# Paper for summer school RUC 2011

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*Due to illness I haven´t been able to write the paper described in the abstract. Instead I would like to present my project plan. The oral presentation is concerning subject positions in person-centred rehabilitation.*

# Ageing and person-centered rehabilitation

**Introduction**

During the past few years rehabilitation has been put on the agenda of welfare politics as one of the useful means in handling demographic changes implying an increasing amount of elderly citizens in the danish society. In the period of 2000-2030 the Strategic Research Council expects an increase of 353.000 in the number of citizens +65 years and a fall of 208.000 in the number of young citizens and citizens engaged in active employment under 65 years in Denmark – and with that a larger part of citizens with health problems and increasing treatment expenses can be expected. In a publication concerning the handling of these challenges, the Research Council gives priority to the main research theme being rehabilitation of the great age-related diseases and recommends that the municipalities gives high priority to geriatric/gerontological rehabilitation when taking over the responsibility of a greater part of the rehabilitation after 1.1.2007 (Det strategiske forskningsråd, 2006).

The research project **Ageing and person-centered rehabilitation** is focused on rehabilitation as the institutionalized social handling of disease and disability in old age. In a multi-local (Marcus 1995) case-study 9 old citizens’ treatment and rehabilitation in various organizational settings and in both an institutional and daily context are followed. Taking a social constructionist approach as my point of departure the attention is focused on the institutionalized identity work of rehabilitation, where the handling and significance of disease and disability in old age is negotiated in different relations presenting various discursive and material options and conditions, situated in time and place.

The purpose of this study is to illuminate how ageing and handling of disability is negotiated and constituted in meetings between professionals and sick and disabled old people, and how these negotiations are situated in time and place between institutions and people’s everyday life.

The research is carried through as a ph.d.-project linked to the Graduate School in Lifelong Learning at the Department of Psychology and Educational Studies. The work is co-funded by Center for Sammenhængende Forløb (CSF), Centre for Integrated Care in Health and Social Services at the Metropolitan University College. Among other things CSF is involved in developing education and practice in the field of senior citizens and rehabilitation, and several projects have revealed a need for research-based knowledge concerning ageing and rehabilitation.

**New ways of handling disease and disability in old age**

Knowledge about ageing processes is constantly altering, and with it the conception of how disability in old age may be handled also changes. In Denmark gerontological research and knowledge production is developing in the second part of the last century in the social as well as in the natural sciences. In social medicine research new multi-factorial models of disengagement is developed, opening for new political, professional and individual ways of handling disability, disease and risk (Verbrygge & Jette 1994, Schroll 2002). Politically, the rapports of the Elderly Commission from the early eighties indicate that the loss of the ability to function should no longer be seen as an inevitable condition of old age (Andersen et al 1996). Processes of decay which earlier on have been considered natural and inevitable aspects of ageing is now referred to as processes open for intervention and change, and ageing is regarded manipulable both socially, culturally and medically.

The new ideas are institutionalized in different ways. Geriatric treatment is established in Denmark in the seventies (Wagner and Nygren 2007) and is defined as the hospital-based interdisciplinary effort that includes diagnosis and treatment of illnesses, often concerning multi-morbidity, assessing and optimizing functioning and assessing and optimizing of social conditions. Interventions can be focusing on both disease, psychosocial problems and disability and takes place in an interdisciplinary environment where geriatric physician, physiotherapist, OT, nurse, social worker, home care etc. are participating (Rønholt-Hansen, Moe & Schroll 2002, Holm & Frølund 2003). In the municipalities training and rehabilitation for the elderly is developed in the last 30 – 40 (Institut for Pensions- og Ældrepolitik, Serrvicestyrelsen 2011) and in the same period new principles such as selfcare (”help to help yourself”) and activation is integrated in education and professional practice, in particular in education of professional care takers (Andersen et al 1996, Fuglsang 2000, Swane 2003, Dørfler og Hansen 2005).

Rehabilitation of senior citizens is organized within the municipality or in integrated cross-sectoral processes. By the “Structure-reform” in 2007 the municipalities have taken over a larger part of the rehabilitation, thus fully brought out only the kind of rehabilitation that requires participation of medical specialists must be carried out at the hospitals. The integrated cross-sectoral rehabilitation progresses are linked with considerable challenges concerning both organizational, professional and cultural aspects (Beyer 2010), that contributes to the complex circumstances of senior citizens’ rehabilitation processes.

