibility for self-care and making decisions, slowing down the pace of life, developing patience, developing routines, staying motivated, having faith in God, having a sense of humour, maintaining friendships and staying active.

As recovery progresses, some survivors feel that life has changed for the better. They may experience an accentuated appreciation of life and the world, new insights into the evaluation of what is meaningful and valuable, an intensification of feelings of love towards family members and friends and a greater sense of connectedness with other people in general. A person may feel

that formerly submerged qualities have blossomed and that they have become more compassionate, tolerant and sympathetic. At a practical level a person may achieve a better work–life balance, a healthier lifestyle, new friends, new knowledge and insights and new outlets for their creativity and energy. These positive outcomes of stroke, ‘the silver lining’, have recently been recognised and studied (Gillen, 2005; Gangstad, Norman & Barton, 2009). An improved understanding of the factors that promote such positive outcomes could be a significant step in helping professionals to improve psychological recovery.

Implications

The powerfully moving personal accounts of stroke and its aftermath listed in Tables 1.1 and 1.2 graphically depict the life-changing nature of this condition and the events and forces that determine individual reactions to stroke and its consequences. For these insights, we should be thankful those who have shared their experiences of times of great personal adversity. (See also Table 1.4 for another personal account of stroke.) Many aspects of the experience of stroke survivors, such as the loss of muscle control and feelings of depression and desolation, have been extensively researched, and approaches to assessment and treatment have been, and are being, developed. Other experiences, such as the potential for positive, life-enhancing outcomes, have only more recently been recognised. Others, such as the way some people have the capacity to make contact and reassure people soon after their stroke when they are in mental turmoil and anguish, have yet to be fully explored.

This section will have succeeded in its purpose if it provides readers with a glimpse of the world of stroke survivors and the lived experiences that underlie some of the topics covered in the remainder of this text. It would be an immense bonus if it also helped some readers, including those who work with stroke survivors, to understand something of the fractured and tumultuous world of those who have recently experienced stroke in ways that inform and guide their endeavours to reach out, make connections and relieve psychological suffering and enhance well-being. More formally, some of the experiences revealed by survivors might be incorporated into staff training programmes and service elements. These might include training to foster an appreciation of the devastating effects of impaired communication ability during the early stages of stroke, training in approaches that reassure and develop the trust of newly admitted stroke survivors, training in approaches to goal setting that are sensitive to survivors’ priorities and expectations, the development of service configurations that acknowledge and respect survivors’ individuality and humanity, enhanced monitoring (and psychological support if necessary) in the crucial period following discharge and increased opportunities to make contact with, and receive support from, other stroke survivors.

Table 1.4 Linda's Story

One ordinary December day in 2005 when I was 37, I was sitting in my car preparing to leave work and go home. It was really cold so I had the heater on to warm the car up. I started to drive along the road, and got into second gear and then forgot how to drive the car! I was not in any pain, just simply bewildered. I managed to call my work colleague Lesley and told her I'd forgotten how to drive my car. Initially she thought I was mucking about (part of my pre- and post-haemorrhage character was that of a 'funster'). I actually had to convince her I was serious and asked her to come and collect me.

Lesley drove me home. By which time I was experiencing severe pains in the left hand side of my forehead. It felt like someone had stuck a knife into my head and was twisting it round. I really wanted Lesley to go so I could just lie down and sleep, but luckily she realised that something was very wrong. She called the out-of-hours doctor who told her to dial 999.

The next time I was fully conscious was four weeks later, and I was in the Neurology Unit of Frenchay Hospital, Bristol. During that time I was drifting in a dreamlike state without realising what had happened. I could see my son Stuart (who lived in Australia) and he looked like he'd been crying and I thought 'If I shut my eyes he might go away'. The nursing staff kept coming up and asking me puerile questions; the name of the queen, the prime minister, which month we were in, etc.? I thought I answered them correctly, but actually I still don't know if I did.

All my family was present and the priest came and gave me the last rites. None of this panicked me as I thought I was in a dream. The knife twisting pain was ever present, then, and after recovering consciousness. I had it for months and even morphine didn't relieve it. Curiously, when I tried ibuprofen it did the trick. The whole experience was really weird, rather like the film 'Groundhog Day' reliving the same 'dream' – I thought – for months!

