Dansk Resumé

I afhandlingen undersøges patienters meningsskabelse med hjertesygdom, og hvordan patienters perspektiver formes af både subjektive og institutionelle tolkningsressourcer.

Undersøgelsen af patienters perspektiver og meningsskabelse med sygdom aktualiseres af et stigende fokus på patientinddragelse i sundhedsvæsenet, og af hjerteområdets efterspørgsel på disse perspektiver med henblik på at forbedre indsatsen indenfor hjerterehabilitering.

Undersøgelsen er socialkonstruktivistisk og etnografisk forankret. Empirien er produceret gennem feltarbejde på sygehuset og gennem gentagne åbne interview. Fem deltagere med iskæmisk hjertesygdom følges over en periode på et år. De interviewes tre gange hver: før deres påbegyndelse af den ambulante rehabiliteringsindsats, kort efter deres deltagelse i indsatsen og til sidst et år efter deres hjerteepisode. Under deres deltagelse i ambulant rehabilitering følges de til indsatsens aktiviteter, hhv. patientundervisning, fysisk træning og individuelle konsultationer med varierende sundhedsprofessionelle fra forskellige professioner. Etnografisk trækkes på perspektiver fra institutionel etnografi (Smith, 2005), narrativ etnografi (Gubrium & Holstein, 2009) og multi-sited etnografi (Marcus, 1995).

I afhandlingen fremlægges tre teoretiske perspektiver, som går i dialog med det empiriske materiale på forskellig vis. Her er tale om en videnssociologisk del, som med Berger og Luckmann (2004) rammesætter rehabiliteringsindsatsen som en sekundær socialiseringsproces, hvor udveksling af viden har en funktion. Her kastes også blik på vidensformer i patientperspektiver (med afsæt i Pols (2010, 2013, 2014) og Smith (2005)), som forholdes til forståelser i inddragelseslitteraturen af patientperspektivet som et rent erfaringsperspektiv. Herefter introduceres en narrativ del, som med Järvinen (2004), Mattingly (1998), samt Gubrium og Holstein (2009) etablerer en ramme for at analysere både subjektive og institutionelle dimensioner af narrativ meningsskabelse. Den tredje del er Ganniks (2005) sygdomsteoretiske perspektiv, som fremlægger sygdom som et socialt og relationelt fænomen, der er integreret i hverdagslige virkeligheder.

Afhandlingens 4 analysekapitler indeholder særskilte foci på hhv. rehabiliteringsindsatsen som institution og på patienters meningsskabelse og perspektiver på sygdom. Sidste analysekapitel sætter fokus på mødet mellem patient og rehabiliteringsindsats, og på hvordan institutionelle og subjektive tolkningsressourcer sammenfiltres i patientens måde at skabe mening.

Første analysekapitel er udformet som sygdomsportrætter af de fem deltagere. Analysen er centreret omkring de subjektive tolkningsressourcer, deltagerne trækker på i deres meningsskabelse med hjertesygdommen. Sygdomsportrætterne tilvejebringer indsigt i, hvordan hjertesygdom meningsmæssigt kobler sig til deltagernes partikulære livssituation og subjektive narrativer.

Afhandlingens andet analysekapitel er i artikelform og tilvejebringer indsigt i, hvordan institutionelle reguleringer af de sundhedsprofessionelles interaktioner og aktiviteter med patienterne er med til at forme, hvordan patientinddragelse kan udfolde sig i konteksten af rehabiliteringsindsatsen.

Afhandlingens tredje analysekapitel analyserer rehabiliteringsindsatsen som en kontekst for meningsskabelse, der indeholder institutionelle tolkningsressourcer. Analysen har afsæt i rammesætningen af rehabiliteringsindsatsen som narrativ omgivelse og sekundær socialiseringsproces. Her er fokus på den viden og på de forskellige vidensmæssige lag, som patienter inddrages i igennem deres deltagelse i indsatsen, og på hvilken patientrolle, dette peger frem mod.

Afhandlingens sidste analyse er en forløbskronologisk analyse af et enkelt patientforløb. I analysen rettes fokus mod udviklinger og skift i perspektivet på sygdom, på hvordan sygdomsudtryk fortolkes og forandrer sig gennem forløbet, og den rolle, viden spiller for dette. Ligeledes rettes fokus mod, hvordan patientens subjektive narrativer

og viden træder ind i forløbet, hvordan dette gribes af de sundhedsprofessionelle, og hvordan generaliserede institutionelle narrativer indgår og får betydning eller konsekvenser i patientforløbet.

