Work is key to participating in society. This paper reports two independent studies, which addressed different aspects of returning to work after a stroke. Study I, using the Canadian Occupational Performance Measure and the Role Checklist, established the perception of returning to work of 26 participants aged 34-55 years post-stroke. Study II, using interviews, established the support required and obtained for six participants who returned to work post-stroke.

Both studies found that the participants considered work to be important, that they wished to return to work and that help was needed to do so. Study II found that occupational therapists had a limited role in providing support and recommends their greater involvement in work rehabilitation service provision for those who have had a stroke. The findings of these studies suggest that there is a gap in providing appropriate support to enable people to carry out an occupation that both they and society value.

Returning to Work after a Stroke: an Important but Neglected Area

Susan Corr and Sorrel Wilmer

Introduction

Work is a very important feature of everyday life because from it individuals draw an income and have the opportunity for social contacts, status and a structure to their lives (Kelly 1990, Marmot and Feeney 1996). It is key to developing and maintaining a person's identity and can add to a sense of belonging and physical wellbeing (Pettifer 1993). However, just being in any job may not be adequate to maintain a person's wellbeing, because he or she may not gain satisfaction from the job (Pettifer 1993).

Literature review

Disability and work

Krupa et al (1998) considered work to be one aspect of a person's life that would be affected if he or she had a disability. Yerxa (1998) agreed and suggested that it was only when the opportunity to work was affected by an impairment that there was acknowledgement of the potential impact of unemployment and the loss of a work role on health. In 1998, Richards reported that there were 2.2 million people of working age with a disability or long-term illness in the United Kingdom and that over half of these wanted to work. Matheson (2001) suggested that the opportunity to work became complicated for people with chronic disease and disability.

The British Society of Rehabilitation Medicine (BSRM 2000) outlined several obstacles to re-employment that could occur quickly, such as a deterioration in physical and/or mental health and an adaptation to life on benefits, and suggested that the financial gain from returning to work might feel unacceptably small. It also acknowledged that if people have been out of work for some time, they may become satisfied with their new lifestyle which allows the pursuit of other interests. Wellwood et al (1994) suggested that the attitudes of the family of the person with an illness or disability might affect return to work.

Occupational therapy and work

Richards (1998, p296) stated that work must be on the occupational therapy agenda, because it 'provides the opportunity of moving from dependency to economic freedom'. Wilcock (1986) also agreed that during treatment, individuals' return to work should be considered by occupational therapists. According to Matheson (2001), a focus on returning to work has been integral to occupational therapy since it began, because even the early founders provided opportunities for the development of work skills and behaviours.

Yerxa (1998, p6) considered the goal of occupational therapy to be to 'enable the individual, regardless of extent or type of disability, to function in his or her environment competently and with personal satisfaction; to be a productive participant in the world'. Reed and Sanderson (1992) and Law et al (2001) considered enabling people to undertake a productive role as key to the functioning of society. However, the BSRM (2000) reported that few occupational therapists, although they had an important role, were employed to address the issue of returning to work. It suggested that the low commitment to vocational rehabilitation might reflect 'the need to divert scarce therapy resources to the acute sector' (p15).

Work after a stroke

A stroke in a younger person often results in a change in his or her employment circumstances. It can devastate the

person's career and result in a reduction of professional activities (Stroke Association 1996, Bogousslavsky et al 1998). A number of studies have been conducted to identify if a return to work occurs. Getting back to work after a stroke is not just a milestone in recovery; it is a means of boosting confidence and self-esteem and having a sense of achievement (Burningham 2001). Many people hold the belief that a person should rest after a stroke and that activity will bring on another stroke, but Warlow et al (1998) argued that this misconception might result in ruling out the possibility of returning to work. There are conflicting findings from studies looking at return to work following a stroke. According to Wilcock (1986), only a small proportion of stroke patients return to the workforce because many are beyond working age and have already retired and others have a residual impairment that prevents them from returning to a previous field of employment.

