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Work after Stroke: focusing on barriers and enablers

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Work after Stroke: focusing on barriers and enablers

Abstract

Previous research on work after stroke has used quantitative methods and a medical model approach to identify factors that influence return to work. This study uses an inclusive, qualitative methodology (focus groups) to begin to explore stroke survivors' own perspectives about what helps and hinders paid or voluntary work after stroke. The research was conducted in partnership with Different Strokes, a British organisation of stroke survivors. Five focus group discussions were held with 37 stroke survivors and 12 of their supporters. Data was analysed using an adapted Framework approach to identify themes within and across individuals and groups. Factors representing barriers to or enablers of work were identified in four key themes: rehabilitation process, employer agency, social structural and personal. The study found evidence of social oppression via infrastructure, institutional structures and practices, and some individuals' attitudes. Alongside this, some supportive individuals, practices and strategies were identified.

Work after Stroke: focusing on barriers and enablers

Stroke is the largest single cause of severe impairment in the UK (Martin et al, 1988), and every year over 10,000 people of working age in the UK have a stroke, including more than 1,000 people under the age of 30 (Asplund et al, 1995). Perhaps because stroke is most commonly associated with old age, comparatively little attention has been paid to stroke survivors' return to work. For example, the British National Health Service (NHS) National Service Frameworks (NSFs) include stroke in the NSF for Older People (Department of Health, 2001). Despite the belief of the British government in power since 1997 that employment is *the* best way to combat poverty and social exclusion among all disadvantaged groups of working age, including disabled people, the NSF contains no mention of return to employment after stroke. This paper begins to explore the nexus between stroke and paid or voluntary work. Different Strokes is an organisation of stroke survivors in the UK. At their instigation, we worked collaboratively to explore work issues. Different Strokes had identified work as an important issue for its members and was keen to improve its guidance on employment to stroke survivors, their families and friends and employers. This paper draws on the first stage of the research project, which comprised focus groups whose primary purpose was to assist in the design of a questionnaire that has since been sent to the 3,000 stroke survivors on Different Strokes' mailing list.

The underlying theoretical framework for the study was the social model of disability. The project aimed to go beyond the investigation of social barriers and social oppression to distinguish what helps disabled people who wish to work to do so, and to identify and disseminate good practice. The team recognised from the outset the incongruity between the social model theoretical framework and a project based on a particular medical category. However, this conflict arose naturally from the research team's commitment to working in partnership with stroke survivors and ensuring their maximal involvement in the research process (Stone & Priestley, 1996; Moore et al, 1998), and the strong desire of the stroke

survivors for their experience in relation to employment to be investigated for their and other disabled people's benefit.

Predictably, the social model focus on social barriers and social oppression proved to some extent incompatible with the exploration of stroke survivors' experiences. Stroke starts as an illness (disturbance of blood flow or haemorrhage in the brain), which usually requires a considerable period for recovery to a point at which survivors feel reasonably well in themselves. Stroke often leads to residual physical, communication, sensory, memory and/or emotional impairments. Thus younger stroke survivors have to deal with the combined effects on their employment chances of (usually) long-term sick leave and of returning to work as a disabled person. Any investigation of stroke survivors' experiences regarding employment needs to take this pattern of illness leading to impairment into account. Such a trajectory is not peculiar to stroke survivors. It also applies to other disabled people such as some who have had accidents, including road traffic accidents. The finding that 'seven out of ten disabled people become disabled during their working lives' (Labour Force Survey, Winter 1997/1998 quoted by RADAR, 2000, p. 7) suggests wider relevance among disabled people of at least this aspect of stroke survivors' experiences. Barnes et al (1998) suggest that the experience of becoming disabled in work is little-researched.

Within the social model approach there is increasing recognition of what Thomas (1999) calls 'impairment effects'. Ongoing impairment was clearly a major factor in return to work and stroke survivors' lives more generally. Stroke can lead to any combination of the wide range of impairments already noted. An added complication is that some stroke survivors have subtle impairments about which there is a lack of understanding in the general population. People who have 'recovered' from stroke illness commonly continue for some time to experience marked

fatigue. Stroke survivors share some impairment effects with other groups of disabled people, in particular people who have suffered brain damage due to head injury or brain infection.

