

Health and functioning in a stroke population five years after first incidence

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Purpose: To isolate characteristics of a stroke population five years after first stroke, focusing on functioning and health. **Methods:** The subjects in the present study were identified in a computerized National Bureau of Health Register over a six month period in 2003 in a well-defined area of 353,284 inhabitants. **Results:** Survival rate five years after first stroke was 52%. As regards functioning 50% of the group were able to look after own affairs. Thirty-one percent reported themselves as being moderately disabled. Seventeen percent had moderate to severe disability. In the responding group 53% below 65 years of age were disability pensioners. Half of the responding group had suffered a further stroke or another severe illness during the previous five years. There was a positive correlation between functioning and health. **Conclusion:** Stroke survivors cannot be seen as a homogenous group as regard to functioning and health five years after the incidence. It is recommended that professionals identify the stroke individual's level of functioning before rehabilitation is concluded, and that they give stroke individuals with moderate to severe disabilities a well-considered and individualized follow-up. Professionals should be more aware of the working potential of stroke survivors below 65 years.

Keywords: stroke; follow-up; health; functioning; questionnaire

Introduction

Stroke is one of the most commonly occurring illnesses in modern society. Worldwide, stroke is the second most common cause of death (Donnan et al. 2008), and survivors often live with critical disabilities (Sundhedsstyrelsen 2003).

Classification of stroke severity is generally based on functional impairment ranging from no impairment to mild, moderate, severe and very severe disability (Appelros and Terent 2004). There do not seem to appear any gender differences in stroke severity (Taub et al. 1994).

The incidence of stroke increases with age but it can also occur among younger individuals, though their mortality rates are generally lower. Estimates of stroke incidence and mortality are that about 500 people out of 100,000 live with the consequences of stroke. Since stroke mortality is decreasing more rapidly than stroke incidence, the proportion of stroke survivors is likely to increase, which will place

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increased demands on systems of health and social care (Donnan et al. 2008). Previous population-based studies have shown that men appear to have a higher risk of stroke (Bonita et al. 1994, Brown et al. 1996). Women live on average longer than men, and stroke rates increase with advancing age, so that in persons over 85 years of age, women have a higher incidence of stroke (Barker and Mullooly 1997). A Swedish five-year follow-up study found that 40% of stroke patients were still alive five years after first stroke (Lindmark and Hamrin 1995).

A survey of over 1000 UK Stroke Association members, found that only 22% of these informants felt that they had got over the stroke and built a new life (Hedley 1994).

The long-term physical and psychological consequences of stroke often have significant impact on social functioning and well-being, and can frequently result in reduced ability to work and limitations in activity and social participation (Bays 2001; Teasdale and Engberg 2002; Vestling, Tufverson, and Iwarsson 2003). Returning to work is, moreover, a major factor in promoting high subjective well-being and life satisfaction (Vestling et al. 2003).

For individuals surviving stroke decrease or loss of the ability to work and to continue with their former active lives presents emotional and social difficulties and challenges.

These issues are rarely taken into account in the early rehabilitation of stroke symptoms (Ellis-Hill, Payne, and Ward 2000), even if there has been a striking increase in the array of therapeutic interventions to reduce mortality and improve clinical outcomes (Donnan et al. 2008). Despite these advances in management, stroke continues to pose major therapeutic and management challenges, both to clinicians and to health care professionals in the community services. One way to overcome these challenges is through understanding the interrelationship between disability and coping; an understanding that could lead to focused interventions at critical times during the life experience of a person with stroke.

This article will deal mainly with the impact of stroke on various aspects of functioning and how affected functioning influences health and well-being. The term functioning is here to be understood in a wide sense as both physical, mental, emotional and social issue as described in the concepts of ICF (WHO 2001). 'Well-being' is a term related to salutogenesis and comprises of physical, psychological, social, and existential dimensions that reflect the individual's subjective health. It points out the individual's perception of his/her condition related to self (e.g. being calm or anxious), to other people (e.g. being independent or dependent), and to his/her very existence (e.g. being hopeful or without hope) (Nilsson et al. 2001).