One of the earliest studies was conducted by Holbrook (1982). In her study of 92 participants, 30 were working prior to their stroke. Only eight of these 30 returned to work, three of whom left work later for health reasons. At follow-up, 2-3 years later, five people were still in work. In explaining these findings, Holbrook (1982) stated that those whose strokes left them with minimal residual disability, and whose employers wanted them back, were able to go back to work. The three who went back to work and then gave it up did so because one had another stroke and the other two found that they could not cope. Poor motor function and/or communication problems were factors that contributed to not returning to work.

Howard et al (1985) also found that only a small number had returned to work after a stroke. In their study of 379 people, 73 (19%) reported employment outside the household at a 12-month follow-up. This study, however, included 174 people who were over the age of 66 years and, therefore, would not be expected to be working. For those that did return to work, the authors attempted to identify the influencing factors and concluded that 'people with higher incomes, more education and more skilled forms of employment have a greater probability of returning to work after a stroke' (p230). They also suggested that those aged 55 years or younger were more likely than those aged 56-65 years to return to work following a stroke, especially if their disability was not severe.

In a study carried out in Oxfordshire, 76 (24%) of 318 men and 39 (11%) of 357 women were in paid employment before their stroke (Warlow et al 1998). Of these, 68 (59%) returned to work at some stage, the majority within 6 months of the stroke. Several issues affected this return to work, including the nature of previous employment, residual impairments and disabilities and the person's own wishes.

A Stroke Association (1996) survey showed that many younger people were trying to cope with the loss of their career and had financial hardship as a result of their stroke. Of the 230 people surveyed, 80% of those that were in full-time employment at the time of their stroke had given up their jobs, 10% had had to give up their jobs but had since found other employment and only 10% were able to continue in their jobs. Seventy-six per cent had not received any careers advice on retraining, while 27% felt that they had been discriminated against in the job market. The Stroke Association did not indicate the exact number of those in employment at the time of the stroke, which makes the interpretation of its findings difficult. In tandem with the reduction in employment, it found a fall in income as a result of the stroke, with 166 (72%) participants reporting a drop in income and 133 (58%) relying on state benefits.

Two recent studies in the United Kingdom have looked at the issues following a stroke for younger adults. Bryan et al (2002) surveyed 3000 stroke survivors (under 55 years). Of the 672 respondents, 503 (75%) indicated that they wanted to return to work. Kersten et al (2002) conducted a study to identify the unmet needs of younger people (18-45 years) with a stroke. Of the 315 respondents, 138 (65%) of the 213 who were working prior to their stroke were no longer working and 30 (14%) had changed or reduced their hours. It was found that those who were working reported statistically significantly fewer unmet needs than those who no longer worked.

It is evident that some studies have considered the issue of returning to work. As can be seen, the reported percentage of those returning to work varied greatly, from 0% to 59%. In addition, the majority of the studies related to small numbers. On the whole, quantitative measures were used to record the return to work. There were few qualitative data indicating people's views on returning to work, the importance of the work role to them or the support that they required or would have liked to have received in returning to work. It is these issues that the two studies reported in this paper attempted to address. The aim of Study I was to establish if work was an important issue for individuals post-stroke, while the aim of Study II was to establish the support that was received or that individuals would have liked to have received when returning to work.

Method

Study I

This study was part of a larger study, which established the characteristics and needs of adults aged 18-55 years who had had a stroke and which evaluated a pilot service available to them (Corr 2003). This voluntary agency service ran one day a week and provided social support and the opportunity to participate in a range of activities, including arts and crafts and outings to community events and facilities. All individuals referred to the service between June 1998 and February 2000 were included in the study. All needed to be independent in toileting and to live within the service catchment area in order to meet the criteria for attendance. Each person was visited, by the first author, in his or her own home shortly after referral to the service.

Prior to the visit, the person was given the opportunity to provide consent and was assured that confidentiality would be maintained throughout. As the people recruited to this study were members of the public accessing a voluntary service, the local National Health Service ethics committee confirmed that local research ethics committee approval was not required.