The literature on return to work after stroke is mostly located in a medical model approach. It is primarily concerned with using quantitative research methods to identify factors associated with return to employment. Factors considered include the nature and degree of individuals' impairments, previous employment status, educational qualifications and available social security systems (Bergmann et al, 1991; Angeleri et al, 1993; Saeki et al, 1993; Saeki et al, 1995; Hsieh & Lee, 1997; Howard et al, 1985; McMahon & Slowinski Crown, 1998). No studies have explored in any depth stroke survivors' own perspectives on factors and/or processes relating to return to work. Small-scale research in relation to speech and language impairments (aphasia) rather than stroke *per se* has addressed these issues to some extent. Factors people with aphasia say influence their return to work include availability of alternative jobs, working patterns and conditions, attitudes of employers and family members, and availability of education/training (Rolland & Berlin, 1993; Jordan & Kaiser, 1996; Parr et al, 1997; Garcia et al, 2000). One focus group study has shown that such factors may interact with the person's impairments to create barriers to employment (Garcia et al, 2000). Research into employment and disabled people suggests that attitudes of doctors, rehabilitation and social care professionals, transport and access to the workplace are also influential. (Branfield & Maynard Campbell, c. 2000; Maynard Campbell & Maynard Lupton, 2000; Keetch, 2000)

As indicated at the beginning of this paper, the policy context within which this study took place includes a strong bias in favour of employment, with an emphasis on the first phrase of the New Labour slogan 'work for those who can and security for those who cannot' (Blair, 1998, p. iii). Many, though by no means all, of the stroke survivors who chose to participate in the research were keen to work. The available evidence regarding the proportion of working age stroke

survivors who return to work is inconclusive, with rates from 7% to 84% in 20 studies across a number of countries (Saeki, 2000). The two UK studies included in Saeki's (2000) review give return to work rates of 38% and 24%, but neither study is very large and the more recent was published in 1982. The present researchers aimed to maintain a neutral stance as to the desirability or otherwise of return to work after stroke. This was necessary both in order to elicit stroke survivors' own perspectives and in accordance with our commitment to being supportive to stroke survivors and valuing diversity.

Methodology

In Spring 2000 we conducted five focus group discussions about work after stroke with younger stroke survivors. Focus groups have been found to be a reliable and effective method both of studying attitudes and experiences and of assisting in the development of questionnaires (Kruegar, 1994; Morgan, 1997; Kitzinger & Farquhar 1999).

Participants

Different Strokes has a 'self-help' ethos. Some members organise, support and attend local exercise classes and groups. These promote a healthier life style, provide a forum for exchange of practical information and mutual support, and encourage participants to regain their independence. Co-ordinators of five Different Strokes groups (four in the south-east of England, where the majority of the membership lives, one in a large Scottish city) were each sent an explanatory letter inviting them to recruit a focus group. All accepted. The only criteria for attendance were that participants should be aware of the aims of the study and focus group, and willing to discuss their experiences of work after stroke.

Overall, 37 stroke survivors participated in the five focus groups, 12 of whom were accompanied by a partner. It was considered inadvisable to expect participants to reveal their age, but in some instances this information was volunteered or could be deduced. Nearly all focus group members were below retirement age. The one exception was a man over 65 who was self-employed as a company director and now working part time. The youngest participant

was 20. Two participants had had strokes as teenagers (at 15 and 17 years). Prior to their stroke, 33 had been in full-time paid employment. Of these, eight had returned to full time employment at the time of the focus groups, three had returned part-time, six were doing voluntary work, and 16 were not working. Of the four people not working at the time of their stroke, one had taken early retirement but was seeking part-time employment, one was a full-time homemaker, one had been a full-time student, and one had been unable to work due to poor health. The stroke survivors had a range of post-stroke abilities and difficulties, ranging from minimal residual impairments to severe communication or physical difficulties. Time since stroke ranged from 6 weeks to 10 years for 36 of the stroke survivors, with average time post-onset being 3.9 years. One participant was 32 years post-stroke. The characteristics of each group are summarised in Table I.

[Table I about here]

Venues and materials

Each focus group was carried out in a meeting room at the usual venue of the Different Strokes group, i.e. in a sports centre. The surroundings were made as relaxed and comfortable as possible. Group members sat round a table. Discussions were recorded. Consent was obtained prior to recording.

Facilitating discussion

Each focus group was facilitated by the first author (a speech and language therapist specialising in acquired neurological disorders) and a second member of the research team. The goals of (i) the overall study and (ii) the focus group were outlined, and the role of group members in the development of the questionnaire was explained. The notion of barriers to and enablers of employment existing outside the individual was introduced, and group members were encouraged to think about such factors in terms of their own employment. Participants were given the opportunity to discuss their own expectations of the discussion and seek clarification of any issues. They were encouraged to use all methods of communication at their disposal and

were provided with pen and paper. All communicated verbally, but those members with severe communication difficulties were aided by their partner and/or the group facilitators. Notes were kept about which contributions were directly from stroke survivors and which were facilitated. Partners were encouraged to let the stroke survivors give their views first, although they were also given the opportunity to discuss their own views and experiences.