Salutogenesis was proposed by Aaron Antonovsky in 1979 (Antonovsky 1979, 1993). Antonovsky's theories (salutogenesis) reject the traditional medical-model dichotomy separating health and illness. The term, salutogenesis, describes an approach focusing on factors that support human health and well-being, rather than on factors that cause disease. More specifically, the 'salutogenic model' is concerned with the relationship between health, stress and coping (Antonovsky 1987). 'Sense of coherence' is a key issue and a theoretical formulation of salutogenesis that provides a central explanation and role in coping with stressful life events.

According to Antonovsky, 'sense of coherence' is important. If a person experience no sense of coherence the person believes there is no reason to persist and struggle to survive and confront challenges, and will have no motivation to comprehend and manage events. Antonovsky's essential argument is that 'salutogenesis' depends on experiencing a strong 'sense of coherence.' His research

demonstrated that the sense of coherence predicts positive health outcomes (Antonovsky 1979, 1993). Antonovsky developed an instrument to measure ‘sense of coherence’ (SOC) which has been used in many studies of illness and health (Eriksson 2006) and in a few with stroke as well (Nilsson et al. 2001; Forsberg-Wärleby, Möller, and Blomstrand 2002). The sense of coherence of the spouses of stroke victims were investigated in the study of Forsberg-Wärleby et al. and the focus in Nilsson et al.’s study were stroke survivors, but the study had only ten participants.

Our study includes 101 stroke survivors. Most of the stroke individuals were hospitalized. A small group was outpatients who had entered a rehabilitation programme through referral from the general practitioner.

The main aim is to investigate characteristics of health and functioning of a stroke population five years after first stroke. How many are still alive? How do they live? How do they report their functioning and health? And are they able to work or participate in social activities?

The results should help to give coordinators and medical officers in charge of health and rehabilitation services in the community an overview of stroke in general and thereby help to identify those stroke individuals that are in need of specialized support and follow-up.

Methods

Data sources

The study was conducted in Vejle County in Denmark, which had a population of 353,284 in 2003. This area is located in the middle of Denmark and consists of both urban and rural populations. The stroke units in Vejle County went through a Health Technology Assessment in 1999, which improved the level of rehabilitation and harmonized the various units in the county.

The subjects were identified from a computerized National Bureau of Health register of hospitalization. The register has documented all instances of somatic hospitalization in Denmark since 1977 and all outpatients since 1995. A search of the register was carried out to identify all cases of stroke in Vejle County during a six-month period from the first of January 2003 to the 30th of June 2003. To identify first instance of stroke, the individuals registered with below codes before this period were excluded. According to the International Classification of Diseases ICD-10, the following diagnoses and codes were used:

Intracerebral haemorrhage (I61, I610, I610A, I611, I611A, I611B, I612, I613, I614, I615, I616, I618, I619).

Infarctus cerebri (I63, I630, I631 I632 I633 I634 I635, I636, I638 I639).

Stroke without specification (I64).

The above diagnoses without any hospitalization (but with rehabilitation) – Z50.8.

The subjects identified in the register were then screened in two further national registers. First they were screened in the Danish Register of Deaths. Secondly they were identified in the Danish Central People’s Registry to record name and address. Ethical approval for this study was given by the Danish Data Protection Agency and completed in accordance with the Helsinki Declaration (Figure 1).

