

## **Resuming everyday life after stroke and Early Home Supported Discharge**

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## **Abstract**

Early Home Supported Discharge (EHSD) is a new approach to stroke rehabilitation that aims to improve the link between the hospital stay and future home life by starting rehabilitative training in the home while the patient is still under hospital care. This study explored the experiences and perceptions of four stroke patients who had participated in an EHSD program. The information that emerged from the semi-structured interviews was interpreted within the framework of an analysis of everyday life. Recurring themes were the importance of returning home and of resuming particular everyday activities that were meaningful to the individual. The stroke had disrupted the usual symbolic order of everyday life that is normally taken for granted. A program that included domiciliary rehabilitation and early home discharge gave the informants an early goal of resuming their activities of everyday life, which gave back meaning to their lives and motivation to work actively with rehabilitation.

## **Introduction**

Early Home Supported Discharge (EHSD) is a new approach to rehabilitation after stroke that attempts to better incorporate the patient's own individual needs and wishes into the rehabilitation program. Rehabilitative training is started in the patient's home while the patient is still under the hospital rehabilitation program, thus improving the link between the hospital stay and the future life at home. Compared to a standard hospital-based approach, EHSD involves greater emphasis on independence of the patient in his or her own home, and a higher degree of cross-sectoral collaboration.

In comparison to hospital-based programs, domiciliary rehabilitation programs have resulted in significantly shorter length of hospital stay (Bautz-Holtert et al. 2002, von Koch et al. 2001, Anderson et al. 2000, Mayo et al. 2000, Rodgers et al. 1997, Rudd, Wolfe, Tilling & Beech 1997) and lower rates of admission to institutional care (Bautz-Holtert et al. 2002, Indredavik et al. 2000). While there are some reports of higher levels of independence for patients receiving domiciliary training (von Koch et al. 2001, Mayo et al. 2000, Fjaertoft, Indredavik & Lydersen 2003, Hvid 2001), others report no statistically significant differences with respect to functional status (von Koch et al. 2001, Rudd et al. 1997, Roderick et al. 2001, Jepsen 2001). The reported effects on caregivers also vary, with some evidence for higher levels of burden on family caregivers (Teng et al. 2003) and poorer mental health (Anderson et al. 2000), but also studies where no major differences have been found regarding the well-being of family caregivers or the time devoted to looking after the patient (Holmqvist, von Koch & Pedro-Cuesta 2000).

Some of these variations may be due to structural differences between the programs assessed, e.g. the division of labour between communal and hospital-based rehabilitation services, the level of involvement of the family doctor and home help services, and the length of the domiciliary training period. The study methodologies also differ with respect to use of randomization, length of follow-up and the approach used to assess patient outcome (e.g. level of independence, social functioning and/or well-being).

Burton (2000) conducted a series of in-depth interviews with seven people who had suffered a stroke. It was concluded that rehabilitation should be performed according to the individual's own circumstances and that the social context may be more important for the person rather than the absolute level of functional ability. A recurring theme was that 'the real work of rehabilitation...was the translation of learning from the institutional setting to their home environment'. It was recommended that stroke services be structured to take account of the long-term needs of patients and their families in their home environment. This is especially important in view of the evidence suggesting that the experiences and expectations of stroke patients and health professionals differ (Bendz 2000, Becker & Kaufman 1995, Doolittle 1992).

There has been limited investigation into patients' experiences after a stroke, and whether the EHSD approach is successful in fulfilling patient's needs. The aims of this project were to learn more about the experiences and perceptions of patients participating in an EHSD program after stroke.

## **Materials and Methods**

### *The Early Home Supported Discharge program*

A one-year trial EHSD program was recently started in Svendborg, Denmark. Soon after a patient is acutely admitted with stroke, a multi-disciplinary team is established that comprises a physiotherapist, occupational therapist and nurse from the stroke unit. They meet with the patient and relatives to discuss expectations and goals for the patient and the resulting rehabilitation plan is shared with the local district council. A home visit is made as soon as possible, where the hospital physiotherapist, the occupational therapist or the nurse accompanies the patient home with a view to assessing the need for home adaptations. Rehabilitation continues both in hospital and in the home, where the number of home sessions depends on the needs and abilities of the individual patient. A district therapist is involved as required. On discharge from hospital, the rehabilitation plan is revised with involvement of the hospital and district personnel, as well as the patients and relatives. The district services then take over responsibility for further training, although hospital staff may still be involved. Six months after discharge, EHSD program leader makes a final assessment of the patient's level of functioning.