I was moved to Bath RUH and I still felt like I was dreaming. I thought all the nurses were foreign as none of them could understand me. When I needed a wash I tried to tell the nurse what I needed. To me my voice sounded completely normal, but I ended up having to sign it to make him understand. (All of which was difficult because I'd been left paralysed down the right side of my body – as luck wouldn't have it I am right handed). The nurse didn't understand, however, and subsequently went and got an air freshener to spray around the bed. He obviously thought I was complaining of the smell in the ward!

I was not at all horrified by my predicament because I still assumed I was dreaming. My prevailing emotion was irritation at not being able to communicate. Visitors were coming and going and smiling, but I simply thought I was in a big dream bubble! It wasn't until I actually realised what had happened to me, about eight weeks after the stroke, that I got upset. It was while still in Bath RUH that it slowly sank in that this was reality and I had actually suffered a huge subarachnoid haemorrhage.

A neurologist told me I would be transferred to Chippenham Hospital. This fact horrified me as I had worked there years ago when it was a geriatric hospital. In retrospect I think I was shielding myself from my 'real' problems by worrying about insignificant things.

(continued)

Table 1.4 *(Continued)*

When I was a patient I felt like I was transparent and that the staff weren't listening to me. My family and friends (many of whom lived in Kent) came to visit me regularly. My son came back, three times, from Australia to visit me in hospital. I was able to communicate with friends and family much more easily than the staff. I sounded as though I was drunk and incoherent.

I hated it in Chippenham hospital. I felt like I was in an old people's home. But fortunately I was in a room on my own.

I had a gradual realisation of how physically limited I had become; horrifically I was doubly incontinent and catheterised. I was very keen to get physiotherapy. However, with the added staffing pressures on the nurses I often missed my appointment slot with the physiotherapist. I became really frustrated that I could not push forward with my recovery and at being unable even to sit up in bed. I had learnt to eat with my left hand; I could even peel an orange one handed. I also learnt to write left handed. Radio 4 and talking books from the hospital library keep me sane!

At the hospital I religiously performed all the physical exercises given to me. I also had psychological counselling which I found a great help. I felt isolated in my predicament because all other patients were old enough to be my parents.

I was in Chippenham hospital for eight months. My home was adapted so I could return to it in my electric wheel chair. By the time I left hospital my speech was slow but understandable. I was on copious amounts of medication.

Coming home I was very scared having become more or less institutionalised in the hospital regime. Where I (still) live is quite isolated. I did not have a partner at the time. I had brought up my children on my own. In retrospect the fact that I had lived many years as an independent, career minded, person probably helped me cope better. I have never been scared of being on my own. I had three visits a day from a personal assistant (PA), and the Care in the Community Team came in three times a week. I was house-bound, but fortunately my incontinence had cleared up.

The initial physical setbacks engendered by the subarachnoid haemorrhage I dealt with quite positively when I returned home. My days were spent trying to make basic improvements to my mobility. I was angry and depressed about it all, but used the energy positively (as I still do) because I did not want to be in wheel chair for the rest of my life. Even during the first year I never gave up on the idea I could make a full recovery and I still haven't!

During my time in the wheel chair I felt transparent again and frustrated because people in shops, etc., generally talked to the person pushing me, or talked to me as though I was 'simple' which, with a degree in business finance, I knew I wasn't! People even spoke loudly to me in single syllables, and this I felt was almost more crushing than the disability itself!

Nowadays I rarely feel sorry for myself, but during the early days of recovery I used to think 'Why me?', but I never dwelled on it. It has made me realise that this can happen to anyone at any age, anytime. I am now acutely aware of the fragility of human health.

Previously, I had worked as a Group Facilitator for the charity Mind, successfully setting up and running four drop-in centres for people with mental health problems.

Table 1.4 (Continued)

Therefore, I was aware of the danger of becoming depressed. To this day, I believe that it was my tendency to turn any anger outwards, directing the energy into my recovery that enabled me to avoid becoming overly depressed.