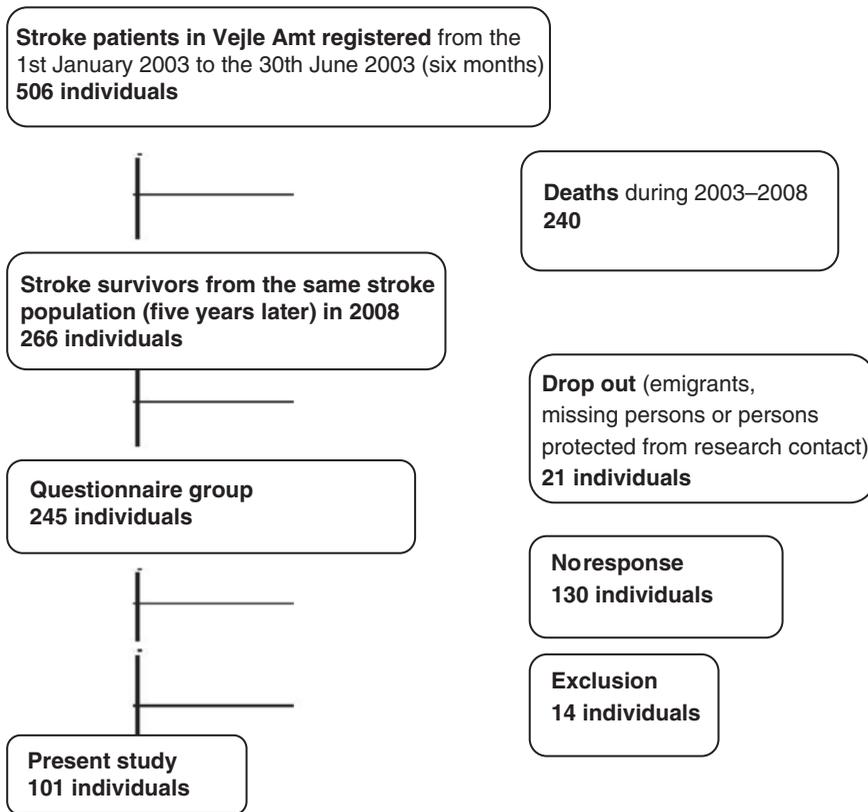


Figure 1. A follow-up of 516 stroke patients, from which the population of the present study was drawn.

Reason for drop-out and exclusions

In the six-month period 506 individuals were registered as having had a stroke in Vejle County. All cases, both primary and secondary diagnoses of stroke were identified as well as non hospitalized stroke individuals and are an explanation of the high number.

The present follow-up of all survivors in Vejle County was made five years later. The search identified 266 stroke survivors. Those surviving five years after first stroke make up 52%.

Twenty-one persons could not be contacted. They had either emigrated, were missing or were otherwise inaccessible for contact. Questionnaires were sent by post to 245 individuals. Fourteen individuals were excluded, four because they had had a stroke prior to January 2003. Six later received second diagnosis that discounted stroke and further four, who had had very transient symptoms and had never known that they had had a stroke, did not want to participate in the study. Of these 130 did not respond. Individuals joining this study counted 101 (44% of the reachable stroke population).

Questionnaires

A postal questionnaire was conducted containing questions concerning living, personal circumstances, occupation, functioning and health.

Research tools that focus on the different kinds of handicap that stroke individuals confront (motor problems, language complexity and cognitive difficulties) were chosen, paying special attention to the simplicity of the tool's design to make it easy for stroke individuals to respond and to assess themselves.

Modified Rankin Score (mRs) was chosen to cover level of functioning. MRs contain six grades (0–5): (0) No symptoms at all; (1) No significant disability despite symptoms; (2) Slight disability; (3) Moderate disability; (4) Moderately severe disability; and (5) Severe disability (van Swieten Swieten et al. 1988). In an earlier Danish stroke study mRs provided the strongest predictor of later quality of life (Teasdale and Engberg 2005, 2007), and in that study self-rating was performed successfully (Teasdale and Engberg 2005). Construct validity and convergent validity of use of the mRs for stroke victims were confirmed, while the reliability was found satisfactory (Wilson et al. 2005; Banks and Marotta 2007).