Institutionsanalyserne peger på rehabiliteringsindsatsen som en praksis med et patientuddannende sigte, rettet mod at indføre patienterne i sundhedsfaglig viden. De sundhedsprofessionelles handlinger og interaktioner med patienter er orienteret mod at identificere videnshuller og risikofaktorer i patienternes livsstil, og dette ærinde former definitionen patienternes problemer ”oppe-fra, ude-fra”. Analyserne identificerer et centralt plot om progressiv udvikling, som strukturerer narrativer i rehabiliteringsindsatsen, og får betydning for den sundhedsprofessionelle fortolkning af patienten. Narrativen bygger på en forestilling om, at patienten mangler viden og skal uddannes, for at kunne varetage hjertesygdom, hvilket er ensbetydende med efterlevelsen af hjertevenlige anbefalinger. Der peges på, hvordan der i indsatsen arbejdes med, at patienter skal overtage sundhedsfaglige og biomedicinske forståelser af hjertesygdom med henblik på at opdyrke og understøtte compliance-rettet adfærd på måder, som både griber ind i patientens ”ydre” handlinger, såvel som ”indre” indstillinger, tanker og følelser. Inddragelse handler her mindre om at udforske patienters perspektiver, og mere om at forme deres perspektiver ved at tilføre sundhedsfaglig viden.

Der peges på, at rehabiliteringsindsatsens prægivne forståelser af patientens problem, og den dominerende orientering mod at skabe kompliante ekspertpatienter, efterlader begrænset rum til patienters subjektive måder at definere problemer, behov og løsninger, samt skaber ringe mulighed for at patientens viden kan komme i spil. Samtidig stilles krav til patienten, der nogle gange viser sig modstridende og paradoksale. Der overdrages endvidere et væsentligt ansvar til patienten. Her peges på en central problematik i forhold til hjertesygdom, som vedrører vurdering af risiko, som er et usikkert foretagende for både patienter og sundhedsprofessionelle.

På baggrund af analyserne af patienters meningsskabelse og perspektiver peges på, at patienter foretager et stort og nuancereret meningsskabende arbejde, og at patienters i deres måder at skabe mening med sygdom trækker på både sundhedsfaglige og subjektivt forankrede vidensformer. Deres sygdomshandlinger må ses som mangeartede og i tæt sammenhæng med deres individuelle livssituation, som indeholder partikulære emergente problemer af relevans for håndteringen af hjertesygdom. Livssituationens emergente problemer kan være tættere eller løsere koblet til selve hjertesygdommen, men har afgørende betydning for, hvilke handlinger der bliver relevante for den enkelte. Derved bliver patienters perspektiver væsentlige for de sundhedsprofessionelle at få viden om, i lyset af indsatsens ambition om at understøtte patienten.

På baggrund af den kronologiske analyse et patientforløb fremhæves, at patienten indgår i forløbet på varierende måder afhængigt af de emergente problemer, som træder frem. Her peges på et patientperspektiv som i nogen henseender kan betragtes som mere eller mindre stabilt og i andre henseender som skiftende og på mange måder afhængigt af den sundhedsprofessionelle fortolkning, som imidlertid også fremstår skiftende og ustabil. De sundhedsfaglige vidensformer leder ikke til nogen samlet eller sammenhængende fortolkning af patienten, hans symptomer eller tilstand. Analysen peger på, hvordan patienten både artikulerer indsatsens narrativer, men også fastholder sine egne, og at dette er et dynamisk og situeret foretagende. Samtidig peges på, at patientens perspektiver først og fremmes lyttes til, når de harmonerer med de dominerende forståelser i indsatsen.

Endelig peges på, at idéen om, at patientens problemer afhjælpes ved at tilføre patienten viden, er problematisk. Forestillingen om en patient, der mangler viden, resulterer i en indsats, som ikke henvender sig til patienten med interesse for patientens viden og perspektiver på de problemer, som indtrædelsen af sygdom involverer. Hermed risikerer indsatsen at gøre sig irrelevant for patienten. Yderligere problematiseres det ansvar, som overdrages til patienten i indsatsen.

Perspektiverende diskuteres patientperspektivers relevans og legitimitet, og der peges på, at en opmærksomhed på at patientinddragelse ikke er det samme på tværs af kontekster, vil være frugtbar i diskussionerne af patientperspektivers relevans. Der er forskelle i hvordan patienters viden bliver relevant i forhold til patientinddragelse i fx diagnostiseringsprocesser, behandling og rehabilitering, der retter sig mod håndtering af sygdom i patientens hverdag.