### *Study design*

A qualitative approach was chosen as the study was explorative and aimed at understanding the patients' experiences of rehabilitation after stroke. An ethnological methodology, described by James Spradley (Spradley 1979), was used. Ethnography is concerned with the meaning people ascribe to events and activities and refers to a theory of culture. People make constant use of complex meaning systems to understand

themselves and others, to organize their behaviour and to make sense of the world they live in. Some of these meanings are directly expressed in language, many are taken for granted and only communicated indirectly through words and actions, while others consist of tacit knowledge. Ethnographic analysis comprises identification of i) relevant aspects of a culture, ii) the relationships between these aspects, and iii) the contribution of these aspects to cultural themes (Spradley 1979).

### *Interviews*

The interviews were semi-structured and started by asking the informant to tell about his/her stroke. The conversation was guided along the following topics: i) the experience in hospital after the stroke, ii) how it was to come home for the first time after admission to hospital, iii) the importance of being able to retrain at home, iv) any disadvantages of home training, v) experiences surrounding final discharge from the hospital programme, and vi) suggestions for improvements to the domiciliary rehabilitation program. The interviews lasted 45-90 minutes and were taped. The interviews were transcribed in a condensed form by the researcher.

The ethnographic methodology distinguishes between 'emic' and 'etic'. Emic represents the informant's understanding, concepts and wordings. During the interview the researcher seeks and accepts the informant's concrete descriptions and experiences within the topic of the interview, including new and unexpected themes, concepts and interpretations. Etic represents the perspective of the researcher which influences the way in which the information is interpreted and analysed (Spradley 1979).

### *Analysis*

In the ethnographic approach, the researcher must understand the specific in order to understand the general (Spradley 1979). In the current study, relevant aspects of culture and their interrelationships as perceived by the informants were identified through listening to the interviews and reading the transcripts.

These aspects were then interpreted within the framework of an analysis of everyday life. This was based on the theory propounded by the Danish sociologist, Birthe Bech-Jørgensen (Bech-Jørgensen 1994, Bech-Jørgensen 1995), who described 'everyday life' as that life we recreate and reproduce every day. Everyday life occurs within our immediate surroundings (the world-within-reach) and is structured with respect to space, time and relationships. Everyday activities involve different forms of unperceived actions, thoughts and feelings, where repetitions produce a 'symbolic order of taken-for-grantedness'. An analysis of everyday life is based on the conditions of everyday life and the ways in which these conditions are handled and any changes are tackled. By analysing the experiences of four people who had experienced stroke as 'a disruption of their everyday life', it was possible to interpret the importance of coming home and of finding new ways of tackling everyday activities. This analysis highlighted the interrelationships between the various aspects mentioned by the informants and formed the basis for identifying some common cultural themes.

### *Informants*

The first four people who had participated in the Svendborg EHSD program were invited to participate in the study by the EHSD program manager. All four agreed to participate and were shortly after interviewed by two researchers in their own homes.

For the purposes of this article, the informants are referred to as Agnes, Betty, Christian and Daniel. Agnes and Betty, aged 77 and 84 years respectively, lived alone in their own homes. Christian, aged 88 years, lived at home with his wife and had suffered two previous strokes; he was interviewed with his wife and adult daughter present. Daniel was a 46-year-old married man with teenage children living at home. All had been acutely admitted to hospital following a stroke; all had suffered paralysis, but for differing periods of time. All had participated in the home training program with the objective of being discharged to their own home – admission to a nursing home had not been considered for any of them.

### **Results**

Three cultural themes were identified as being central to these patients' experiences of an EHSD program after stroke: i) a stroke implies a disruption of everyday life, with loss of time and space structure and the perception of a sense of chaos, ii) an early return to the home and its associated activities is important in dealing with this disruption, and iii) the re-establishment of everyday life is a central element for patients after a stroke.

### *Disruption of everyday life*

Bech-Jørgensen (Bech-Jørgensen 1994) identifies the 'symbolic order of taken-for-grantedness' as a fundamental prerequisite for everyday life. This order is determined by factors both internal and external to the individual and is subject to constant changes. The individual seeks to maintain order through the development of norms, rules and daily habits and by ascribing certain meanings to one's daily activities and social relations. The symbolic order of taken-for-grantedness allows the individual to perceive the world as more or less reliable; this gives a feeling of security, makes it possible to distinguish between time and place, and means that individuals can perceive their daily activities as changeable but not as a chaos of subjective impressions.