The European Brain Injury Questionnaire (EBIQ) (Teasdale et al. 1997) was used to assess functioning. EBIQ measure a total score of symptoms and problems. This research tool has been specifically designed in two parallel versions, an individual version for use by individuals with brain injury (stroke and TBI) and a version to be performed by relatives. The individual version was used in this study. It contains 62 questions relating to problems/difficulties people sometimes experience in their lives, as well as three questions about the impact the stroke has had on their partners. They were asked to what degree they had experienced any of these within the previous month. The result is coded on a three-point scale (1) 'not at all'; (2) 'a little'; and (3) 'a lot'. The construct validity is regarded satisfactory and the reliability is high (Teasdale et al. 1997).

Finally, health and well-being were assessed using concepts taken from 'sense of coherence' (SOC) scale by professor and medical sociologist Aaron Antonovsky (Antonovsky 1993).

The SOC scale comprises 29 statements covering comprehensibility (11 items), manageability (10 items) and meaningfulness (eight items). The questionnaire is arranged as a 7-point scale ranging from agreement to disagreement with anchoring phrases at each end. The higher the score is, the stronger the SOC. The SOC scale has been judged as satisfactory regarding reliability and concurrent validity (Langius, Björwell, and Antonowsky 1992; Langius and Björwell 1993; Nilsson et al. 2001).

The relation between health and well-being was assessed within the conceptual framework of SOC. The patients rate their own health and well-being with respect to a range of physical and psychological conditions. These include somatic conditions, cognition, motivation, impulsivity, depression, isolation and communication. The rating of these issues is combined into a SOC index, giving an overall score for of the patient's perception of his own condition of health and well being.

In addition the questionnaire included questions about employment, pension, symptoms and problems related to their first stroke and other illnesses over the previous five years. These questions were constructed for this study. In the letter included with the questionnaire, respondents were told that they could complete the document themselves or make use of a relative as secretary. This was intended to help the stroke individual who was unable to read or write. Six relatives/employees from nursing homes helped the stroke respondents answering the questionnaires.

Statistics

A descriptive analysis of the sample was used to provide an overview of the respondents and an insight into their patterns of functioning and well-being.

The potential effects of EBIQ and MRS upon SOC were assessed by linear regression models. Exploratory plots suggested (not surprisingly) a strong correlation between EBIQ and mRS. Having both variables included in the same model would thus lead to multi-collinearity. Linear regression models were therefore fitted for each of these two main explanatory variables. Beside these the models also included gender and age as background variables. The variable providing the best description of the variation in the data was determined by use of Akaikes Information Criteria.

Results

Survival, gender and age

506 first time strokes were registered in six months in a population of 353,284 inhabitants corresponding to a first stroke incidence rate of 2.86‰ per year. Fifty-two percent of the stroke victims were alive five years later. The mean age of all 266 survivors was 71 years. Mean age for women were 73 years and 70 years for men.

The responding stroke sample (101 individuals) was 60% men and 40% women (Figure 2A). Compared with the full stroke survival sample (266 in all), which have 55% men and 45% were women.

The mean age of all 101 responding stroke survivors was 68 years, compared with 71 years in the stroke survival population (266 in all). Mean ages were 69 years for women and 68 years for men.

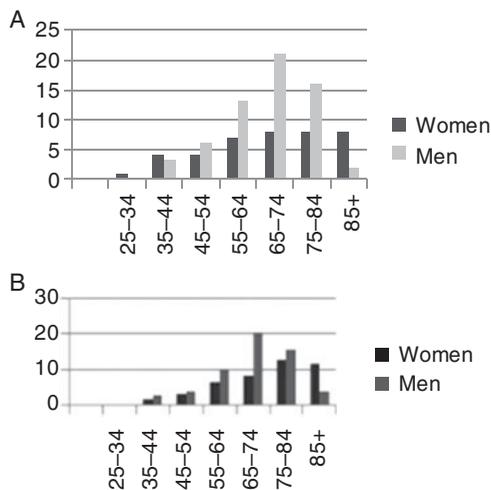


Figure 2. (A). Age distribution of individual in the sample by gender (N=101). (B). Distribution of individuals in the stroke population, divided by age and sex in percents of numbers (N=266).