Paradoxically, although my movement is still limited on my right-hand side (I still define myself as hemiplegic), I am in some ways healthier than I was before the subarachnoid haemorrhage. My diet and fitness regime is now much more important to me. I do not take my health for granted.

I would rather be dealing with this disability than a mental health problem which is invisible to the outside world. I want to get to the stage where my physical disability fades and is not noticeable.

Between the subarachnoid haemorrhage and complete recovery I work toward manageable goals, some small ones, for example, getting to the gym regularly and sticking to a healthy eating programme. Larger ones included visiting my son (unassisted) in Australia last Christmas and my best friend in Canada this June. Something a couple of years ago I would not have even considered. I am also having refresher lessons in an adapted car as I have now had my driving license returned from the DVLA. I remain very focused. Prior to the subarachnoid haemorrhage I was a slender, energetic woman who loved to skate, ski and dance, I am determined to do these things again.

The medication and the loss of mobility made me put on three stones. I have taken control of this by joining a slimming club and have lost over two stone which has improved my mobility. I have made additional friends by doing this and it's made me realise that even people who have not survived major trauma still have mobility and health issues from such everyday things as obesity/and or other eating disorders. The whole experience has radically altered the nature of my 'friendship' groups. This sort of thing really sorts out the 'wheat' from the 'chaff'. I have always had a large cross section of friends. It was quite strange because many friends who were ever present when I was in hospital disappeared when I was discharged. Good friends who I had shared holidays and life experience with simply vanished. Some remained consistent, seeing me as much as they ever did. In a way this is good because it is not patronising but sometimes I feel certain close friends and family try to ignore my disability and this has its own set of problems. For example in practical terms I cannot cope with late nights as well as before.

Other people, like my original and continual life saver Lesley, and close friend Dagmar, did not feature heavily as friends before my subarachnoid haemorrhage. They were not in my social set. They are now indispensable, and I value their friendship. It's made me realise qualities in people perhaps I wouldn't have done without the stroke. In addition I have met a completely new set of people of all ages and social backgrounds. I have a male personal assistant, Chris, who has a wicked sense of humour who says, I quote, 'this job is like the Hotel California you check out but you never leave!' I have become close to a fitness trainer, Brigid, who has encouraged me in the gym and swimming pool. She even entered me for a Concept 2 (stationary rowing machine) series of Rowathlon challenges over six months in which I was competing against nondisabled rowers. I beat many of them!

(continued)

Table 1.4 *(Continued)*

When I am out and about now people tend not to realise I am disabled, thinking only that I have sprained my ankle or something as I wear a leg splint. This can be difficult. For example, when I am in the supermarket people can get impatient with me. My right hand has limited movement which makes payment and packing at the checkout impossible to do unaided.

Since losing weight and gaining more mobility, my self-image has improved and I am beginning to feel more like me! I try to make my recovery and not my disability define me. I use my hatred of being disabled to spur me on! I have also used various cognitive techniques to enhance recovery, for example, hypnotherapy, positive visualization, etc.

The experience has activated me toward helping other survivors of brain trauma. I'm a Stroke Patient, Carer and Public (PCIP) Involvement volunteer for the Avon, Gloucester, Wiltshire and Somerset (AGWS) Cardiac and Stroke Network. I am also being used in a drug trial HPS2-THRIVE. I am a volunteer for Salisbury Hospital for Functional Electrical Stimulation (FES). I am open to trying any new technique that will aid recovery. I have taken up swimming (I was never very confident in the water before) and am conquering my fear of 'going under' both in and out of the pool!

I am looking forward to the future.

The effects of stroke: the professionals' perspective

Models of disability

The tangible, observable effects of stroke can be conceptualised according to a model developed by the World Health Organisation (WHO), the International Classification of Functioning, Disability and Health (ICF; WHO, 2001). This model can assist in understanding the relationship between the early effects of stroke and the subsequent outcomes.