Identification of barriers/enablers through discussion of personal experiences

A funnel strategy (Morgan 1997) was adopted for each group, i.e. contributions regarding personal experiences fed into a discussion structured around emerging themes. Themes were summarised on a flip chart. Members were then asked to think about and share their individual experiences in relation to each theme, and to discuss how factors relating to their experiences acted as barriers to or enablers of employment. The discussion here was led and developed by the participants themselves. When the main themes identified by the participants had been exhausted, the facilitator introduced themes from a prepared topic guide informed by previous research into barriers to and enablers of work for disabled people. The topic guide covered eight topics: employers, adaptations at work, transport, doctors and rehabilitation staff, people who advise about work, family/friends, benefits and education/training. This prompt was rarely necessary as the themes were consistently introduced by the participants during discussion.

Data analysis

Qualitative methods have proved particularly suitable for the analysis and interpretation of focus group interview data (Morgan, 1997; Miles & Huberman, 1984). We adapted the Framework Method developed by Ritchie & Spencer (1994). This involves a systematic process of sifting, charting and sorting material according to key issues and themes. Two members of the research team listened independently to each recorded discussion and made detailed notes of all points made. Key ideas and recurring themes were identified and indexed on a framework by the first author (Table III). Verbatim transcripts were made to illustrate each theme. The thematic

framework was systematically applied to the data from each group, with individuals' contributions referenced using the numerical system and textual labels featured in Table III. This process enabled the data to be read and scrutinised by two other members of the research team and agreement on thematic coding to be reached. The data were then summarised on to charts according to their appropriate thematic references and examined more fully for the range and nature of the phenomena discussed during the focus groups.

[Table II about here]

Results

Four main themes and several sub-themes were identified as representing factors that act as barriers to or enablers of employment after stroke. These are presented below and illustrated with verbatim transcripts. Excerpts are from the stroke survivors unless otherwise noted.

Pseudonyms are used throughout.

1. Rehabilitation process factors

All groups perceived barriers to employment stemming from within the rehabilitation system. These extended across the full spectrum of UK NHS provision, in several cases beginning with admission to unsuitable wards and misdiagnosis of their condition:

early identification is where the key lies... if you're younger they don't suspect stroke... they treated me for meningitis... at [hospital] they didn't have the ability to scan me and find the stroke... went from there to another hospital

(Jennifer, Group E)

The experience described here led this stroke survivor to question whether she would have recovered more quickly and to a greater extent had her stroke been identified earlier.

Many participants felt that negative attitudes of medical staff and other healthcare professionals with whom they came into contact hindered their rehabilitation and well-being:

The psychologist in this hospital painted me ...[as having] cognitive difficulties ... I never had. It's obvious I had a severe stroke... so he [assumed I] must have ...

cognitive difficulties. That's why I get mad about psychologists (Bill, Group B)

Bill's wife related how the psychologist had upset Bill by giving him seemingly pointless assessments of up to an hour, until Bill told the psychologist that he would not do tests any more. Professionals' negativity sometimes actively discouraged consideration of return to work:

The consultant wasn't very helpful or encouraging... he said 'go home and smell the roses'... I thought it's only 7½ weeks since the stroke and this guy's written me off, I'll never work again (Alan, Group B)

The most striking finding in relation to the rehabilitation process was the widespread perception that rehabilitation stops when minimal function is regained and is insufficient in duration or scope to prepare people for work after stroke. This insufficiency was assumed by many participants to be linked to a lack of NHS funds and the resulting shortage of rehabilitation staff and services, or to the limited remit of staff:

Rehabilitation gets cut off very early: if we had more physical and speech therapy we would all be able to do our jobs much better... I have to pay for physiotherapy and I have no private insurance (Daniel, Group C)

They just don't have the money to come out any more. It all comes back to money (Jennifer, Group E)

Rehabilitation staff are people who help you in your illness – they're not [concerned with] after your illness (John, Group E)

Participants called for help in making the transition from rehabilitation to independence, and for long-term reassessments to provide them with information about their workplace capabilities. Rehabilitation limitations were sometimes attributed to services not being geared towards younger people:

*I didn't get much attention at all... because I was **young** they probably thought, she'll be alright... they can only see us for three months, they have to go on and help other people*

(Annie, Group E)

Overall, very few participants identified factors in the rehabilitation process which acted as enablers of employment. Only one person reported that rehabilitation had prepared her sufficiently for work. Some professional groups (such as occupational therapists (OTs)) were identified as being proactive regarding rehabilitation for work, although there was no uniform consensus about who should or could provide the lead role in vocational rehabilitation.

I've had guidance from my OT such as planning and helping me to plan out what I could/can't do... give me good advice

(Pete, Group D)

An outreach nurse visited us at home and answered questions and offered to look up anything – I felt Bill was listened to

(Bill's wife, Group B)

Liaison between rehabilitation professionals and employers was seen as an important factor in enabling people to access appropriate services and to eventually return to work. However, such liaison was seen as rare rather than a regular occurrence.