Table 1. Domestic circumstances: personal and accommodation.

N = 101	living alone	living with spouse	Not known	Living at home	Home for elderly/ nursery	Service flats/ Disability shared house	Not known	
Total	101	32	68	1	83	10	7	1
Women	40	15	24	1	32	6	1	1
Men	61	17	44		51	4	6	

Personal circumstances

The personal circumstances of the responding survivors are summarized in [Table 1](#).

The per capita distribution of stroke individuals living alone or with a partner was similar to the standard distribution for the Danish population ([Statistics Denmark](#)). Furthermore 82% of respondents were still living in their own home.

Various difficulties as a consequence of stroke

[Table 2](#) lists the frequency of the various difficulties the subjects were dealing with.

Some 11% did not have any problems related to stroke or another illness. Generally the respondents had a variety of problems of both physical and psychological nature. The level of disability and functioning varied greatly.

New illness has aroused during the previous five years for 45% of the responding group. Thirteen percent had suffered another stroke and 32% were living with another serious medical condition, for example diabetes, cancer or amputation.

Current level of functioning

[Table 3](#) half of the group did not have any symptoms or, if there were symptoms, they had no significant disability. The rest of the group, however, both men and women, had a level of functioning that ranged from mildly disabled to moderately disabled or severely disabled.

Table 2. Various physical and psychological consequences of stroke the subjects had to face every day shown by frequency and category.

N = 101	Frequency	Combined with other problems
No problems	11	
Problems with:		
Fatigue	56	50
Memory	40	38
Concentration	34	34
Muscle weakness, paralysis and/or spasticity	34	27
Writing and reading	31	31
Speech	28	28
Change of personality	26	26
Pain	18	18
Emotions	22	22
Sight	13	13
others	16	12

Table 3. Self-assessed level of present functioning (Modified ranking score).

		0 – No symptoms at all	1 – No significant disability despite symptoms	2 – Slight disability	3 – Moderate disability	4 – Moderately severe disability	5 – Severe disability	Not known
<i>N</i> = 101								
Total	101	15	36	18	13	14	3	2
Women	40	7	15	7	5	4	2	
Men	61	8	21	11	8	10	1	2

Employment and pension

Table 4 not surprisingly a very high proportion of the group lived on a pension or disability pension, since 62% of the group were over 65 years of age and would therefore probably have stopped working even if they not have a stroke. However even though more than half the group below 65 years of age reported having no or only mild disability as reported using mRs (Table 5), also more than half of this group received disability pension.

Level of functioning for the stroke group below 65 years

Some 38% of the responding group was below 65 years of age. More than half of this age group received a disability pension. We looked into the self-reported level of functioning by using mRs.

Functioning and well-being

This figure illustrates the correlation between functioning and well-being.

The linear regression models for the SOC score using either EBIQ or MRS as explanatory variables in addition to SEX and AGE were reduced by removing insignificant terms one at a time followed by a re-estimation. In both cases all effects of SEX and AGE appeared insignificant so that the SOC score was described by either EBIQ or MRS as the only significant term. The EBIQ-model showed a smaller AIC value (724.3) than the MRS-model (747.9) and was consequently chosen as our final model. Estimates and standard errors are listed in Table 5.

Figure 3 shows the fitted linear regression model with a 95% confidence band. It is noted that the individual observations fluctuates considerably around the fitted mean line. This is also reflected in the relatively low R² value of 0.38. Inspection of residuals and check for normality via a Q-Q plot gave no cause for concerns.

Table 4. Self-reported employment and pension.

		Full-time job	Part-time job	Unemployed	Pension benefit payable	Pension and disability pension	Full-time job – age over 67
<i>N</i> = 101							
Total	101	8	6	2	2	81	2
Women	40	7	2	2		29	
Men	61	1	4		2	52	2

Table 5. Parameter estimates for the regression of EBIQ upon SOC.