Herudover diskuteres implikationerne af en forståelse af patientperspektiver som sammensatte og dynamiske. Her peges bl.a. på, at forståelser (både i forskning og i praksis), af patientperspektiver enten som rene erfarings- og hverdagslige perspektiver, eller som formet af institutionelle diskurser først og fremmest, begge repræsenterer en afgrænsning af patienters perspektiver. Hermed er der også risiko for, at der lægges begrænsninger på, hvad patienter kan sige noget om, og hvad der tæller som erfaring. Yderligere peges på, at når patientperspektiver anskues som situerede, dynamiske og skiftende, må patientinddragelse ses som en proces, der fordrer kontinuerlig opmærksomhed, refleksion og lydhørhed.

English summary

This PhD thesis investigates patients' ways of making sense of heart disease, and how patient perspectives are shaped by both subjective and institutional resources of interpretation.

Researching patient perspectives and patients' ways of making sense of disease/illness is actualized by a growing interest in patient involvement within healthcare services and by the call for more knowledge of patients' perspectives within the field of cardiac rehabilitation with the aim of improving cardiac rehabilitation programs.

The thesis is anchored in social constructivist and ethnographic approaches. The empirical material is produced through ethnographic fieldwork and open, in depth, and repeated interviews. Following five patients with ischemic heart disease over a period of one year, the participants were interviewed three times: before initiating the cardiac rehabilitation program, shortly after its termination, and lastly one year after their cardiac incident. During their participation in outpatient cardiac rehabilitation, I attended their activities which consisted of patient education sessions, physical exercise, and individual consultations with varying healthcare professionals from different professions. The ethnographic approaches employed draws on institutional ethnography (Smith, 2005), narrative ethnography (Gubrium & Holstein, 2009), and multi-sited ethnography (Marcus, 1995).

Theoretically three perspectives that addresses different aspects of the empirical material are employed. One perspective contains a focus on knowledge and exchanges of knowledge, and within the framework of Berger and Luckmann's sociology of knowledge cardiac rehabilitation is framed as a process of secondary socialization, in which the exchange of knowledge is considered to have a function. This section of the theory chapter also addresses knowledge forms within patients' perspectives (based on ideas from Pols (2010, 2013, 2014) and Smith (2005)), which are then discussed in relation to common conceptions in the patient involvement literature in which the patient perspective is regarded as a perspective containing mere experiential knowledge. In the second section, a narrative framework (Gubrium & Holstein, 2009; Järvinen, 2004; Mattingly, 1998) is established to analytically address subjective as well as institutional dimensions of creating meaning narratively. The third section present Ganniks (2005) theory of illness as a social and relational phenomenon, which highlights illness as integrated in the structures of everyday life.

Analyses are divided into four chapters that shift focus dedicating analytical attention respectively to the institution and to patients' ways of creating meaning and their perspectives on disease/illness. The last chapter sets focus on the entanglement of subjective and institutional understandings present in the patient's ways of creating meaning.

The first analysis contains disease/illness portraits of the five participants. The analysis is centered on the subjective resources of interpretation that participants draw on in making sense of their condition, its causes, and consequences. The portraits provide insights on how heart disease is linked to the particularities of the life situation and to subjective narratives.

The second analysis (article) employs an institutional ethnographic approach and provides insights on how institutional ruling relations impact the activities of cardiac rehabilitation and the ways in which healthcare professionals interact with patients, and hence also shape how patient involvement can unfold in the context of the cardiac rehabilitation program.

The third analysis focuses on the rehabilitation program as an environment, that contains specific resources of interpretation. The analysis frames the rehabilitation program as a narrative environment and as a process of secondary socialization. The focus is on the different layers of knowledge that patients are introduced to during the outpatient program and what kind of patient role the exchange of knowledge points to.

In the last analysis one single patient's pathway is analyzed chronologically. Focus is on developments and shifts in the patient's perspectives on disease/illness and on how symptoms are interpreted in changing ways and how different forms of knowledge play a part in this. It is analyzed how the patient's subjective knowledge and narratives

are handled by healthcare professionals, and how generalized institutional narratives are articulated by both patient and healthcare professionals in ways that are significant and consequential.