It depends on where you live and which area of health authority you come under.

The stroke co-ordinator liaised with [a person from local authority], who made contact with [rehabilitation service]. That set me up for another six months

(Jennifer, Group E)

All groups discussed the benefits of membership of Different Strokes. The organisation was seen as having an important role in providing the physical and psychological support for recovery towards work which was unavailable within state-funded rehabilitation services.

In an ideal world everyone would be helped when they're ill... we can't afford that as a country, so it comes down to a lot of self-help and organisations like Different Strokes

(John, Group E)

2. *Employer agency factors*

The main factors associated with employer agencies were sick leave arrangements, adaptations and attitudes, all of which could act as enablers and barriers to work after stroke.

Whilst on long-term sick leave, the issues of sick pay and whether and for how long stroke survivors' employment would be held open for them were sources of anxiety. Arrangements often failed to cater sufficiently for the unique needs and situations of stroke survivors, who may need very long term sick leave:

If you have a heart attack, you can be two months off work and go back to work and continue as before, but this goes on and on and on... my doctor said 12 months for the physical side, to make the major improvements, then 12 months psychologically... they perhaps need to make much longer allowances to recover from stroke

(Alan, Group B)

Employers' negative attitudes, inflexibility and failure to implement adaptations to the stroke survivors' work role, hours or equipment were perceived as barriers. These were often linked to the perception that employers put profitability and productivity before the employee:

I couldn't be on the phone and take notes at the same time, so I needed an adaptation. They did promise... nothing happened. If work hours were adapted I could work, but they were not

(Joe, Group A)

It was get on with the job, and if you can't do the job we'll get somebody else to do it. I'm afraid that's the commercial world we live in. That's the attitude of big and small companies (John, Group E)

Of the eleven people who were in full- or part-time employment at the time of the focus groups, nine identified adaptations or employer attitudes that had enabled them to return to work. These included the provision of adapted equipment, such as a computer keyboard for use with one hand, and allowing people to work fewer hours or days or to modify their responsibilities. Positive attitudes were frequently seen as stemming from employers having some first-hand or familial experience of stroke.

What enabled me to work was the encouragement and support of the company. My immediate boss's brother had died of a stroke, and his mother had a stroke, so he was very aware, and aware of stresses on people, but as a whole the company was very supportive (Jennifer, Group E)

The 1995 Disability Discrimination Act (DDA), which requires most employers other than small firms to make 'reasonable adjustments' to the workplace/working arrangements to assist a disabled person, was recognised as a powerful ally to stroke survivors wishing to remain at work:

My boss thought it was time for me to leave but the DDA wouldn't allow him to... he's ignored me since (Lucy, Group B)

However, it was widely felt that many employers and employees are unaware of the DDA or that employers can purposefully ignore the legislation

If I tried to force that [DDA] on my employer they'd probably say fine, we'll do that for you, but they're in control, they can do whatever they want behind the scenes (Alan, Group B)

Several group members who had been in paid employment or full time education before their stroke were doing voluntary work at the time of the focus groups. Despite some suggestion that volunteer roles can be demeaning, they recognised that voluntary work offered certain rewards.

I don't want paying... I need work for my sanity (Gina, Group C)

I liked my job [as an architect] but I can't do it now. I help [a voluntary organisation]... post, only that... but I like working (Tony, Group E)

Social structural factors

We defined social structural factors to include those related to the benefits system, realities of the job market, access/transport, training opportunities and societal attitudes to and awareness of stroke. These factors were perceived as linked with lack of government spending to create barriers to employment.

The benefits system was seen as being unfair, discriminatory and inaccessible to people with the reading, writing and/or comprehension difficulties associated with stroke. Several participants were afraid to attempt to return to employment in case they could not regain benefits if they found that they could not cope with work. Others were deterred from seeking work by the perceived competition of the job market, and called for job creation schemes that were suitable for the particular impairment effects associated with stroke:

The woman at the job centre said... you will be competing with able-bodied people. People are fighting for jobs anyway. They say they've got jobs for the disabled [sic]. Yes they may have if you've got an arm missing or one disability that is not as severe, but when you're talking about speech, mental, that sort of ability, they might have jobs for very straightforward disabilities but that's not stroke

(Len's wife, Group A)

One factor that was common to all the major themes identified in the focus groups, and which acted as both an enabler and a barrier, was information. Participants called for more information and a greater ease of accessibility at all stages in their rehabilitation. They noted a particular paucity concerning searching for work or retraining.