**New relations and new user-expectations**

While the new principles for handling ageing and disability are institutionalized a fundamental change takes place regarding the relation between the welfare institutions and the people who use them, producing new discursive ways of being a “patient”, “user” or “citizen”(Petersen 2008, Kjær & Reff 2010). The tendencies are perhaps most accurately articulated in the modernization-program of the Danish Government from 2002 “Med borgeren ved roret” (ie: “The citizen at the helm”), in which the government formulates its ambition to renew the public sector, to put the person before the system and to grant the individual greater freedom in the forming of one’s own life (Regeringen 2002, Højlund 2006). Ideologies concerning user-orientation, person-centering, client-centering and patient-centered practice are professionally developed during the last 50 years of the former century (LePlege et al 2007). A new anthology on Health Care Management describes the political and professional ambitions to create a new kind of health service in which the relation between patient and health authorities are characterized by a new sense of equality where the patient is actively participating in the work and development of the health service. This new concept of the patient is in opposition to the formerly patientrole, e.g. described by the american sociologist Talcot Parsons. Parsons argues that becoming a patient primarily means the individual’s yield of sovereignty to the health authorities, who by virtue of their expert knowledge can take on full responsibility for the diagnosis and treatment. Contrary to this, according to Kjær and Reff, is the idea of an active, responsible and authoritative patient and a treatment system who is run not only by expertise and administrative demands but is designed to meet the patient’s demands, expectations and experience (Kjær and Reff 2010). Petersen describes the prevailing political discourse regarding the patient as a user or consumer who is expected to be able to act, demand, chose and participate on the basis of individual preferences (Petersen 2008).

The idea of the patient or user actively participating in decision-making processes is clearly articulated in modern rehabilitation discourse. According to “The White Paper on Rehabilitation – Rehabilitation in Denmark” ( “Hvidbog om rehabiliteringsbegrebet - rehabilitering i Danmark”) that came out in 2004 containing direction standards for action in rehabilitation practice, the rehabilitation process must be characterized by “user-orientation” and “person-centering”. Consequently the work must be carried out on the basis of the citizen’s awareness of the situation and all decisions be made by the citizen in concert with the professionals involved. Notions like empowerment, democracy, fellow citizenship and participation are in The White Paper connected with the person-centered paradigm (Rehabiliteringsforum Danmark 2004). And nordic scientific literature on geriatric rehabilitation describes principles concerning the geriatric patient’s involvement in rehabilitation through active participation in objective, planning and adjusting content (Rønholt-Hansen, Moe and Schroll 2002, Wekre 2004, Bredland, Linge & Vik 2002, Bredland & Linge 2007, Nygren et al 2001, Wagner & Nygren 2007).

By establishing geriatric/gerontological rehabilitation and referring to the patient as actively participating in the planning and implementation of the interventions a picture emerges of ageing as negotiable, and the elderly patient being an important negotiation partner. Processes formerly regarded as inevitable can now be grasped as open and susceptible to influence and intervention, and the elderly patient/user is invited to define how the intervention should be.

The above describes political and professional ideals and visions. How negotiation works in practice is less clear, and the field is underexposed and not adequately researched, which the next chapter will reflect.

**Research concerning elderly people as active, participating patients/users in geriatric/gerontological rehabilitation**

Rehabilitation research on participation and person-centered geriatric/gerontological rehabilitation is dominated by perspectives of the professionals or of the system and is primarily focused on smaller, limited steps of the progress. The complex is the senior citizens’ lack of influence on the rehabilitation process, incoherence between the goals of the senior citizens’ and the professionals, and senior citizens’ lack of knowledge about their treatment and rehabilitation plan (e.g. Glazier et al 2004, Kramer 1997, Vik et al 2007, Hvalvik 2008, Lund, Tamm 6 Brännholm 2001). Other studies query senior citizens’ lack of participation in the rehabilitation process: An investigation of patient’s experience of their participation in the rehabilitation process describes the seemingly paradox that a good deal of geriatric patients don’t appear to be very interested in participating in planning their rehabilitation but immediately accept the plans and decisions made by the professionals: “They understand that better, being experts” (Lund, Tamm & Brännholm 2001, p. 157). In the study in question the geriatric patients are categorized according to their participation preferences in 3 categories: Relinquishing, participating and occasionally participating. The relinquishing group is the biggest counting 40% of the persons interviewed.