The onset of the stroke and the associated paralysis meant that the informants could no longer perform their usual activities; they were no longer able to do what they used to do. This disruption of everyday order was experienced by the informants as chaotic. The sudden and unexpected nature of the stroke had been frightening for the informants. The loss of movement in one or several parts of the body, coupled with the inability to talk was 'like the walls and ceiling falling down around me'. The inability to answer simple questions or to write made Agnes feel like a three-year-old, and the informants recalled feelings of helplessness and fear for the future. 'It was terrible – I couldn't do what I usually do'. Daniel, a younger man who was director of his own company, recalled that he had cried a lot the first few days – actually more than expected with respect to how he felt, but he just could not control it. Despite this, he had never been in doubt that he would get through it, as he was used to tackling and overcoming difficult situations.

The feeling of chaos was amplified by the admission to hospital, which removed them from their usual time- and space-structured existence. The structure of going out and coming home was suspended. The hospitalization meant being out without knowing when to go home. 'I didn't ask about it (going home), I knew that was of no use'. Time seemed to have lost its context and the informants found it difficult during the interview to determine how long they had been in hospital and at what stage the rehabilitation had started. They had all discussed this with their relatives and close friends in an attempt to structure the time and events surrounding the stroke. Daniel had insisted on sleeping at home a couple of weeks after the stroke; the routine of going to the hospital for training and then returning home again gave structure to his day. Agnes described how awful it had been to return to hospital after a home visit; the days in hospital seemed never ending – 'I just sat there, I couldn't even eat'.

### *Returning to everyday life*

The disruption of the usual everyday order meant that those life activities that were normally performed repeatedly but unnoticed came to the fore and became highly visible. In an attempt to re-establish the normal order and to overcome the consequences of the stroke, the informants had created symbols and metaphors for thoughts and feelings that at the time were insuperable. Despite the confusion and uncertainty that had categorized the early days after the stroke, the informants described a strong desire and need to return to a meaningful life – even if this was somewhat altered from their previous life.

It was important for the informants to get back to being themselves again so that they could go home, but going home was also the way in which they could become themselves

again. For Betty, the gradual improvement in control over her senses and her need to get back home were highly motivating for her training 'Dear God, I didn't have time to lie there – I had to get home and play cards, live life again'.

Despite the importance of getting home, it was difficult for the informants to explain precisely why it was so important - 'I can't really say why', 'To be able to lie in my own bed', 'To see television and drink coffee – I could do that in hospital too, but it wasn't the same'. Christian recalled thinking that if the hospital stay had been going to be longer, he was not sure that he could have maintained his motivation – 'It's good to be out and about, but home is best'.

The way in which the informants talked about the home was significant. It was not just a place with four walls where they slept, but represented their lives with their various roles, activities and belongings – it was the context for much of their everyday life.

Agnes went home for the first time on a day visit with her adult son. It had felt good to be in her own house and it was very hard to go back to the hospital again, even though the staff were kind and competent. It had been important for her to go into her garden, to be able to look after her home, to have lunch at home. It gave her motivation to train and to restart some of her prior activities such as cleaning the windows and reading (although now with a magnifying glass). She expressed a desire for arm strengthening exercises that would help her to get around more easily with her walking frame. She had also expected to do more about the house while the therapist was present so that she could either have help with the activity or get some advice as to how best to do it.

Christian described the hospital training as intensive, comprehensive and skilful and it had given him motivation and helped keep his spirits up. It had been important for him to resume his earlier activities and it was hard for him not to be able to go shopping as this had been a main role for him before. He was in hospital for a little longer than a week and during that time made a home visit with the physiotherapist to investigate the need for house adaptations and to go for a walk with the therapist in the surrounding area.

It gave Daniel a sense of well-being to be able to come home and sleep in his own bed. He described a difference between knowing you would be going home at some stage and actually being at home. Although he was officially in hospital for about four weeks, he slept at home most of the time and was also home for long weekends.

#### *Re-establishment of everyday life*

Being at home enabled the informants to better tackle their new circumstances by re-establishing or recreating their everyday life (the symbolic order of taken-for-grantedness). By re-introducing this order, they could experience a more reliable world around them and could perceive their daily activities as changeable but not chaotic. Their new circumstances were considerably different to the previous ones, however, and were continually being altered by strong internal and external influences. This meant that they had to find new ways of tackling these situations and to re-ascribing certain meanings to daily activities and social relations.