Are there actually people that actually advise about work, because I didn't find them?
(Neil, Group A)

Focus group participants bemoaned the widespread lack of awareness of stroke in younger people, reflected in poor service provision and general ignorance about the impairments that stroke leaves behind, which are often invisible or not easily comprehensible:

Most people think stroke is for the elderly, not a young person's complaint
(Mavis, Group D)

When I can't make myself understood they think that this guy's mentally retarded (sic)
(Bill, Group B)

You look normal so they think you're all right. They can't make allowances at all... it's outside their normal experience
(Joe, Group A)

Nine of the 11 people who had returned to paid work had their own means of transport. However, lack of funding for appropriate transport that would enable people to seek or get to work was a major issue for all groups.

Without [financial assistance] I can't get a car. I'm housebound without a car. I can't carry much when I'm walking and getting buses or a tube is too difficult. Being independently mobile would give me my life back
(Gina, Group C)

Personal factors

Focus group members recognised that their individual characteristics (including their impairments), their family and their financial situation all influenced their work prospects after stroke. Difficulties with memory, processing information, speech and language, vision, walking, using the dominant hand and the effects of fatigue were all reported as barriers to employment.

I get very tired. When I first started voluntary work I would collapse for four hours after. Now it's better, I only sleep for two! (Annie, Group E)

Most work involves using the eyes. If I read for half an hour I'm physically tired and go to sleep (James, Group A)

In discussing employer agency barriers, some unemployed focus group members felt strongly that with reasonable adjustments, such as special equipment and employer flexibility, they were capable of holding down a job. Others blamed their lack of work entirely on their impairments, rather than attributing some responsibility to a system that made work difficult or impossible for them.

I had short-term memory problems, which I didn't actually realise, so they were probably quite justified in sacking me (Dorothy, Group B)

Some focus group members expressed pride in the personal qualities that had enabled them to return to work.

Determination enabled me to work. Apart from my family I had no help, but getting back to work was what I wanted to do (John, Group E)

We're all positive people, which is probably why we come to Different Strokes. Your future is in your hands, you can do something that makes a difference

(Jennifer, Group E)

Discussion

The results of focus group discussions with 37 members of an organisation of younger stroke survivors suggest that return to work after stroke is influenced by a variety of factors which are situated within the rehabilitation process, employer agencies, social structure and characteristics of the individual. Stroke survivors and partners in the focus groups saw their impairments as barriers to work. However, impairments were generally seen as just one element within a complex constellation of factors that act and interact to influence work reintegration (Garcia et al, 2000)

Stroke survivors' journeys towards work begin with their earliest post-stroke experiences, which usually involve the rehabilitation system. Our focus groups saw this system as creating immediate barriers to work by being inadequate at all stages: too little, for too short a time, and (sometimes) too late. Rehabilitation was seen as sufficient only to get people back on their feet and out of acute hospital care, but not to prepare them for work. Staff were perceived as having predominantly negative attitudes about stroke survivors' scope for recovery and ability to return to work. These findings add weight to the argument for better service co-ordination (Department of Health, 2001; Kelson & Ford, 1998), more emphasis on vocational rehabilitation (Mountain et al, 2001) and funding for this within the NHS (British Society of Rehabilitation Medicine, 2001; Disler & Pallant, 2001).

Some stroke survivors required more information about their contractual employment rights and their employer's policy and practice in relation to long-term sick leave. Recent work by James et al (2003) should contribute to employers' clarity regarding such issues (though this cannot be expected always to benefit individual disabled people). Employers' support and practice regarding reasonable adjustments varied considerably (though some reported incidents may have occurred prior to the introduction in 1996 of the employment provisions of the DDA 1995). The DDA could be helpful, though this was not necessarily

without cost in terms of working relationships. There was some scepticism regarding its enforceability.

This study confirms previous findings about factors in the wider environment: negative workings of the benefits system for disabled people (e.g. RADAR, 2000; Keetch, 2000); the importance of accessible transport (e.g. Branfield & Maynard Campbell, c. 2000); information gaps (e.g. Branfield & Maynard Campbell, c. 2000) and a need for increased official and public understanding of stroke in younger people (e.g. Jordan & Kaiser 1996). It exposes frustration at *de facto* exclusion from help into employment for people with multiple and/or complex impairments, despite government rhetoric about assisting disabled people to work.

Most participants identified a range of barriers and enablers from different sources. A few stroke survivors' emphasis on impairment as the source of their difficulties might be interpreted in terms of the dominance of the medical model and an absence of social model thinking, something anticipated by Stone & Priestley (1996). An alternative explanation would be that it shows a realistic assessment of the realities of a capitalist labour market (Russell, 2002).