Each visit consisted of an interview using both structured and semi-structured formats and both quantitative and qualitative approaches. Structured interviews consist of specific items that an interviewer asks in a standardised manner and are, according to Robson (1993, p205), 'effectively a questionnaire where the interviewer fills in the responses'. Semi-structured interviews have a loose structure, consisting of open-ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail (Britten 1995).

Baseline information was collected, including the participants' age and time since stroke and their general ability in activities of daily living using the Barthel Index (Mahoney and Barthel 1965). The information regarding work was collected using the Canadian Occupational Performance Measure (COPM) (Law et al 1994) in a semi-structured format and the Role Checklist (Kielhofner 1985) in a structured format.

The COPM was selected because it ensures that the problems identified have relevance to the person (Toomey et al 1995, Ward et al 1996). It was designed for use with people with a variety of disabilities and across all developmental stages (Law et al 1994). It establishes the problems experienced in the area of productivity as well as the areas of self-care and leisure. Participants indicate their rating of importance, performance and satisfaction for each problem. The COPM is a reliable and valid assessment (Law et al 1994, Bodiam 1999, Law and Baum 2001).

The Role Checklist was selected because it was designed specifically to assess a person's involvement in a range of roles, the perceived importance of each role and the balance of current roles. The instrument also provides information about the expectations of people regarding future role involvement (Kielhofner 1985, Kielhofner 1992). The checklist has content and face validity and test-retest reliability (Kielhofner 1985).

The data reported in this paper relate to the findings relevant to the issue of work; the findings of other aspects of the COPM, such as self-care and leisure, can be found elsewhere (Corr 2003). The data analysis method used in this study was descriptive statistics.

Study II

This study was conducted by the second author and aimed to establish the support received in returning to work after a stroke. This qualitative study used a phenomenological approach because it was investigating the single phenomenon of the experience of returning to work after a stroke. Bowling (2002, p128) considered this approach to be 'the study of conscious human experience in everyday life'. The approach involves interaction between the researcher and the participant. The data collection vehicle was interviews, which were in depth with open-ended questions. The questions related to the participants' experience following their stroke in relation to returning to work, including the influencing factors on their decision making regarding returning to work and the support sought and/or obtained in this area.

Recruitment to the study was through advertisements in local public settings, such as libraries, post offices, supermarkets, retail outlets and the local paper. The criteria for inclusion were individuals of working age who had returned to or were in the process of returning to work following a stroke and were able to travel to an agreed neutral meeting place for an interview. When people responded to the advertisement, indicating their willingness to consider participating, they were sent an information sheet and a consent form. As these people were members of the public, the local National Health Service ethics committee was approached for advice. It subsequently advised the researcher and granted the study local research ethics committee approval.

The analysis of each transcript was conducted using a content analysis process, including coding data into themes (Bowling 2002). A second coder was used to ensure reliability when categorising themes.

Results

Twenty-six people were recruited to Study I and six to Study II. Table 1 shows the demographic details of the participants

Table 1. Details of demographic characteristics of participants for both studies

Characteristic	Study I n = 26	Study II n = 6
Age		
Mean	48	52
Range	34-55	38-62
Sex		
Men	15	4
Women	11	2
Months since stroke		
Mean	21	90
Range	1-141	10-132
Barthel scores		
Mean	17.5	Not
Standard deviation	2.3	available
Median	17.5	
Range	12-20	
Body side affected		
Right	16 (62%)	4 (66%)
Left	10 (38%)	2 (34%)
Speech affected		
Yes	18 (69%)	Not
No	8 (31%)	available

in the studies. The mean age for Study I was younger than that for Study II (48 v 52 years respectively). The length of time since stroke for those in Study I was considerably less than that for those in Study II (mean 21 months v 90 months respectively). Information regarding basic activities of daily living ability and speech was only collected in Study I. The Barthel scores (mean 17.5) indicated a relatively high level of function (the maximum possible is 20) for the participants in Study I. None of the participants in Study II had communication problems, but 18 (69%) participants in Study I reported that their speech was affected by the stroke. Some indicated that they did not have expressive problems but that they lacked confidence in social situations