Parameter	Estimate	Std. Error
Intercept	210.43	9.59
EBIQ	-0.6788	0.0967

The figure shows a negative correlation between functioning and well-being. It is not surprising that the extent and the severity of deficits after a stroke along with their accompanying problems have important impacts on the individual's health and feeling of well-being. But it is interesting to see that, despite a high score of problems, some individuals still could have a high score of sense of coherence. Likewise some individuals with a low level of problems had a low sense of coherence.

Discussion

A first stroke incidence rate of 2.86‰ per year is a very high number. Denmark had about 12,500 cases of hospitalization of stroke in 2009 (Sundhedsstyrelsen 2011), corresponding to an incidence rate of hospitalization of 2.27%. As we searched both diagnoses of hospitalization and diagnoses without any hospitalization (but with rehabilitation needs) in the National Bureau of Health register it seems that we have had a more complete sample of stroke survivors as point of primary reference.

As regards to limitations of this study there are slight differences in the demographic characteristics of the stroke population in Vejle County compared

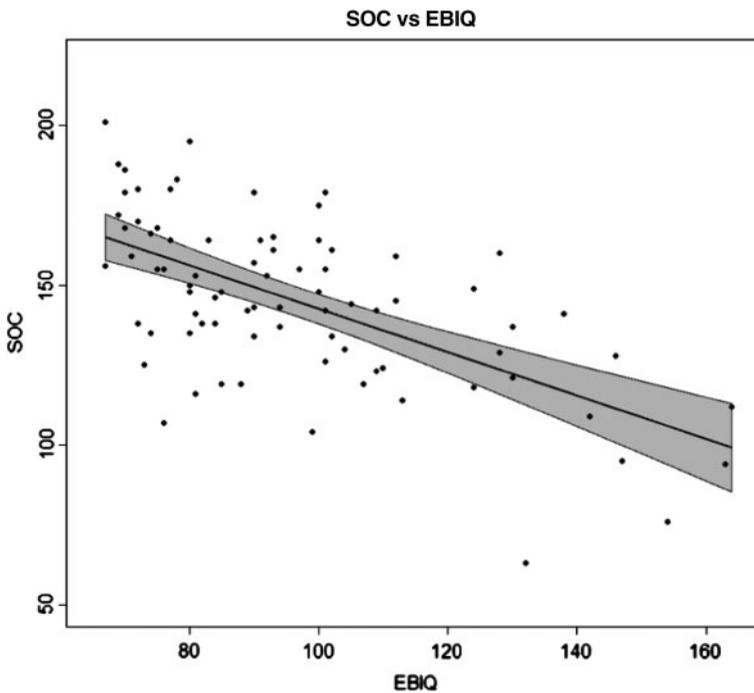


Figure 3. Observations and fitted regression model. Grey area is a 95% confidence band.

with those of the responding group. The responding group is on average three years younger than the stroke survival group. Furthermore there are fewer women over 75 years of age in the responding group than expected.

The response group was biased with respect to age distribution relative to the entire stroke population (Figure 2B), with the higher age classes being under-represented. The conclusions should hence be taken more cautiously for the elder classes. The reduced response for these classes may however not be due to more severe impacts from the stroke but could also be a general trend caused by age. However all age classes are represented in reasonable numbers.

A Danish follow-up study with a responding group of 999 patients 10 years after their stroke concluded that stroke is equally severe in men and women. However, while short-term survival may be the same, having survived stroke women do appear to live longer (Andersen et al. 2005).

A second consideration is the low proportion of respondents (44%). A common reason for a low rate of response from stroke respondents is their advanced age and the facts that these are individuals who are living with a large number of disabilities (among them memory difficulties and problems with writing, reading or verbal comprehension) that make it difficult for them to respond to a questionnaire. The scope and volume of the questionnaire could seem overwhelming, a fact that could have contributed to the low response rate. Potential responders may consequently have been unable to complete the questionnaire, forgot or mislaid it, or have not been able to see the point of responding. We only did the postal delivery once without any later reminder. A reminder could have lead to a higher rate of response.