The institutional analysis points to cardiac rehabilitation as a practice with an educational aim directed at transferring health(professional) knowledge to the patient. The healthcare professionals' actions and interactions with patients are oriented towards identifying patient's gabs of knowledge and risks in the patient's lifestyle. This endeavor defines the patient's problems from an "outside and above" point of view. A central plot of progress is identified as structuring the narrative environment of the rehabilitation program. This plot of progress is significant in healthcare professionals' interpretations of the patient. The narrative of progress builds on the understanding of a patient with a lack of knowledge and consequently must be educated to be able to manage disease, which is synonymous with complying with heart friendly recommendations. There is an endeavor to make the patient understand and adopt health professional and biomedical understandings of the cardiac condition with the aim of cultivating and support compliance. This is conducted in ways that aim to intervene in the patient's "outer" actions as well as their "inner" thoughts, feelings and mental approaches towards the disease and lifestyle changes. On this background patient involvement is a matter of shaping the patient perspective and less a matter of exploring or understanding the perspectives of the patient.

Furthermore, it is highlighted that the pregiven understandings of the patient's problems and the dominating orientation towards creating a compliant expert patient leaves little room for patients' subjective ways of defining problems, needs and solutions and reduces possibilities of bringing patients' knowledge into play. At the same time the rehabilitation program place conflicting and ambivalent demands on the patient, while also transferring considerable responsibilities to the patient. Here a problematic central to heart disease is highlighted, namely the assessment of individual risk, which is an uncertain endeavor for patients as well as for healthcare professionals.

Regarding the patients' perspectives and ways of creating meaning, the analysis points to the nuanced and comprehensive interpretive work that patients engage in, and that patients in their ways of making sense of disease/illness draws on interpretive repertoires of both health professional and subjectively anchored forms of knowledge. Their actions towards disease/illness must be regarded as multi-faceted and closely linked to their individual life situation. Individual life situations contain emergent and individually particular problems which are relevant to the management of the cardiac condition. These emergent problems of the life situation may be closely or more loosely linked to the cardiac condition; however they are highly significant for patients' assessment of the relevance and appropriateness of specific actions towards disease/illness. Hence, in the light of the ambition in cardiac rehabilitation to support patients in managing their condition, it is highly significant that healthcare professionals gain knowledge of patients' individual perspectives and subjective ways making sense of and managing disease/illness.

The analysis of one single patient pathway highlights that the patient engages in the interactions with healthcare professionals in different ways relative to which emergent problem that is foregrounded. It points to a patient perspective that in some regards is stable and coherent and in other regards is shifting and dynamic and, in many ways, dependent on interpretations of healthcare professionals. However, the analysis shows that interpretations of healthcare professionals are also shifting and unstable and that the health professional knowledge forms does not lead to any unified or coherent interpretation of the patient, his symptoms or condition.

Furthermore, the analysis shows how the patient articulates institutional narratives and interpretations at some points in time and in some regards, but also maintains and insists on his own perspectives and that this a dynamic and situated matter. At the same time analysis highlights that the patient's perspectives are listened to first and foremost when they are in line with the dominant institutional understandings.

Finally, a central point in the thesis is that the idea that the problems of the patient can be remedied by transferring health professional knowledge to the patient is problematic. The conception of a patient with a lack of knowledge leads to a program that does not meet the patient with an interest in the patient's knowledge or perspectives on the problems that the disease/illness give rise to. Hereby cardiac rehabilitation risks rending itself irrelevant to the patient. The responsibilities that are transferred to the patient in cardiac rehabilitation are problematized as well.

Following these conclusions, the thesis addresses discussions about the relevance and legitimacy of patient perspectives in health care services. The argument highlights that it would be fruitful in the discussions of the relevance and legitimacy of patient knowledge to recognize that patient involvement is not the same across contexts, and how the patient's knowledge becomes relevant varies and must be discussed with attention to specific contexts. Consider for example the differences in how patient knowledge is relevant with regards to patient involvement in the process of diagnosis, treatment or rehabilitation concerning the management of disease/illness in everyday life.

Furthermore, the implications of the conception of patient perspectives as dynamic and composed of different forms of knowledge are discussed. The argument highlights that the understandings of patient perspectives (in practice as well as in the research) as either a perspective composed of experiential everyday knowledge alone, or as a perspective primarily shaped by institutional discourse, can both be seen to represent a delimitation of the perspectives of patients. There is a risk that such understandings place restrictions on what patients can talk about and what counts as experience. Furthermore, it is pointed out that when the patient perspectives are viewed as situated, dynamic and shifting, patient involvement must be seen as a process requiring continuous attention, reflection, and receptiveness.