Study I

Table 2 shows the proportion of the population who had had each of the 10 roles of the Role Checklist in the past, currently had the roles and hoped to have the roles in the future. The vast majority (24, 92%) of the participants had had the roles of worker, home maintainer, friend, family member and hobbyist prior to their stroke. The current role profile was low, with only one participant reporting a return to work. Only 4 (15%) participants had an active hobby as opposed to 24 (92%) prior to their stroke. Many indicated a hope in the future to resume some of their past roles.

Table 2. Details of numbers of participants who indicated having specific present, past and future roles, Study I

	Past roles n (%)	Present roles n (%)	Future roles n (%)
Student	9 (35%)	0	3 (12%)
Worker	24 (92%)	1 (4%)	20 (77%)
Volunteer	11 (42%)	0	11 (42%)
Carer	17 (65%)	5 (19%)	14 (54%)
Home maintainer	25 (96%)	11 (42%)	22 (85%)
Friend	26 (100%)	22 (85%)	25 (96%)
Family member	26 (100%)	20 (77%)	24 (92%)
Religious participant	11 (42%)	3 (12%)	9 (35%)
Active hobbyist	24 (92%)	4 (15%)	20 (77%)
Participant in organisations	13 (50%)	3 (12%)	8 (31%)

Table 3 shows the value that the participants placed on all the roles, including the work one. The majority (20, 77%) reported the work role to be of great value, with another 4 (15%) reporting it as somewhat valuable. Both the participants who considered the work role not to be valuable were female and one had not had a work role in the past.

Nineteen participants identified work to be a problem using the COPM (Table 4). Of these, 16 indicated that they considered this to be a very important problem to them by rating it at 8 or more on the 10-point scale. Table 4 also shows that there was a view of inability to carry out their previous job. The mean performance rating was 2 and there was great dissatisfaction with the poor functional level.

Table 3. Value placed on each role by participants, Study I

Role	Very valuable	Somewhat valuable	Not very valuable
Student	1 (4%)	1 (4%)	24 (92%)
Worker	20 (77%)	4 (15%)	2 (8%)
Volunteer	6 (23%)	6 (23%)	14 (54%)
Carer	11 (42%)	10 (39%)	5 (19%)
Home maintainer	18 (70%)	8 (30%)	0
Friend	24 (92%)	0	2 (8%)
Family member	24 (92%)	1 (4%)	1 (4%)
Religious participant	4 (15%)	6 (23%)	16 (62%)
Active hobbyist	16 (62%)	9 (34%)	1 (4%)
Participant in organisations	6 (23%)	5 (19%)	15 (58%)

Table 4. Details of ratings for work using COPM, Study I

	n = 26
Work as a problem	19 (73%)
Importance ratings	
Number rated 8 or more	16
Mean rating	8.9
Range	4-10
Performance ratings	
Number rated 8 or more	0
Mean rating	2
Range	1-7
Satisfaction ratings	
Number rated 8 or more	0
Mean rating	1.7
Range	1-5

Study II

Table 1 showed the demographic characteristics of the six participants in this study and Table 5 presents more specific data regarding each participant. Five of these six participants were in employment immediately prior to their stroke. The sixth participant had been a student immediately prior to his stroke. At the time of the study, three participants were in employment and two of these were in their original jobs. One participant was on long-term sick leave, two were seeking employment and the sixth had become a house-husband. Three key themes emerged from the data: motivation to return to work, return experience and support in returning to work.