The study confirms experiences from practice showing that a significant part of senior citizens more or less reject the position in which they could play active part in the planning of their rehabilitation and thereby fail to live up to the demands for participating in the negotiation. The article doesn’t question this further, and a quest in the database on health-studies suggests that the issue hasn’t been met with research attention within the healthcare and rehabilitation research. We have to look to the social sciences to find research on patient- and consumer-constructions in modern welfare society. Danish research points out that ideals of the active participating patient/user enter into complex and incompatible contexts in practice. Højlund and Knudsen describe how the new expectations concerning how to be a patient/user mix with other structures. In their analysis of elderly care and rehabilitation in particular Danish municipalities they describe how role-ecpectations in cross-sectoral rehabilitation processes and in New Public Management structures are various and from time to time contradictory (Knudsen and Højlund 2010, Højlund 2006). According to Højlund it is a question of complex ascribing of identity when senior home care recipients are expected to be able to get on in old roles as home care recipients in need and at the same time act like empowered dialogue partners (Højlund 2005, p. 125).

Højlund is not explicitly occupied with the interactions between the professionals and the senior patients/users nor with their acting within and across the complex and diverse connections they participate in.

**Problem formulation**

In this research project I will investigate how handling of disease and disability in old age is constituted and negotiated in meetings between sick and disabled senior citizens and professionals in treatment- and rehabilitation progresses, and how these meetings are situated in time and place in everyday life in institutional progresses.

The research is based on the premise of rehabilitation being a work of identity that takes place in the everyday life of senior citizens in institutions, characterized by complex and sometimes contradictory discourses regarding the handling of disease and disability in old age.

**Theory**

The main topic of the study is institutional meetings between users and professionals. The theoretical and analytical frame of reference is positioning theory and institutional ethnography. This opens for analyzing the meetings as social interactions, situated in specific institutional and cultural contexts.

Positioning theory offers a dynamic alternative to the sociological concept of role as previously referred to. Whereas roles can be perceived as fixed and regular, positions are produced and negotiated continuously in the social life in discursive practice (Davies & Harre 1990, van Langenhove & Harré 1999). According to the positioning theory, positions, actions and narrative conventions (story lines) are mutually constituting (Harré & Moghaddam 2003). Story lines offer particular subject positions in which the individual is invited to enter: “By giving people part in a story, whether it be explicit or implicit, a speaker makes available a subject position which the other speaker in the normal course would take up” (Davies & Harré 1990, p. 48). But how this positioning is taken up and what meaning it offers to the individual, differs, and thus positioning is not a matter of determined processes. The individual may for example chose to discuss a subject position or not (ibid.).

Positions and acts in social interaction thus relate to hidden rules and conventions existing independent of the production (ibid.). In the positioning theory these are characterized as story lines and discourses, where individuals in a conversation may refer to different story lines that constitute their actions and the way in which they position themselves (reflexive positioning) and the other (interactive positioning) (Davies and Harré 1990).

As already mentioned my intention is to complement the positioning theory with an institutional ethnographic perspective with reference to display the institutional embeddedness of the social interactions and the influence the institutions have concerning the actions that might take place during the interactions. By using an institutional ethnographic theory it becomes possible to analyze treatment and rehabilitation processes as different kinds of interaction mutually related. Rehabilitation progresses take place in different localities, and what happens in one locality interferes with what happens in another. Dynamics like that are conceptualized in institutional ethnography (Smith 2002, 2006).

Institutional ethnography originally was formulated by Smith as a sociological theory problematizing and drawing attention to the translocal character and ruling of the institutions. By the notion “social relations” she conceptualizes how peoples’ actions in one locality are connected and intervene with other peoples’ actions in other localities. Thus activities in a locality are “(…) hooked into sequences of action implicating and coordinating multiple local sites where others are active” (Smith 2002, p. 31). Along with ie. discourses and bureaucracy institutions constitute extra- and translocal “ruling relations”, coordinating and interfering with the actions of individuals elsewhere. According to Smith the “architecture” of institutions is textual and she suggests that the scientist analyzes institutions with a focus on texts and text-mediated discourse. Smith identifies texts as material texts of the kind that makes replication possible (paper/print, movies, IT-programmes etc.)(Smith 2002, p. 45).

In analyzing the senior citizens “subjectivity” I draw on a poststructural conceptualization of the subject, among others described by Davies (2007) and Søndergaard (2005). According to Søndergaard the subject must basically be understood as both formed and forming. Subjectification is perceived of as an ongoing process of becoming containing a subjectivating and in that way forming element, but which at the same time - as a result of this subject-forming - also holds the starting point of the creating power of the subject itself (Søndergaard 2005, p. 240). According to Davies subjectification takes place for instance when the subject adopts certain story lines as its own and acts according to them (Davies 2007). The actions of the subject and the choices one continuously makes all refer to the story lines, you consider yourself living out. It applies to story lines, we have observed, heard or read, imaginary and realized, as well as institutional discourses and story lines, we are invited to take part in (Davies & Harré 1990). In the study I look into the way senior patients/users are invited to participate in institutional discourses and story lines concerning the handling of disease and disability. Mattingly describes the rehabilitation process as a negotiation between different narratives, where the professional narratives are negotiated with the patient’s narratives that may be ambiguous and sometimes contradictory (Mattingly 1998).