- Functioning refers to the physiological functioning of body systems and structures. Thus the functioning of the brain is affected by stroke. Impairments are problems in body function, occurring as a significant deviation from or loss of former functioning. The loss of motor ability, sensory ability and memory, as a result of damage to the brain, are impairments.
- Disability involves both activity limitation and participation.
 - Activity is the execution of a task or an action by an individual. Activity limitations are difficulties in executing activities. For example, if someone is unable to get dressed, this is an activity limitation.
 - Participation is the involvement in a life situation. Participation restrictions are problems in fulfilling life roles, such as the inability to work or to go out socially. (WHO, 2001, pp. 212–13)

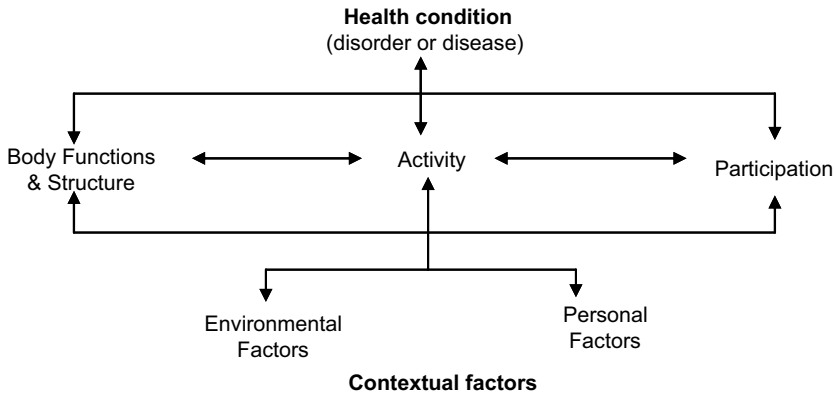


Figure 1.1 International classification of functioning, disability and health. Reproduced with permission from World Health Organization. (World Health Organization. 2001. *International classification of functioning, disability and health (ICF)*, p. 26. Geneva: World Health Organization.)

The ICF highlights how a person's health condition interacts dynamically with contextual factors to create problems with functioning, activity and participation, as shown in Figure 1.1.

For someone with a stroke, there may be loss of movement in one arm, an impairment; problems with personal self-care, an activity limitation; and a desire not to engage in social occasions, a restriction in participation. Further contextual factors may include the attitude of a partner, living in a geographically isolated place and lack of availability of alternative support.

Impairments after stroke

Strokes lead to a broad range of impairments, which depend on the blood vessels involved and the parts of the brain affected, as discussed further in chapter 3. The relation between the lesion and the final outcome is a reflection of treatment, management and natural recovery, as well as individual patient factors. It is therefore perhaps unsurprising that stroke confers a wide spectrum of effects. The most prominent impairments are motor and sensory deficits, aphasia and visual field problems (Bogousslavsky & Caplan, 2001). Symptoms that are less prominent, but nevertheless important for understanding the psychological effects of stroke, include cognitive, behavioural and emotional problems (Bogousslavsky, 2003). The impact of these, for both the people affected and their families, could be viewed as an inevitable consequence of the lesion; they will, however, be influenced by the success (or failure) of acute treatment, rehabilitation and the support provided after stroke. Whilst many with stroke have similar symptoms, very few will have all of the same symptoms. It is, in part, this heterogeneity of symptoms, and the resultant problems in daily life, which necessitates a comprehensive and individual in-depth

assessment of every stroke patient, and subsequently, the development of individualised treatment and management plans. In addition, those with stroke frequently have substantial comorbidity, such as diabetes, osteoarthritis, myocardial infarction, heart failure, osteoarthritis and generalised cerebrovascular disease, all of which compound the effects of stroke (Sturm, Donnan, Dewey, Macdonell, Gilligan & Thrift, 2004).

Disabilities after stroke

Disabilities, according to the WHO ICF model, include both the loss of activities and the effect on participation. Loss of activities includes the loss of ability to carry out activities of daily living. These are often classified into personal self care activities, such as washing, dressing and bathing, and instrumental activities of daily living, those needed to be independent on the home, such as making a hot drink, cooking a meal and cleaning the house. Loss of participation covers much wider roles, such as the ability to work, engage in leisure activities and have a social life. The latter is also affected by the environment and patients' lifestyle, and not just the direct consequences of the stroke.