Table 5. Background details of participants in Study II

Participant	Previous job	Current job	Age	Gender
A	Management training instructor	Seeking employment	46	Female
B	Personal assistant	Seeking employment	39	Female
C	Computer company manager	Freelance computer engineer	53	Male
D	Student	Teacher	62	Male
E	Warehouseman	Warehouseman	58	Male
F	Solicitor	Unemployed, house-husband	57	Male

Motivation to return to work

The first theme relates to motivation to return to work. The participants identified various reasons that they wished to return to work, including the fact that they:

> Got bored with being at home (*Participant A*)
> Wanted something to keep me occupied (*Participant D*)
> Wanted to keep busy (*Participant F*)
> Needed to work for financial reasons (*Participant B*).

One person returned to work because:

> Firm had kept job open to me, if they had not I wouldn't have bothered seeking employment (*Participant E*).

Return experience

The initial return to work experience was another issue identified. Two participants reported experiencing an unsuccessful initial return to work while the remaining participants experienced a positive successful initial return. For one unsuccessful participant, the employer had a key role:

> Work refused to have me back until I could operate a keyboard with both hands (*Participant B*).

For the second unsuccessful individual, Participant F, the residual problems following his stroke, in particular memory loss and exhaustion, influenced the return experience. Some participants, although reporting a successful return to work, still had difficulties in returning. Participant E returned to work for just a few hours a week and gradually increased the working hours. Others stated:

> Employers didn't understand the effects of my stroke. They expected me to resume work at the pace I previously had, working a 50 to 60 hour week (*Participant A*).
> My employers didn't want me back ... I think they were concerned about the productivity levels and image. I did stay at the firm for three years (*Participant C*).

Support in returning to work

When reporting support in returning to work, three participants indicated that they had had no support from occupational therapy while planning and actually returning to work. Two found accessing occupational therapy support easy, with one stating:

> My occupational therapist was very useful in reassuring, encouraging and assisting me in returning to work and providing equipment (*Participant A*).

The sixth participant indicated that he had fought to get support. Of the three who had had occupational therapy support, two were still in employment. Some participants were aware of the Placement Assessment Counselling Team (PACT) and one had attended a training session.

When expanding on what type of support they would have liked, the participants identified both general advice and specific skill development as needs. In addition, support to facilitate the gradual return to work was necessary and one participant also wished to have longer-term follow-up support in the workplace. Assistance with benefits, advocacy and guidance on more suitable jobs to match their skills were also requested.

Discussion

The findings of these two studies suggest that returning to work is an issue of importance after a stroke. Only 2 of the 26 participants in Study I indicated that they had not had a work role in the past, while 20 (77%) hoped to work in the future. The work role was important for the participants, judging by their value rating of the role and the importance rating that they gave to work via the COPM. Only two participants in Study I did not value the work role. These participants were not asked to explain their views, although one had not had a work role in the past. The other participant may have felt that her disability was such that work was too difficult. The BSRM (2000) suggested that residual disability was often an obstacle to returning to work. One participant in Study II resented society's estimation of a person's worth through work and only felt that he was making progress when he abandoned the struggle to return to paid employment. He eventually became a house-husband. This view was supported by Steward (1996), who suggested that the assumption that returning to paid work is the ideal goal and measure of success must be questioned.

The participants in Study I who did not value the work role may have hoped to use the time for other activities, such as leisure. The BSRM (2000) acknowledged the possibility of a new lifestyle that did not include work but might include the pursuit of other interests. The findings of Study I in relation to the current roles do not suggest that the participants had taken up new roles, such as a hobby or doing voluntary work, to replace a work role. The mean time since their stroke was 21 months for the participants in Study I. This may be too short a time-frame for people both to consider choosing not to go back to work and to consider developing other roles. The findings relating to participation in other roles, such as hobbies or voluntary work, might have been different if the time since stroke had been longer.

Although it is acknowledged that returning to work may not be the wish of everyone, the findings of Study I are similar to those of Bryan et al (2002) where the majority of people had a desire to return to work. In both studies, the proportion wishing to return to work was over 75%. This would suggest that these people hold work in a similar light to society, that is, as an opportunity to earn an income, to make social contacts and to have status and structure in their lives, all products of work according to Marmot and Feeney (1996) and Matheson (2001).