Conclusion

Overall, the evidence supports the social model view of a disabling society, with oppression of disabled people endemic in widely-accepted institutional practices and expressed in some individuals' negative and patronising words and actions. The stroke survivors in this study saw the following issues as needing to be addressed:

- Rapid and appropriate acute diagnosis and care
- Increased awareness of the existence and impact of stroke in younger people
- Longer term rehabilitation which tackles the individual's functional problems and facilitates planning for return to work
- Rehabilitation staff designated to deal with vocational matters

- Liaison between healthcare professionals and employers
- Identification, negotiation and support of alternative working patterns
- Disabled people's need for appropriate information at all stages

It is possible that, since our focus group study, implementation of the National Clinical Guidelines for Stroke (Wade, 2000) is leading to at least some of the rehabilitation issues in the above list being addressed. Whilst the disadvantages stroke survivors faced were all too apparent, supportive individuals, attitudes, practices and strategies were also identified.

Caution is required in generalising the results of this study to other stroke survivors. Our sampling of Different Strokes local groups was to some extent 'purposive', that is based on 'the researcher's judgement as to typicality or interest ... to satisfy ... specific needs in a project' (Robson, 1993, p. 141-142) but also influenced by convenience factors.

Appropriate uses for 'convenience sampling' include 'getting a feeling for the issues involved' (1993, p. 141). As explained in the introduction, our focus groups were primarily for this purpose rather than to produce generalisable results. Nevertheless, the extent of findings in common with other studies both reinforces these earlier findings and increases the likelihood of them holding for stroke survivors in general. In the present study it is acknowledged that group size, compilation and dynamics may have impacted on what participants reported during discussions (Morgan, 1997; Kitzinger & Farquhar 1999). However, several factors promoted open, frank and meaningful discussion. These included open recruitment to the groups; facilitation techniques that encouraged contributions from all participants; and sessions based on themes which the participants themselves felt were important.

The focus group method was useful in three ways: First, it highlighted barriers to and enablers of work from the perspective of stroke survivors themselves. These are important in their own right. Second, this information was then used to construct a postal questionnaire. Stroke survivors were thus actively involved in the initial development of this research tool. The questionnaire allowed the themes that emerged in the focus groups to be explored more quantitatively with a larger population of British stroke survivors. Finally, through the focus group stage we ensured that the project focused on issues from the perspective of stroke survivors rather than the traditional models espoused by clinicians and many researchers.

Focus group members appeared to value the opportunity to share their experiences of both social and personal factors regarding return to work. Later stages of the Work After Stroke research project involved in-depth interviews with stroke survivors, their supporters and employers, enabling further exploration of the interplay of different factors.

References

- ANGELERI, F., ANGELERI, V.A., FOSCHI, N., GIAQUINTO, S. & NOLFE, G. (1993) The influence of depression, social activity and family stress on functional outcome after stroke, *Stroke*, 24, pp. 1478-1483.
- ASPLUND, K., BONITA, R. & KUULASMAA, K. Multinational comparisons of stroke epidemiology: WHO MONICA Stroke Study. *Stroke*.1995;24;355-360.
- BARNES, H. THORNTON, P. & MAYNARD CAMPBELL, S. (1998) *Disabled People and Employment: A review of research and development work* (Bristol, Policy Press).
- BERGMANN, H., KUTHMANN, M., VON UNGERN-STERMBERG, A. & WEIMANN, V.G. (1991) Medical educational and functional determinants of employment after stroke. *Journal of Neural Transmission Supplement*. 33, pp. 157-161.
- BLAIR, T (1998) Foreword to White Paper 'A New Contract for Welfare: Principles into Practice' Cm 4101 (London: Stationery Office).
- BRANFIELD, F. & MAYNARD CAMPBELL, S. (c. 2000) *Common Barriers and Their Removal* (Manchester, Breakthrough UK Ltd. "Trailblazers Project").
- BRITISH SOCIETY OF REHABILITATION MEDICINE (2001) *Vocational rehabilitation: the way forward* (London, British Society of Rehabilitation Medicine).
- DEPARTMENT OF HEALTH (2001) *National Service Framework for Older People* (London, Department of Health).
- DISLER, P.B. & PALLANT, J.F. (2001) Vocational rehabilitation: Everybody gains if injured workers are helped back into work, *British Medical Journal*, 323, pp. 121-123.
- GARCIA, L.J., BARRETTE, J. & LAROCHE, C. (2000) Perceptions of the obstacles to work reintegration for persons with aphasia, *Aphasiology*, 14(3), pp. 269-290.
- HOWARD, G., STANWOOD TILL, J., TOOLE, J.F., MATTHEWS, C. & LIONEL TRUSCOTT, B. (1985) Factors influencing return to work following cerebral infarction, *Journal of the American Medical Association*, 253, pp. 226-232.