Models of need

It is also helpful, particularly when planning the development of services relevant to stroke survivors and their carers, to consider not just problems and their consequences, but also needs and, perhaps most importantly, unmet needs (French, Leathley, Radford, Dey, McAdam, Marsden, Sutton *et al.*, 2009). These are defined (French *et al.*, 2009, p.13) as:

- **‘Problem:** a condition, impairment or functional limitation acquired as a consequence of stroke;
- **Need:** an ability or aspect of life where support for either the stroke survivor or carer may be required to promote health and well-being, or to maximise activity and participation;
- **Unmet:** need: an area of need which is perceived by the user to be unmet, or which does not meet specified standards’.

French *et al.* (2009) conducted an extensive mapping study of the available literature and consulted with user groups of stroke survivors and carers to identify categories of need. These included everyday living needs, physical needs, emotional and well-being needs, social needs, communication and cognition needs, financial, legal and care needs, re-enablement needs and carer needs. A framework of needs was produced, which is shown in Figure 1.2 and demonstrates the breadth of issues identified.

Further work is needed to explore, not just the aetiology and time course of particular problems, but also the nature of the complex relationships between

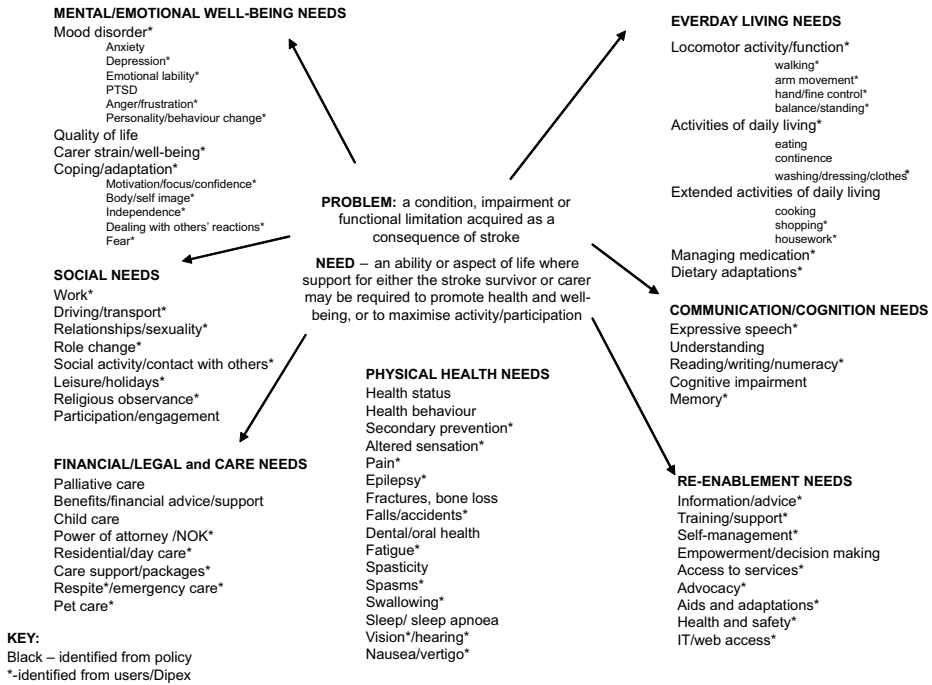


Figure 1.2 Framework of needs and problems identified from policy and stroke survivors and carers. Reproduced with permission from French, B., Leathley, M. J., Radford, K., Dey, M. P., McAdam, J., Marsden, J., *et al.* (2009). UK Stroke Survivor Needs Survey Information Mapping Exercise. Report to the Stroke Association. © University of Central Lancashire 2008.

these different categories of need. It is the understanding of these relationships that will give greater insight into how to ensure mental and emotional well-being, to provide prevention and treatment strategies that are tailored to individual patient needs and circumstances; and to deliver patient-orientated services in the future.

Conclusions

There is a broad range of effects of a stroke across a wide range of domains, subjective as well as physical. Both the patients' perspective and the professionals' perspectives need to be understood to gain a comprehensive awareness of the psychological effects of stroke. Identification of the full range of problems, the needs that arise in the patient and family and the extent to which any unmet needs can be met will facilitate the development of a comprehensive plan for the management of the effects of a stroke.