Agnes found that she needed home help to assist with cleaning the house, as she could do less than before and everything took a longer time. She placed extra meaning on those activities she could do, however. The garden was not kept as well as before, but just to be able to go out and do some gardening was meaningful to her, just as it had become more important to be among familiar objects and to be able to structure her own day. She had also previously gone to gymnastics and swimming, but she didn't feel that she could cope with the social effort that these would require. She did want to take up her bicycling again, but this would apparently not be possible. It was important to her to have some control over her life and she was afraid of having to sit in a chair all day long and feel superfluous.

It had been arranged that Betty would go to a rehabilitation centre once a week where she could train and participate in social activities. She was also an avid card player who had played in tournaments for many years. Unfortunately, a worsening of the function in her arm had put a stop to both the rehabilitation and the card games; one of her card playing friends had now also become ill. She felt despondent and spent much of her time in bed. She had tried to practice with writing, but found it too difficult; her son had now taken over the paperwork. She lived in her own flat, but wanted to move to a place where she would be in walking distance to a centre offering meals and an opportunity to meet other people.

Christian was having problems with walking and had fallen several times since discharge from hospital. Both he and his family were worried that it would happen again so he was no longer left alone in the house and no longer out walking alone. He didn't want to be

admitted to hospital again as he did not feel ill. Following the previous strokes and prior to the current episode, he had been driving himself to a local rehabilitation centre for training. As he could no longer drive, he had to use shared transport which entailed being away from home for 4½ hours. He felt that he didn't have the strength for this now and had given up the training even though he found it beneficial.

Since discharge from hospital, Daniel had been to several rehabilitation courses with intensive training where he could also sleep at home. He felt that he was re-establishing aspects of his everyday life, but was impatient to make further progress. He found rehabilitation more frustrating now as he was not making such quick progress as he did at the start; he used up a lot of energy simply to talk. He was beginning to realize that he may not be able to return to his job as company director after all, a realization that was difficult for him and required changes in expectations and priorities.

## **Discussion**

Interpreting the information gained from the interviews within the framework of an analysis of everyday life made it possible to understand why it had been so important for the informants to come home after their stroke and to resume their everyday life. The stroke had disrupted a 'symbolic order of taken-for-grantedness' that is fundamental to everyday life. The resulting efforts to re-establish this order were not aimed so much at finding peace and stability, but avoiding chaos.

The order of everyday life is based on collective and individual interpretations of the surrounding world as well as on objects, notions and actions that act as symbolic expressions for these interpretations. These different elements together give everyday life its meaning. The informants in this study had experienced a stroke followed by varying degrees of paralysis and inability to be self-reliant. These significant life changes were tackled by attempting to resume particular previous activities that were meaningful to the informants. In this way, their everyday life would again have meaning.

The informants described the early home visit as a very rewarding experience. For some it was reaffirmation that they would get home eventually, for others it gave reassurance that their belongings – and their previous life - were still there, ready for use again when the patient could manage it. The ability to see and touch familiar things and to do usual activities provided reassurance. It could be supposed that such an early visit home might give the patient an unwelcome shock from the difference between what he or she used to be able to do and the current limitations. None of the patients mentioned this, however. Rather than act as a depressing factor, this early home visit gave meaning back to their lives and increased their hope and motivation to participate in rehabilitation. It may also help patients to be more equal partners in the rehabilitation process - in a study in which the behaviour of two therapists and their patients was observed during therapy sessions in the hospital and in the patients' homes, the patient in his own home was markedly better to take the initiative and to express his goals, than the patients observed in hospital (von Koch, Wottrich & Holmqvist 1998). A study of recovery after stroke described a woman who did poorly with rehabilitation in the hospital setting, who had not walked more than a few steps and was interested only in going home; as soon as she was carried up the front

steps of her home, 'she stood up and walked into her house, crossed the living room, and seated herself in her favourite armchair....She was soon able to walk alone, unassisted, without even a cane' (Doolittle 1992).

*Activities - that have meaning to the individual*

Reference to functional ability was limited in the interviews. There was little discussion as to the degree of strength or movement they had in their arm or leg, the ability to dress or wash themselves, or to use the stairs. This was possibly due to the informants' relatively rapid progress during rehabilitation and the fact that the interviews took place after discharge from the program. The informants had moved on from specific functional problems and were more concerned with everyday life. It was clear that the informants focused mainly on *activities*, whether these were participation in family events (e.g. going to the summer cottage with relatives), family roles (e.g. the ability to do the family shopping), hobbies (e.g. playing cards, riding a bicycle) or, for the younger informant, a return to working life. While the level of functional ability was important for these activities (e.g. the weakness in my arm stops me from playing cards and from doing my own paperwork, the problems with my balance mean that I cannot go out alone and limit my independence), it was the activity that was the ultimate goal and not the level of functional ability. As long as the activity could be undertaken, the way in which it was done was of secondary importance – being able to read a novel again even it involves the use of a magnifying glass; being able to walk to see friends and to shop, even though it required the use of a walking frame.