HSIEH, C. L. & LEE, M.H. (1997) Factors influencing vocational outcomes following stroke in Taiwan: a medical centre-based study, *Scandinavian Journal of Rehabilitation Medicine*, 29, pp. 113-120.

JAMES, P., CUNNINGHAM, I & DIBBEN, P. (2003) *Job retention and vocational rehabilitation: the development and evaluation of a conceptual framework*, Research Report 106 (London, Health & Safety Executive).

JORDAN, L. & KAISER, W. (1996) *Aphasia - a social approach* (Cheltenham, Stanley Thornes).

KAPELLE, L.J., ADAMS, H.P. JR., HEFFNER, M.L., RONER, J.C., GOMEZ, F. & BILLER, J. (1994) Prognosis of young adults with ischemic stroke. A long-term follow-up study assessing recurrent vascular events and functional outcome in the Iowa Registry of Stroke in Young Adults, *Stroke*, 25, pp. 1360-1365.

KEETCH G. (2000) *Breaking the Barriers* (Hemel Hempstead, Dacorum Borough Council)

KELSON, M. & FORD, C. (1998) *Patient and carer's views of stroke rehabilitation* (London, College of Health/Royal College of Physicians).

KITZINGER, J. & FARQUHAR, C. (1999) The analytical potential of 'sensitive moments' in focus group discussions, in: R.S. BARBOUR & J. KITZINGER (Eds) *Developing Focus Group Research* (London, Sage).

KRUEGER, R.A. (1994) *Focus Groups: a practical guide for applied research* (2nd edition) (London, Sage).

MCMAHON, R. & SLOWINSKI CROWN, D. (1998) Return to work factors following a stroke. *Topics in Stroke Rehabilitation*, 5(2), pp. 54-60.

MARTIN J., MELTZER, H. & ELLIOT, D. (1988) *The prevalence of disability among adults. OPCS Surveys of Disability in Great Britain Report 1* (London, Stationary Office).

MAYNARD CAMPBELL, S. & MAYNARD LUPTON, A. (2000) *Bureaucratic barriers to normal day-to-day activity* (Derby, MusclePower).

- MILES, M.B. & HUBERMAN, M. (1984) *Qualitative Data Analysis*. (California, Sage).
- MORGAN, D.L. (1997) *Focus groups as qualitative research* (2nd edition) (London, Sage)
- MOORE, M., BEAZLEY, S. & MAELZER, J. (1998) *Researching Disability Issues*. (Buckingham, Open University Press).
- MOUNTAIN, G., CARMAN, S. & ILOTT, I (2001) *Work Rehabilitation and Occupational Therapy* (London, College of Occupational Therapists).
- PARR, S., BYNG, S., GILPIN, S. with IRELAND, C. (1997) *Talking about aphasia*. (Buckingham, Open University Press).
- RITCHIE, J. & SPENCER, L. (1994) Qualitative data analysis for applied policy research. In A. BRYMAN & R.G. BURGESS (Eds) *Analysing Qualitative Data*. (London, Routledge).
- ROBSON, C. (1993) *Real World Research: A Resource for Social Scientists and Practitioner-Researchers* (Oxford, Blackwell).
- ROLLAND, J. & BELIN, C. (1993) The person with aphasia and the workforce, in: D. LAFOND, Y. JOANETTE, J. PONZIO, R. DEGIOVANI & M. TAYLOR-SARNO (Eds) *Living with Aphasia: Psychosocial issues* (California, Singular Publishing).
- ROYAL ASSOCIATION FOR DISABILITY AND REHABILITATION (RADAR) (2000) *Mind the Gap: Disability, Opportunity and Employment* (London. RADAR).
- RUSSELL, M (2002) What disability civil rights cannot do: employment and political economy, *Disability & Society*, 17(2), pp. 117-135.
- SAEKI, S. (2000) Disability management after stroke: its medical aspects for workplace accommodation, *Disability and Rehabilitation*, 22(13/14), 578-582.
- SAEKI, S., OGATA, H., OKUBO, T., TAKAHASHI, K. & HOSHUYAMA, T. (1993) Factors influencing return to work after stroke in Japan, *Stroke*, 24, pp. 1182-1185.
- SAEKI, S., OGATA, H., OKUBO, T., TAKAHASHI, K. & HOSHUYAMA, T. (1995) Return to work after stroke: a follow-up study, *Stroke*, 26, pp. 399-401.

STONE, E. & PRIESTLEY, M. (1996) Parasites, pawns and partners: disability research and the role of non-disabled researchers, *British Journal of Sociology*, 47(4), pp. 609-716.

THOMAS, C. (1999) *Female Forms: Experiencing and understanding disability* (Buckingham, Open University Press).