Smith does not define the subjective in specific, but I see no direct conflict between institutional ethnography and a post-structural understanding of the subject as outlined. Smith is criticizing the poststructuralists to be deterministic in their account of experience as always already structured by discourse and always mediated through the discursive structure, in which the uttering takes place. But her own concept of experience inspired by Bakhtin’s dialogical approach seems not too far from Davies’ notion of experience as discursively formed and forming. Smith views experiences as dialogical, under constant innovation during current conversation where you discuss experiences with each other and where you may dispute discursively and utter new experiences. “Discourse does not determine: it is dialogically engaged with what the speaker or writer is trying to find a way of telling” (Smith 2002, p. 43).

**Design and method**

The research is carried through in a multi-local ethnographic design (Marcus 1995) where I produce data on interactions, on the institutional order and on the perspective of the elderly people according to the theoretical framework mentioned above. Methodically I will apply interview, observation of participants and document analysis.

The fieldwork takes place in 2 geriatric hospital wards and in 2 municipalities. It will be framed after a so called “tracking” strategy (Marcus 1995) as I follow 9 persons during a year, from admission to geriatric ward until the discharge to home residence. Tracking is a strategy in multi-local ethnography designed along paths and tracks, on connections and contradictions between locations in which the scientist establishes a physical presence. A way to arrange a multi-local study is to follow your object on different locations and situations. According to Marcus there is no theoretical concept or model describing which paths the multi-local ethnographer must follow and which places to pass, so the track must to some extent be made on the way by following the object.

He describes how a multi-local ethnographer must move across localities and levels in society but gives no definition of how to go about it (Marcus 1995). I understand Smiths institutional ethnography as a multi-local ethnography, and Smith suggests that you chose a position in peoples’ everyday life in an institutional context and follow people in the way they relate to and participate in various connections (Smith 2002, p. 24). Furthermore she suggests that the scientist focuses especially on the texts that form part of institutional connections, for instance plans or schedules.

In practice the field work is initiated by my stay in 2 geriatric wards where I lead off by following different professionals doing patient-focused work. Then 8 patients are included according to simple criteria: The included are more than 75 years of age and they are expected to be discharged to their home residence with plans releasing further intervention in the municipality. The included persons are living in one of two specific municipalities.

The patients are followed at the hospital during and after their meetings with various professionals, especially meetings and interactions where plans, arrangements and decisions are meant to be made. By the discharge and after I follow the included during meetings with the care manager (kommunale visitator) and during potential meetings with therapists, nurses and others, where the purpose is to make arrangements, schedule and evaluate. The multi-local track is made on the way determined by the arrangements and plans that are drawn up. It is impossible to take part in all the interactions in which the included persons participate after their discharge. That being f.ex contact with the GP, follow-up at the hospital, contact with other wards and other specialists, which geriatric patients often have, home care services, rehab-centre, social day-care and care management. I will select on a diversity criterion in a way that interactions regarding different subjects are represented.

The research position will be varying in different localities. According to Marcus (1995) (and Haraway, whom Marcus refers to) a scientist is part of the various situations and cannot pick a perspective from outside or above. In multi-local ethnography the scientist has alternating positions and relations with his/her object. By understanding ones object as situated and follow it in varying situations the scientist gets access to other experiences than if he/she studied the object only in a single locality or setting. Marcus describes the scientist as a “circumstantial activist”, and by that he refers to the movement between sites and levels in society, which almost provides the research with a touch of activism. The scientist is engaged in very different relations and negotiates the researcher-identity gradually while knowledge of “a slice of the world system” is obtained (Marcus 1995, p. 112).

Methodically I will apply observation of participants, interviews and document analysis. Multi-local ethnography is defined by the use of different methods, due to the multiple settings and sites that enters into the production of data.

Observation of participants is used in field work at the hospital and during observation of meetings, and here too the scientist’s position will vary. Due to the multi-local design of this research project it is reasonably difficult to describe the type of participant observation in terms of the scientists’ relation to the field (Kristiansen and Krogstrup 199, p. 101), since “the field” doesn’t exist as a given place and since the relations regarding the people inhabiting the field will differ.

Qualitative life world interview will be carried through after discharge, after ½ year and after 1 year. The interview after discharge will be about the experiences of the included concerning the admission and the daily life after the discharge.

For each of the included persons documents and plans from the hospitalization are obtained. Plans for follow-ups on the hospitalization are obtained from the municipalities.

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