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Conference abstract

## Understanding patients and their spouse's experiences of home rehabilitation after a stroke

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### Abstract

**Purpose and theory:** In a Danish multicenter randomised controlled trial (RCT) patients received training sessions in their home, as part of their rehabilitation at a specialised inpatient stroke rehabilitation unit. With the purpose of understanding how patients and their relatives experience and understand home training a qualitative study using a phenomenological approach was carried out.

**Methods:** Focus group interviews provide access to knowledge in relation to social practises, and the meanings and norms embedded in practice. Interviews with patients and relatives respectively were carried out in each of the three rehabilitation centres by the end of the trial. Informants were recruited by the project managers among participants in the intervention group of the RCT. Patients, and their spouses, were eligible for participating if the patient: i) had participated in at least six home training sessions, ii) were able to tell and reflect, and iii) were able to participate in a group session. A semi-structured interview guide and a poster showing the course of the rehabilitation was used for the interviews.

**Results:** In all, ten patients participated in the three focus group interviews. The informants were 35–79 years of age, seven were male. Their social background and present situation varied greatly. Three were living alone. At the time of interview eight were receiving social benefits, one was unsettled and one had returned to work. All reported several handicaps, five had speech problems and one had visual problems. Time-frame from discharge to interview ranged from; the same day to one year. In all, eight wives and one husband participated in the two focus group interviews for relatives. For half of them, their spouses had participated in the patient interviews. They all reported their spouse to be physically handicapped and six of them experiencing changes in personality after suffering a stroke. The patients had suddenly been struck by a disease changing not only their own but also the lives of their close relative. After long period of hospitalization it had been of great importance to visit the home. This and the home training sessions had helped clarifying as well as focussing and motivating further training. For the relatives home training had meant a greater peace of mind and better knowledge, e.g. how to act and support their handicapped spouse. It had been of great value establishing the contact to the primary health service before discharge. Barriers for benefit were long distances, meaning long and exhausting travelling and limited time at home. It was of importance that the purpose of going home was clarified and that the therapists were receptive of and respecting the wishes of the patient in relation to his/her dealings in the home and changes of the home environment.

**Discussion:** Focus group interview is an acceptable and valuable method in understanding experiences with rehabilitation among patients and their relatives after suffering a stroke. Usual considerations such as; size of group, a safe environment, appropriate time, mutual respect, structure as well as room for reflection and discussion, probes and ensuring rounding-off themes and interview are highlighted when interviewing persons experiencing problems in relation to cognition, speech and energy, and discussing sensitive topics. The participants expressed general satisfaction and even gratitude for participating in a collective and structured reflection together with peers.

### Keywords

**stroke, home rehabilitation, Denmark, RCT**

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PowerPoint presentation available from: <http://www.integratedcare.org/Portals/0/uploads/congresses/Lee%20Understanding%20patients%20and%20their%20spouses.pdf>