WADE, D. AND THE INTERCOLLEGIATE STROKE WORKING PARTY (2000) *National Clinical Guidelines for Stroke* (London, Royal College of Physicians).

Table I. Characteristics of five focus groups

Focus group	No. of stroke survivors	No. of partners	Total in group
A	2 female 7 male	1 mother 3 wives	13
B	2 female 5 male	3 wives	10
C	4 female 6 male	0	10
D	3 female 2 male	1 wife 1 husband	7
E	2 female 4 male	1 wife 1 mother-in-law 1 partner	9
Total	37 (13 female, 24male)	12	49

Table II. Factors identified by stroke survivors as acting as barriers to or enablers of work after stroke

<p>1 Rehabilitation process factors</p> <p>1.1 <i>Identification of stroke</i></p> <p>1.2 <i>Availability of rehabilitation</i></p> <p> 1.2.1 <i>time/duration</i></p> <p> 1.2.2 <i>type</i></p> <p>1.3 <i>Appropriateness of rehabilitation</i></p> <p> 1.3.1 <i>time/duration</i></p> <p> 1.3.2 <i>type</i></p> <p>1.4 <i>Rehabilitation staff attitudes</i></p> <p> 1.4.1 <i>consultant</i></p> <p> 1.4.2 <i>occupational therapist</i></p> <p> 1.4.3 <i>physiotherapist</i></p> <p> 1.4.4 <i>psychologist</i></p> <p> 1.4.5 <i>nurse</i></p> <p> 1.4.6 <i>speech language therapist</i></p> <p> 1.4.7 <i>GP</i></p> <p> 1.4.8 <i>social worker</i></p> <p>1.5 <i>Rehabilitation staff role re work</i></p> <p> 1.5.1 <i>consultant</i></p> <p> 1.5.2 <i>occupational therapist</i></p> <p> 1.5.3 <i>physiotherapist</i></p> <p> 1.5.4 <i>nurse</i></p> <p> 1.5.5 <i>speech language therapist</i></p> <p> 1.5.6 <i>GP</i></p> <p> 1.5.7 <i>other</i></p> <p>1.6 <i>Variation in care</i></p> <p>1.7 <i>Information</i></p> <p>1.8 <i>Transition from rehabilitation</i></p> <p>1.9 <i>Rehabilitation/employer liaison</i></p> <p>1.10 <i>Role of voluntary sector</i></p> <p>1.0 <i>Other</i></p> <hr/> <p>2 Employer agency factors</p> <p>2.1 <i>Adaptations</i></p> <p> 2.1.1 <i>to role</i></p> <p> 2.1.2 <i>to working hours</i></p> <p> 2.1.3 <i>to equipment</i></p> <p>2.2 <i>Employer attitudes</i></p> <p>2.3 <i>Employer knowledge of stroke</i></p> <p>2.4 <i>Productivity/profitability</i></p>	<p>2.5 <i>Colleagues' attitudes</i></p> <p>2.6 <i>Size of organisation</i></p> <p>2.7 <i>Legislation</i></p> <p>2.8 <i>Insurance</i></p> <p>2.9 <i>Pay</i></p> <p>2.10 <i>Alternative employment</i></p> <p> 2.10.1 <i>self employment</i></p> <p> 2.10.2 <i>voluntary work</i></p> <p>2.11 <i>Information</i></p> <p>2.0 <i>Other</i></p> <hr/> <p>3 Social Structural factors</p> <p>3.1 <i>Health care funding</i></p> <p>3.2 <i>Benefits system</i></p> <p> 3.2.1 <i>financial support programme</i></p> <p> 3.2.2 <i>form filling</i></p> <p>3.3 <i>Job market</i></p> <p> 3.3.1 <i>availability of work</i></p> <p> 3.3.2 <i>competition</i></p> <p>3.4 <i>Access/transport</i></p> <p>3.5 <i>Societal attitudes/awareness</i></p> <p>3.6 <i>Training/retraining</i></p> <p>3.7 <i>Information</i></p> <p>3.0 <i>Other</i></p> <hr/> <p>4 Personal factors</p> <p>4.1 <i>Individual characteristics</i></p> <p> 4.1.1 <i>self esteem/confidence</i></p> <p> 4.1.2 <i>motivation</i></p> <p> 4.1.3 <i>speech/language</i></p> <p> 4.1.4 <i>mobility/physical</i></p> <p> 4.1.5 <i>fatigue</i></p> <p> 4.1.6 <i>processing</i></p> <p> 4.1.7 <i>other</i></p> <p>4.2 <i>Family/friends</i></p> <p>4.3 <i>Financial situation</i></p> <p>4.4 <i>Reasons for working/not working</i></p> <p>4.5 <i>Recovery time</i></p> <p>4.0 <i>Other</i></p>
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