Pratt (1997) viewed employment as one of the most important social roles that a person fulfils during his or her life, giving financial security, challenges and friendship. Having a job presents visible evidence to society that a person has value. Economic pressures are frequently at the forefront in motivating people, as shown by two of the

participants in Study II who quoted financial reasons for their need to find work again. This supports the findings of the Stroke Association (1996) survey, where 166 (72%) of participants reported a drop in income following their stroke.

Residual impairments following a stroke were considered to have an impact on returning to work by Holbrook (1982), Howard et al (1985) and Warlow et al (1998). The mean score of the Barthel Index for those in Study I was 17.5, a score that suggests some independent functioning in activities of daily living. However, only one of the 26 participants had returned to work. There may have been other impairments, such as fatigue or cognition problems, that influenced the participants' level of disability. Bryan et al (2002) found that chronic fatigue was a common experience post-stroke and resulted in some people considering work as too demanding, but also that fatigue and cognition problems often went unnoticed. Two participants in Study II indicated that these factors resulted in unsuccessful attempts at returning to work. None of the participants mentioned family attitudes affecting their return, an issue that Wellwood et al (1994) considered an influencing factor.

There is currently no specific support available for people post-stroke to return to their previous jobs or to consider and be facilitated in taking up new employment. Gresham et al (1995) argued that facilitating a return to work should be done in a client-centred manner, which offered the flexibility to change objectives and strategies as the person's capacities increased or the work environment changed. Any return-to-work programme, in their view, should enable the development of skills, offer opportunities for retraining and promote links with employers if the person is to return to work successfully. The findings of Study II suggested that the employers did not fully understand the effects of the stroke nor were they prepared to be flexible in supporting participants to return to work. Bryan et al (2002) also identified the need for designated rehabilitation staff to deal with vocational matters. In addition, they identified the need to establish good liaison between health care professionals and employers so that a staged return to work could be negotiated.

The BSRM (2000, p6) considered the National Health Service to have 'lost the culture and skills of facilitating employment as a key element of effective health care'. It recommended a multiprofessional approach to people in assessment and treatment, from the onset of illness until the return to work. Surprisingly, it did not advocate this support to extend beyond the point of the initial return to work; the participants in Study II requested support to facilitate the gradual return to work and provide longer-term follow-up.

The BSRM (2000) did, however, acknowledge the need for undergraduates in the health care professions to be aware of the importance of employment to good health and the need to promote vocational rehabilitation, where people were enabled to access, return to or remain in employment. It also supported rehabilitation being available to an employee at his or her normal work environment, thus maintaining him or her in a worker role even if on reduced or modified duties. This was considered better for employers, health services and societies as well as for the person, because it should avoid low self-esteem and lack of confidence. It was suggested that support from supervisors and employers resulted in the best outcome for those returning to work.

One of the problems faced by the individual after a stroke is establishing a first port of call and then a pathway back to work, particularly if there is no one person taking charge. A participant in Study II was not told of the existence of the Disability Employment Adviser and found that she was informing her occupational therapists of the procedures necessary to try to regain her job. This suggests that some occupational therapists may not be fully aware of and accessing the support available. Occupational therapy can have a key role in enabling a return to work following a stroke (Reed and Sanderson 1992, Yerxa 1998, Law et al 2001). This role would appear to require liaison with employers and other agencies who offer support in this area and an awareness of recent government initiatives designed to facilitate the process of returning to work for people with disabilities, such as New Deal (1998).

Conclusion

Both these studies were small and, therefore, readers should consider the findings with caution. However, the findings are supported by other studies and they do contribute to the issue of returning to work after a stroke by identifying the value that individuals place on their work and reporting individuals' experiences of returning to work. They highlight the need for comprehensive return-to-work programmes for those who have had a stroke, an area that occupational therapists can address. Further research is recommended to examine why people value work, to establish if this role could be replaced by others such as hobbies, to evaluate current return-to-work programmes, to identify if duplication of services occurs and to establish the optimum timing of involvement of health, social and voluntary return-to-work agencies.

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