It might, therefore, be the case that our sample is biased in that it draws on a group with a high level of functioning, and consequently the level of functioning in this study might be regarded as being too high compared to the stroke population as a whole. If this is the case, these results can be considered to represent the better functioning sub-group of the stroke population.

This study is based on the stroke individuals' self-assessment. Teasdale et al. (1997) concluded that, compared to individuals with traumatic brain injury, stroke individuals assessed themselves as being below the level of their relatives in every domain of EBIQ. This indicates, moreover, that the results of the level of functioning in this study might be overrated by the stroke individuals themselves.

It might seem surprising that we did not find any divergence in personal and social circumstances between the responding group and the standard Danish population. We often have to address deep-seated concerns about the increased rate of divorce among stroke survivors. This study seems to question such concerns.

More than half of the group reported difficulties both by marking categories of physical and psychological consequences and by measuring them using mRs and EBIQ. They reported difficulties relating to fatigue, memory, concentration, muscle weakness, writing and reading, speech, change of personality, emotion and pain. As recorded by mRs, 50% of the group were able to look after own affairs without assistance. Some 31% had reported themselves as moderately disabled, requiring some help in their daily lives. Some 17% had moderate to severe disability and were unable to attend to their bodily needs without assistance or were bedridden and required constant nursing care and attention.

Invisible disabilities such as fatigue and loss of memory and concentration seem to be troublesome issues in everyday living five years after stroke, but such problems are not often taken into account in early rehabilitation.

Teasdale and Engberg (2005) found similar results in a long-term population-based follow-up on the psychosocial consequences of stroke. That study concluded that symptomatology, functioning and social conditions remain affected and perhaps stagnant in long-term survivors of stroke. The same study suggested that return to work, social relations and leisure activities were affected, but that these changes were related to age at the time of stroke and to function levels on discharge rather than to the time lapsed since stroke itself. Teasdale et al.'s study did not look into new illness or reported health as issues that might have impact on quality of life.

In addition to consequences brought on by stroke itself, half of the responding group (both younger and older stroke individuals) in the present study had suffered another stroke or another severe illness during the past five years.

It is not surprising that the present study showed a correlation between functioning and well-being and that, despite a large number of problems, some individuals might still have a high sense of coherence. There is a growing understanding of the fact that consequences of diseases, injuries and impairments vary as a result of individual and environmental factors. Nevertheless, there is still a disparity between rehabilitation at the hospital and the interventions offered by the coordinators and the medical officers in charge of health and rehabilitation services in the community. Furthermore, there is a lack of knowledge that might enable assessment and intervention to target the multiple impairments, personal and environmental relationships. How, for example, do some stroke survivors manage to live with severe physical, communicative, cognitive or perceptual problems while still maintaining a strong sense of coherence?

The current study showed that more than 50% of stroke respondents below 65 years of age lived on a disability pension. Some had lost the ability to work, yet others, though they seem to be functioning well, were nevertheless on a disability pension and unemployed. They were probably granted the pension shortly after finishing rehabilitation or at least as a consequence of not being able to continue to work as a result of the stroke. They might later have recovered furthermore without taking working or job training into account.

A Swedish study that looked into indicators for returning to work after stroke concluded that returning to work is a major factor for improved subjective well-being and life satisfaction. Three factors were identified indicating suitability for return to work: the ability to walk, the maintenance of cognitive abilities and the type of profession (Vestling et al. 2003). According to the present study and other studies (Söderback et al. 1991; Teasdale and Engberg 2005), it is important to focus on work-related issues within the rehabilitation team and to discuss these with the stroke patient as well as with relatives and employers. The current study with the low return to employment and the fact that returning to work improves well-being and a better life provokes further research and new questions such as: Have disability pensioners been offered a job-training programme? And are the existing vocational programmes effective?

We strongly recommend that professionals identify the stroke individual's level of functioning before rehabilitation is concluded and ensure that moderately to severely disabled stroke individuals are offered a considered and individualized follow-up.

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