This focus on activities rather than functions has been reported previously (Sveen et al. 2004), in a study that explored the relationship between subjective well-being and competence in instrumental activities of daily living in a group of (standard care) stroke patients at six months post-stroke. Subjective well-being was most strongly related to the 'leisure activities' subscale of the Nottingham IADL scale.

Another significant aspect of these activities was that they differed according to the individual. Thus for one informant it was the ability to do read, garden and cycle; for another it was to do the shopping and to be able to get around by himself; for another it was being able to play cards with friends; for another it was returning to work. While the activities that the informants had referred to could be categorized variously as household tasks, leisure activities, indoor and outdoor mobility, transport etc., it was all part of their everyday life and apparently required different ways of handling the perceived problems or limitations. This is a demanding task for the therapist, who has to recognize and understand the different needs of different lives and suggest appropriate solutions. Especially when some of these may have to be quite creative e.g. the devising of a set of physical exercises that can help an elderly lady use her bicycle again or perhaps adjustment of the bicycle itself.

The problems as perceived by the stroke patient thus need to be recognized and acknowledged; relevant solutions need then to be proposed and tested. Both processes require a thorough and open dialogue with the stroke patient about his or her plans and thoughts for the future and a precision of the activities that are most important to the patient to be able to take up again. Some of these may not be possible, of course, which

will require further dialogue and exploration of alternatives that are relevant and acceptable to the patient. The difficulties faced by occupational therapists in this context have been recognized (Bendz 2000, Daniels, Winding & Borell 2002, Wohlin Wottrich et al. 2004). While a successful implementation of a rehabilitation plan requires the establishment of realistic goals and sensitivity to the patient's wishes, the identification and implementation of such goals is not always easy for the occupational therapist, especially in the institutional setting (Daniels et al. 2002, Wiles, Ashburn, Payne & Murphy 2004).

#### *Limitations of the study*

The material reported here is based on interviews with only four individuals, who were moreover the first patients to participate in a newly started domiciliary rehabilitation program. Repeated interviews with a larger number of persons would probably have provided a richer data set and more complete coverage of the patterns and dimensions of importance to people after a stroke. The themes identified during the interviews arose quite clearly in each of the interviews, however, so we consider it likely that similar findings would emerge with a larger sample size or with patients going through the program at a later stage. The informants were interviewed some weeks after they had been discharged from hospital; it is not known whether the findings were affected by problems of recall or by any disappointment or dissatisfaction with the results of the rehabilitation.

The study did not deal specifically with the issue of the involvement of family members in the rehabilitation process, although this was clearly important for the informants and was reflected in their desire to participate in family occasions and their concern regarding the

effect of their illness on family members. There was a common fear of being a burden on others, and independence in everyday activities was an important goal. The family caregivers of stroke patients face challenges of their own and can experience feelings of heavy responsibility, uncertainty about the patient's care needs and restraints in social life (Scholte op Reimer et al. 1998, Hunt & Smith 2004, Low, Roderick & Payne 2004). In a study of EHSD versus standard hospital-based care, however, it was reported that caregivers in the EHSD group scored consistently better on a scale measuring level of burden, including the caregivers of patients with major functional limitations (Teng et al. 2003).

### *Conclusions*

It appeared that the early organization of a rehabilitation program that emphasized the patient's independence in his or her own home supported the informants' desire to resume their activities of everyday life, which in turn gave meaning back to their lives and motivation to work actively with rehabilitation. A stroke causes disruption of everyday life and the home plays an important factor in re-establishing this life. Further investigation could be directed towards a better understanding of this importance of 'home' – for example, the relative contributions of simply being at home, undertaking training exercises in the home and the better opportunity for the therapists to understand the patient's priorities and everyday life.

## **Ethics**

The study was explained to the informants both orally and in writing by the manager of the Svendborg EHSD program. Participation was voluntary and acceptance to participate could be withdrawn at any time. Relatives were welcome to participate in the interview. The identity of the participating informants was revealed to the researchers, who then made contact to arrange the interview. In this article the informants' identities are protected from the public by the provision of pseudonyms, but they will be recognisable to the Svendborg EHSD staff. The study is registered with the Danish Data Protection Agency.

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